# **SPRING 2011**





# Caregiver Burnout - 8 Warning Signs

## By Paula Spencer Caring.com Senior Editor

Stress and burnout are the most common problems for those who care for someone with Alzheimer's disease. And, in turn, caregiver stress -- the emotional strain of tending to a loved one -- is one of the biggest reasons people with the disease enter nursing facilities.

you thinks.

There's no formula for defining your stress level, but if your yes answers outnumber your no answers, or if just two or three of the categories seem to apply to you, consider taking steps to ease your situation.

Take stock of your stress level by asking yourself whether you're experiencing any of the following emotional and

physical symptoms. For an even better reality check, have your partner or other loved one answer the questions for you to see what someone close to

Caring for someone with Alzheimer's involves constant vigilance and activity.

# A short fuse

- · Do you lose your temper easily?
- · Do you feel angry with your loved one?
- Do you feel irritable toward other family members or find yourself snapping at them?

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## WHAT'S HAPPENING

· Saturday, May 14th Free Workshop Indigo Palms 740 North Wymore Road, Maitland "How to Communicate When Logic Doesn't Work"

Registration: 9:30 a.m. – 10:00 a.m. Workshop: 10:00 a.m. – 12:00 p.m. RSVP Required 407-843-1910

- Friday, September 16th Black Tie from the Waist High **Charity Auction** Hilton Orlando / Altamonte Springs 6:00 p.m. – 10:00 p.m. Silent and Live Auction Tickets \$100, Sponsorships available
- Saturday, November 5th **Annual Caregiver Conference** Naomi Feil, M.S.W., A.C.S.W. Developer of Validation Therapy Winter Park Towers 9:00 a.m. - 4:00 p.m. **RSVP** Required

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One of the more obvious signs of caregiver stress is losing your patience easily. Frustration may particularly increase when obstacles or challenges come up, whether major or minor.

## **Emotional outbursts**

- Do you cry often or unexpectedly?
- · Do you experience feelings of despair?
- · Do you have dramatic mood swings?

It's natural to grieve as your loved one's condition declines. It's also normal to feel a complicated range of emotions about having to parent your loved one. But if you're increasingly emotional or feeling emotionally fragile, there may be something more going on.

Depression is a real risk for caregivers. Even if you're not clinically depressed, emotional outbursts can be an unconscious outlet for feelings of being overwhelmed.

## Sleep problems

- · Do you have trouble falling asleep?
- · Do you have trouble staying asleep?
- · Do you wake up tired?

Care giving -- especially full-time care giving -- requires tremendous physical effort, even in the disease's early stages. But if your loved one is sundowning, wanders, or has disrupted sleep, you lose opportunities to rest on top of the tiring work you do all day. Trouble getting to sleep or staying asleep can also be caused by stress, anxiety, and depression.

## Significant weight change

- · Have you recently gained weight?
- · Have you recently lost weight?

For some people, stress can result in weight loss when they can't seem to find time to eat adequately or nutritiously.



Anxiety often lowers the appetite as well. For others, feeling stressed or guilty leads to weight gain from mindless or emotionally triggered eating, frequent snacking, or quick but unhealthy food choices. Changes in eating and sleeping habits can also indicate depression.

If your weight has changed by more than five or ten pounds since you began caring for your loved one, your body may be sending you a signal that you need help.

#### Lethargy

- · Is it difficult to get motivated to accomplish things?
- Do you feel sluggish even after a good night's rest?
- Is it hard to concentrate when you read or perform other mental tasks?
- · Do you feel bored?

Caring for someone with Alzheimer's involves constant vigilance and activity. So if you feel "off" instead of "on," it's hard to perform your duties adequately. It may be that you find parts of the care giving puzzle more challenging than others — for example, managing your loved one's finances or other health concerns.

Sometimes the routines that people with Alzheimer's thrive on can become stifling to a healthy adult child. Routines do help you and your loved one get through the day more easily, but they can leave you feeling like you're stuck in a monotonous rut.

## **Physical ailments**

- · Do you get headaches often?
- Have you had colds one after another?
- Does your back or neck ache, or do you have other chronic pains?
- · Have you developed high blood pressure?

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Mental and emotional stress can cause physical disorders. For example, stress can lead to headaches that are more frequent, more persistent, or stronger than you're used to. Under stress, your body is in a constant state of alert, which can cause your body to produce excessive amounts of the hormone cortisol, which can have many effects.

