
The Alzheimer's Support Network News



Fall 2008



As I See It . . .

From Chuck's Desk

Dear Wonderful Caregivers,

Where does the time go? We can hardly believe that it has been so long since we did a newsletter. Amazing! I know that some of you thought you had been taken off our mailing list. Please be assured that we want you to receive this letter for as long as you want it. And we *will do better* at getting it out! We *should!*

Isn't it easy to "should" on ourselves? We all strive to do what we feel that we should do. Perhaps we need to shift that word to "can." For if we do what we *can*, how can we or anyone else require more of us?

People who are caregivers seem to be especially hard on themselves. They have taken on a very self-*less* role. When the care is for someone with a form of dementia, it is generally a thank-*less* role.

But there is certainly nothing at all *less* about your efforts. You do more and more until you collapse. Caregivers often neglect their own medical needs: put off doctor visits; skip exercise; eat poorly. You neglect to consider that scary question: *Who will take care of your loved one if something happens to you, the caregiver?*

There are many things that you can do to lessen the stress of caregiving. The most important is to take care of yourself. Being as healthy, rested and stress free as you can be also happens to be the very best thing you can do for your loved one. Your health is important. And you are the only one who can attend to it.

In news about the Alzheimer's Support Network, Suky and I are thrilled with the wonderful team we have with us right now: Marianne, Nan, Steve and Debbie. Each brings valuable skills and a unique perspective to the services we provide. If you haven't met each of them, we hope you will have an opportunity to do so soon. We have spent the last year strengthening our programs and working together to help you as much as possible. Many of you have told us that we have helped. We hope so!

We are honored to announce the addition of three Board members: Harriet Denny, a wonderful caregiver and long-time Network supporter; Dick Pegnetter, Dean of the Lutgert College of Business at FGCU, and Marty Wasmer, CEO, Wasmer, Schroeder & Co.

With an awesome staff and knowledgeable Board Members, we look forward to continuing to meet the needs of a growing number of families dealing with Alzheimer's or another form of dementia.

Chuck Pollard

ALZHEIMER'S



SUPPORT NETWORK®

REMEMBERING THOSE WHO FORGET



Alzheimer's Support Network News is published by the
 Alzheimer's Support Network
 660 Tamiami Trail North, Suite 21
 Naples, FL 34102
Telephone: (239) 262-8388

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*Thank you for your patience as we bring our lists of donations up to date. The following memorial gifts were some of the many received **during 2007**. Watch for more soon!*

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Caregivers, "The Second Victim" of Alzheimer's Disease

Caregivers, those who meet the needs of the AD patient on what is often referred to as the "36 Hour Day," may be the spouse, adult child, in-law, live-in friend, or hired helper. The stress of providing for some or for all of the needs of the patient can take a tremendous toll on the caregiver, who becomes caught up in the disease process. Caregivers are often referred to as the "Second Victim."

If the caregiver is an adult child of the AD patient and also has children of his or her own, the situation is called "the Sandwich Generation." Sandwiched between caring for an older parent and one's own children further stresses the caregiver, the family, and the caring environment for the AD patient.

The request for help needs to begin early in the process of being a caregiver. A nurse in a local home health care agency said that she pleads with the AD caregivers to get help and not "do it alone." Last winter she visited 12 families where she provided health care services to the AD patient or to the caregiver. In a three month period, eight died - one was the AD patient, the other seven were the caregivers.

Danger Signals That Say

WARNING: Caregiver Needs Help

When should the caregiver cry, "Help, I can't continue like this!?" Many caregivers would rather trudge on under unbearable conditions than to admit what to them is "failure." Their own health begins to suffer, and eventually they themselves need care . . . sometimes too late.

If you notice any of the following danger signals, you, the caregiver, are probably approaching role overload and should seek information and referral from your Alzheimer's organization or other

health and human services agency:

- ☒ You feel that the patient's condition is worsening despite your best efforts.
- ☒ No matter what you do, it isn't enough.
- ☒ You feel you are the only person in the world enduring this.
- ☒ You no longer have any time or place to be alone for even a brief respite.
- ☒ Things you used to do occasionally to help out are now part of your daily routine.
- ☒ Family relationships are breaking down because of the caregiving pressures.
- ☒ Caregiving duties are interfering with your work and social life to an unacceptable degree.
- ☒ You're going on in a no-win situation just to avoid admitting failure.
- ☒ You realize you're all alone — and doing it all — because you've shut out everyone who's offered help.
- ☒ You refuse to think of your self because "that would be selfish" (even though you're unselfish 99 percent of the time).
- ☒ Your coping methods have become destructive; you're overeating, under-eating, abusing drugs or alcohol, or taking it out on your relative.
- ☒ There are no more happy times, loving and caring have given way to exhaustion and resentment, and you no longer feel good about yourself or take pride in what you're doing.

It's okay to cry "Help," by calling the Alzheimer's Support Network at 262-8388 or someone else who can give you the help you need.

Courtesy of Alzheimer's Association
Columbia District Chapter

Caregiver Issues



Sense of Humor is Therapeutic

by Mary Jane Bates, LSW

Recently, while hoeing and weeding in my garden, I was aware of the tensions of the day gradually leaving me. As I sat relaxed at the conclusion of my work, I thought about the kinds of activities which provide release and relaxation for us.

As research reveals more about the functioning of the brain, we understand that there is a real physiological basis for those pastimes and activities which seem to relieve our feelings of stress and move us into more relaxed, comfortable states.

In some people, an activity as simple as petting the family dog can influence heart rate and blood pressure. We now know that music can greatly alter our mood or emotional state, and that exercise stimulates the production of endorphins, to cause immediate feelings of well-being and positive energy.

In the 1970's, Norman Cousins researched the link between humor, laughter and psychological healing. He advanced the theory that laughing, like exercise, also causes the release of endorphins. Science has caught up, providing the data to support his notion. In fact, these endorphins, called the "body's morphine" by some, are known to diminish pain and boost the immune system and the ability to fight off disease and depression.

For the caregiver, the ability to laugh and use humor on even the darkest day is very important in

maintaining emotional and psychological balance. A sense of humor enables the caregiver to keep the proper perspective and the situation from becoming overwhelming.

In thinking about the caregivers with whom I have worked this year, I think it is humor which has enabled the ones coping successfully to make it through. One woman of whom I am particularly fond laughs a lot and shares jokes with her husband who has dementia. Although she continually apologizes for laughing, she once confided, "It's the only way to keep from crying."

One day when I visited, the husband kept referring to her as his girlfriend. Rather than correct him, she teased back that they needed to get on with "planning a date." They both chuckled over that one and their shared sense of peace and comfort is immediately apparent to anyone visiting them. Their life together is not easy, but the ability to laugh together makes their home a very comfortable place.

Caregiving is a serious responsibility to be sure, but a sense of humor makes the stress and sadness of this time easier to bear. The physical and psychological effects of being able to laugh provide important protection against illness and depression for the caregiver. It's okay to laugh. Humor is simply good medicine.

Courtesy of Alzheimer's Association
Central Arkansas Chapter



Coping Strategies For the Alzheimer's Caregiver

Stress!

Many family members of individuals with Alzheimer's disease provide the primary care for their relative. Caregiving is stressful due to increased responsibility, additional decision making and disruptions in lifestyle. Most caregivers do not recognize the association between the stress of caregiving and their physiological/psychosocial distress. You may be experiencing stress if you experience the following:

- You have a desire to eat or fast, drink or smoke more than you usually do
- You experience deep exhaustion that rest will not alleviate
- You have a knot in your stomach, a tightness in your chest, or your teeth are clenched
- You have trouble breathing or there is a dull ache in your chest
- You have hives, itchy skin or rash
- You have diarrhea, constipation or feel queasy
- You become accident-prone
- You are unnaturally hyperactive
- You are abnormally forgetful or lacking concentration
- You experience deep fear of things
- You have the urge to withdraw from people

- You feel angry or troubled
- You have a deep, unrelenting depression
- You've lost your sense of humor and/or perspective

Alleviating Stress

- ✓ Get adequate rest and nutrition
- ✓ Take time for exercise
- ✓ Continue to enjoy a hobby or activity
- ✓ Do not withdraw from friends or relatives (isolation can lead to anger and fear)
- ✓ If religious affiliation is important to you, continue to be involved
- ✓ A hairdressing and manicure appointment can do wonders for your sense of self
- ✓ Find a listening ear (internalization of feelings can erupt into physical/emotional dysfunctions)
- ✓ Reading for fun can help you get away from yourself
- ✓ Monitor your own emotional and physical health
- ✓ Remember, you cannot be all things to all people, all the time

Courtesy Alzheimer's Association
Mobile, AL Chapter

(See more ideas on managing stress on page 7.)