You'll also lack the time or inclination to properly take care of yourself, setting the stage for more stress. Caregivers under stress may also find themselves suffering from high blood pressure or more frequent stomachaches, cold symptoms, muscle aches, or other health problems.

#### Social isolation

- Do you sometimes go a whole day without seeing another adult aside from your loved one?
- Have you dropped out of your usual activities to care for your parent?
- Can you remember the last time you had a whole day to yourself?
- · Do you feel like nobody understands?
- Do you sometimes feel that other family members don't care as much about your loved one's fate as you do?

Getting out can simply be hard if you're responsible for providing care. You may feel you lack the time for your former pursuits. Your parent's changes in behavior may also make you feel embarrassed or make going out in public too difficult to attempt. Whether intentionally or not, you may become withdrawn. Unfortunately, social isolation itself contributes to stress, whereas being with others and taking time for yourself are both replenishing.

## Complaints from family

- Have you been accused of being a "control freak"?
- Have you been told you don't spend enough time with your friends or other family members?

It's a common caregiver temptation -- and mistake -- to take on the entire burden of care. It's also easy to make ourselves think that we have everything under control or that things aren't so bad. Denial is a powerful emotion. When you're in the thick of things, it can be hard to see other ways of doing it. Listening to an outsider can be healthy, even if you don't agree. What may sound like a criticism or complaint may have a nugget of truth that relates to your emotional well-being.

Alzheimer's care can become all-consuming. It's a bit like the frog who stays in the pot of water as the heat is turned up bit by bit; it doesn't realize it's in hot water until it's too late. Every Alzheimer's caregiver eventually needs assistance -- usually sooner rather than later, and usually from a variety of sources.

If you need a hand, know that plenty of forms of help are available. You can make changes in your care routine, enlist the part-time efforts of friends and family, tap into community resources, and hire assistance as well. No Alzheimer's caregiver can go it alone well. And they shouldn't try -- for their sake and their loved one's.

# Caregiver Tips

## Do...

- Keep everything as simple as possible.
- Give instructions one step at a time.
- Keep your loved one occupied with simple chores.
- Remember they will follow you around and want to know where you are at all times.
- Maintain a daily, structured routine.
- Minimize distractions, noise and confusion.
- Provide memory aids and cues when possible.
- Be gentle provide affection and support.
- Maintain a sense of humor and acknowledge the small successes.
- Get respite time away from your role as a caregiver.

#### Don't...

- Expect answers to your questions to be accurate.
- Get irritated when they ask the same question over and over.
- · Give them too much responsibility.
- Expect them to properly identify people, places, or things.
- Get upset, raise your voice or scold the patient.
- Take the person's behavior personally it's the disease!
- Argue with the patient to try to rationalize with them.

## Expect...

- To have normal feelings such as guilt, anger, sorrow, or helplessness.
- Sleep disturbances.
- Patient symptoms worsen in the evening.
- Behavior changes when there are major changes in daily life.
- Patients to be anxious, frustrated and to deny their problems.

## A message from the EXECUTIVE DIRECTOR



Dear friends.

If you haven't already noticed, 2011 has brought a number of changes to our organization. After 27 years of serving local caregivers as the Alzheimer Resource Center, we've changed our name (just a little) to better reflect what we do and who we serve.

We are now officially the Alzheimer's & Dementia Resource Center – providing, as our new tagline indicates, "support and hope for caregivers."

Along with the new name and tagline, our "look" has evolved, as well. Symbolizing growth and renewal, the updated logo resembles the shape of a flower – incorporating three elements that represent our connection to caregivers, patients and other community stakeholders. The soothing, comforting colors make a visual statement about the caring nature of the services we offer.

Outside our building, you may notice a new street sign. But, inside you'll still find the same friendly, knowledgeable staff and full range of resources that we've always delivered – including the very best educational workshops and seminars available in Central Florida.