For Your Reference File



Caregivers Should Say Yes to Help

by Dorothy Seman, MS, RN, Rush Alzheimer's Disease Center

It is not uncommon for the primary caregiver of someone with Alzheimer's disease to say, "I care for him by myself because there is no one else who helps." At the same time, another member of the same family might say, "I want to help with Dad's care, but Mom says she can handle everything." How can we understand and resolve the apparent contradiction, which can be very frustrating for all concerned?

Many of us are taught at an early age, reinforced throughout life, that it is good to tough it out, be strong and suffer in silence. Asking for and accepting help may be seen as a form of personal weakness. Although self-reliance may help develop discipline, courage and character, it is not advisable to be a Lone Ranger in some situations. We pay a heavy price by going it alone when caring for someone with dementia.

Alzheimer's disease is a progressive disease with an average course of eight years, but some people may live for 20 years. A marathon runner and a sprinter require different kinds of training. Caring for someone with AD requires training as if for a marathon. The work is physically and emotionally demanding. Most people can get through a short-term crisis and temporarily set aside their own needs for someone else. However, it is both difficult and dangerous to think that one individual can provide excellent care for years on end without time off.

There must be time for rest and recuperation. Even in major league sports, the best players have time off during a big game. In baseball, there are relief pitchers and others who come in off the bench so

that the starters can function at peak performance when it counts. There is no more important person in providing care for someone with dementia than the family member who provides most of the care.

Spouses may be urged on by the words of their marriage vows about promising to care for the other in sickness and in health. Adult children may think, "Mom and Dad took care of me when I was young, so now it's my turn." These thoughts and underlying values may unwittingly prevent others from participating in the care of a loved one. By the same token, the person in need of care might not get the kind of help that would contribute to a good quality of life.

Because the course of Alzheimer's disease is typically slow, it may not be easy to determine if and when increasing amounts of care may be needed. Caregivers may not be aware of the many sacrifices they are making on a continuing basis. As the person with dementia increasingly becomes the focus of care, it may not be easy to recognize one's own needs or be aware that the demands of care are affecting one's mental or physical health.

Growing numbers of research studies show that chronic stress can exact a great toll, sometimes in ways that diminish the effectiveness of the caregiver's immune system. Moreover, the caregiver's stress can also affect the quality of care to the person with dementia. Therefore, getting help can benefit everyone.

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Caregivers Should Say Yes to Help, Continued

Help can take many forms, such as hiring an in-home companion or enrolling the person with dementia in an adult day-care program. There may be benefits for both the caregiver and the care-receiver. For the person with dementia, day care may mean having greater opportunities to enjoy a range of people who provide stimulation, pleasure and comfort. Socialization may support functional capacity and improve his or her quality of life. In the event that the caregiver becomes seriously ill or dies, the person with dementia will have less difficulty accepting other caregivers.

Although one family member usually takes the lead in providing most of the care, there are often others willing and able to provide care and meaningful interactions, including other family members and friends and staff members of adult day-care centers. This supportive care often brings variety, joy and pleasure to the person with dementia. For family members, it can be a way to stay involved and feel connected with someone they love. Saying yes to help can be a win-win situation for everyone involved.

A Few Suggestions on Managing Stress

Here are a few suggestions about how you can reduce or cope with the stress in your life as a caregiver.

👍 Relax your standards. Perfection is not necessary; it's boring. Life is a lot easier if you ignore your loved one's untidiness or your messy house.

👍 Get help with chores, especially those you hate. Ask friends or relatives to come over and help do things such as mowing, changing oil in the car, etc.

👍 Change your perspective. Instead of worrying about what will happen if . . . try asking yourself, "So what?" So what if your loved one won't eat at the table? So what if he breaks a glass? Even if your worst fears are realized, they often turn out to be not so bad.