And there's other news, as well:

- First, we are proud to welcome Naomi Feil as the keynote speaker for our Annual Caregiver Conference in November. As the developer of Validation Therapy, author of two books and executive director of the Validation Training Institute, Naomi will share her depth of knowledge and expertise with caregivers in Central Florida. We're looking forward to meeting Naomi and hearing how she transformed the way we communicate with patients today. Validation Therapy is a technique of affirming dementia patients' thoughts (whether the listener acknowledges they are correct or not), instead of correcting them. This helps create short-term satisfaction and an environment of respect among caregivers and their loved ones.
- As part of our mission to advance Alzheimer's research, we are pleased to announce a recent partnership with GE Healthcare to find ways to better detect – and correctly diagnose – patients who show early signs of dementia. Currently, GE is testing a new medication that binds to plaque in the brain and is visible on PET scans, allowing for a non-invasive and fairly accurate diagnosis. As one of two agencies in the state to coordinate the Brain Bank Research Program, we strive to enhance diagnostic tools and methods of detecting Alzheimer's disease.

All in all, 2011 promises to be an exciting year for us. We are encouraged by the breakthroughs happening every day – whether in the labs, in a support group or at home.

As we begin this new chapter in our organization's history as the Alzheimer's & Dementia Resource Center, we want to reaffirm our commitment to providing caregivers the resources and motivation they need to face the daily challenges of care giving. As always, thank you for your support!

Sincerely.

Nancy Squillacioti Executive Director

Alzheimer's & Dementia Resource Center

## A New Wave of Giving Donate to Alzheimer's & Dementia Resource Center

Alzheimer's & Dementia Resource Center is excited about 2011, and, of course, this includes identifying new ways to generate income in these economically challenged times. It's no secret that, like other nonprofit organizations, we are faced with the operational challenges of doing more with less. However, I am pleased to introduce an innovative solution in planned giving that enables you, our donors, to combine two important and shared financial ideals: 1) provide support and hope for caregivers and 2) preserve the assets in your estate to

support the future success of your heirs.

It's common knowledge that our current challenging economy is putting a crimp in almost everyone's wallet. For many, discretionary income as well as donor dollars has shrunk. And, you're likely tired of innumerable phone calls and mailers from charities competing and

pleading for every dollar.

This unique, new program of planned giving to the Alzheimer's & Dementia Resource Center offers numerous benefits:

- No net cost to your family.
- The opportunity to donate to the Alzheimer's & Dementia Resource Center without permanently parting with your monev.
- Potential tax savings and estate planning benefits according to your financial plan. It's a win-win opportunity!

Catch the wave. For more information about this innovative mutually-beneficial planned giving program, please contact Nancy Squillacioti, email nancy@ ADRCcares.org or call 407.843.1910 ext. 307.

## A New Hope for Diagnosing A Partnership between GE Healthcare & FL Brain Bank



There is new hope on the horizon for diagnosing Alzheimer's disease. As most of us know, a definitive diagnosis can only be made after death, with an autopsy. The opportunity for getting a "real" diagnosis early in the disease with

the hope of doing something about it is one step closer to reality.

The Florida Brain Bank has partnered with Compass Research to assist GE Healthcare of London, England, in obtaining FDA approval for a new diagnostic drug. The drug would bind tightly to amyloid plague, a compound in the brain that is believed to be a sign of AD. If the drug is successful it will give doctors the first definitive diagnostic tool for determining if a person has Alzheimer's prior to death.

We are looking for interested candidates for this study.

The criteria are simple:

- 1. The study participant needs to be 55 or older.
- 2. The participant must be able to undergo the study procedures – transport to PET site (medical or non-medical), doctor's evaluation, CT and PET scan.
- 3. The participant must have a short life expectancy - approximately 1 year or less.

There is no cost to the patient or family for any procedures in this study, including the autopsy. Compensation for transportation, time spent, and meal vouchers are provided. Please contact Martha Purdy or Jennifer Reynard, at 800-330-1910, if you are interested in participating in this exciting opportunity to contribute to conquering this debilitating disease.



# **Upcoming Events**

# FREE CAREGIVER WORKSHOP "How to Communicate When Logic Doesn't Work"

Date: May 14, 2011

Time: Registration 9:30 AM - 10:00 AM

Workshop: 10:00 AM - 12:00 PM

Location: Indigo Palms

740 North Wymore Road

Maitland, FL 32751

Refreshments: Will be provided Seating is Limited

RSVP by Friday, May 6, 2011 to

Cindi Spurgeon 407- 843-1910 EXT. 301



Black Tie from the Waist High Charity Auction Friday, September 16, 2011 6:00 p.m. – 10:00 p.m. Hilton Orlando/Altamonte Springs

Black Tie from the Waist High is our "signature" fundraising event and helps the Alzheimer's & Dementia Resource Center continue providing critical services to caregivers in the community. Come dressed to impress from the waist up and casually from the waist down. Be original and have fun with your apparel! Be ready to bid on unique items with our silent and live auction. Tickets are \$100 each which includes two drink tickets, appetizers, gourmet dinner and a cash bar. Corporate sponsorships are available. For more information and to make reservations, contact us at 407-843-1910 or info@ADRCcares.org.

# Caregiver Conference Saturday, November 5, 2011 • Winter Park Towers

The Alzheimer's & Dementia Resource Center is offering a special educational conference. Our usual one-day caregiver conference has been expanded to two separate sessions...a morning session for professionals and an afternoon session for our family caregivers, featuring one of the most highly regard pioneers in the field of dementia care.



Naomi Feil, M.S.W., A.C.S.W., developed the concept of Validation Therapy in the 1960s which has proven to be a significant breakthrough in understanding and communicating with those suffering from some form of dementia. Validation is a method of communicating with and helping dementia individuals. It is a practical way of working that helps reduce stress, enhance dignity and increase happiness. Validation is built on an empathetic attitude and a holistic view of individuals. When one

can "step into the shoes" of another human being and "see through their eyes," one can step into their world and understand the meaning of what may appear to be bizarre behavior. Naomi is Executive Director of the Validation Training Institute and a popular speaker in North America and Europe.

Professional Caregivers \$50

Morning Session 9:00 am to 11:30 am

Family Caregivers \$25

Afternoon Session 1:00 pm to 4:00 pm

Registration fees are due by October 28th.
You can register over the phone with a
credit card or by check.
Call Cindi 407-843-1910
for registration form.

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Special thanks go to the following foundations, corporations and individuals for their major contributions:

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• Same Day Results • No Charge

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## caring

**SPRING 2011** 

## **Meet Other Caregivers**

The Center has several support group meetings available throughout the Central Florida community. If one of these does not fit your schedule, please give us a call so that we can put you in touch with other support groups that can assist you.

#### 1st Tuesday @ 10 A.M.

Easter Seals Daybreak at the Miller Center 2010 Mizell Avenue Winter Park, FL 32792 (Respite Care Available 407-629-4565)

#### 1st Tuesday @ 6:30 P.M.

The Heritage of Lake Forest 5433 West State Road 46 Sanford, FL 32771

## 1st Thursday @ 10 A.M. and 3rd Thursday @ 10 A.M.

"Men's Breakfast Club"
(An informal and unstructured gathering of male caregivers)
Mt. Vernon Inn
110 S. Orlando Avenue
Winter Park, FL 32789

## 2<sup>nd</sup> Tuesday @ 10 A.M.

Reeves United Methodist Church 1100 N. Ferncreek Avenue Orlando, FL 32803 (use the fellowship entrance in the back)

#### 2nd Tuesday @ 6 P.M.

Arden Courts 1057 Willa Springs Drive Winter Springs, FL 32708 (Respite Care Available 407-629-4565)

#### 2nd Friday @ 12 Noon

Osceola County Council on Aging (bring brown bag lunch, if you want) 700 Generation Pointe Kissimmee, FL 34744

## 3rd Thursday @ 12 Noon

"Coping as Couples" - Patient & caregiver open and willing to share their challenges dealing with dementia. For new attendees, contact Martha at 407-843-1910 Ext. 308 prior to attending.

Arden Courts
1057 Willa Springs Drive
Winter Springs, FL 32708

#### 3rd Thursday @ 6:30 P.M.

Emeritus at Ocoee 80 N. Clark Road Ocoee, FL 34761

## 4th Monday @ 6:30 P.M.

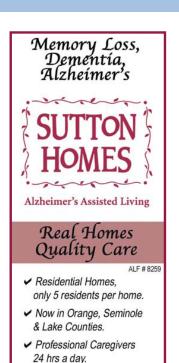
Horizon Bay at Lake Orienta 217 Boston Avenue Altamonte Springs, FL 32701

## 4th Tuesday @ 6:30 P.M.

Golden Pond Communities 400 Lakeview Road Winter Garden, FL 34787

# NEW BEREAVEMENT SUPPORT GROUP

Anyone interested in attending a bereavement support group should call the office at 407-843-1910. No commitment is required at the time of the call, but we are trying to gauge the level of interest in such a group from our caregivers and leaders.



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www.suttonhomes.com

**Call for Information** 

407-740-8815