👍 Write your frustrations and worries in a journal; don't keep your feelings bottled up.

👍 Establish a serene place of your own. While your loved one naps, go to that place and do things you enjoy. Take up a hobby.

👍 Find humor in stressful situations. Sometimes laughter is the best medicine.

👍 Exercise regularly — more often when under stress.

👍 Avoid foods high in sugar.

👍 Limit intake of caffeine and alcohol.

👍 Plan realistically. Allow enough time for things and say "no" more often to obligations that you haven't the energy or inclination to do.

👍 Make time for yourself. Take your loved one to an adult day care center or have someone sit with him while you pamper yourself. Rotate caregiving duty with other relatives.



Advice to the Caregiver

by Sally Hill, Montgomery, Alabama Support Group

Making decisions for persons too incapacitated to aid in the decision-making process can be frightening. Many Alzheimer's disease caregivers find themselves in this position and have no one with whom to share this grave responsibility. Sadly, such caregivers frequently agonize over the decisions they have made. The range of concern is broad, i.e. finances, disposal of property, and provision for the day-to-day care of the person with Alzheimer's. These are the problems that cause caregivers to question themselves the most.

The caregiver frequently has more distress when seeking advice from another individual. Other people may ask questions such as, "Are you really sure that's the best place for her/him to be?" This increases the caregiver's doubts. People who lack experience in caring for an Alzheimer's disease patient may not know this illness is not like other serious illnesses. Unfortunately, an experienced caregiver sometimes forgets this too.

I suggest caregivers remind themselves of the following statements whenever they are worried and anxious about the appropriateness of their actions:

- 1) I did what seemed best at the particular time. I cannot and should not expect more of myself than that.
- 2) My choices have been, and continue to be, very limited due to circumstances not within my control.
- 3) There are no perfect solutions regarding the problems caused by Alzheimer's disease and I should not keep questioning the action I took.

4) If I had selected another course of action, I would have had doubts about the "rightness" of that also.

5) Perhaps things would have been worse if I had chosen another course of action.

6) Many other Alzheimer's disease caregivers faced with a similar problem have taken the same action that I did.

7) New problems which develop are not necessarily related to how I have handled things.

8) I cannot expect all of my friends and family members to understand all of my decisions and behavior.

9) I will not allow other people to cause me to question myself. It is far easier to examine the actions of others than it is to make critical decisions.

10) I will not try to compare how I handle things to the way I think my loved one might handle it if our roles were reversed.

11) I will remember the positive things that have occurred because of the actions I have taken (such as being able to get a good night's sleep).

12) Continuing to question and to doubt my judgement will make it harder for me to handle future problems and decisions.

13) I will consider what is best for me, as well as for my loved one with Alzheimer's disease. In doing this, it is frequently necessary to compromise.

14) I will remember that my loved one is not unhappy and upset because of what I have done. My loved one is unhappy and upset because she/he has Alzheimer's disease.



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Bill and Ursula Allison
 Robert and Charlotte Hardin
 Richard and Barbara Slocomb
 Peter and Shirley Meyers
 Colleen Frawley Mehan and Family
 Katie and Marty Walsh
 Mary L. Merten
 Elizabeth Cahill
 Jane and Greg Schmitt
 Phyllis and Bill Ravensberg & Family
 Leonard and Fairlyn Mooradian
 Mildred Azar

In memory of **William Swift**

by Theodore and Katherine Blachly

In memory of **Christine Taylor**

by Employees of the Community Found. Collier Co.

In memory of **Wilson Touhsaent**

by Robert Schmeckpeper

Anne Greco

Dennis and Arla Van Zanten

Reuben and Darlene Swanson

Mary Harris

Joe and Ginny Dietrich

Pella Corporation

Mr. and Mrs. Jim Huseman

Chuck and Janet Rowley

Sharon Leary

Shirley Sneller

Linda McDonough

Dan Klassen

Mary Van Zante

Christine Headington-Hall

Sam Iogha

Paulette Smigo

Pastor Larry Peterson and Family

Susan and Robert Touhsaent

Judy and Dave Price

Louise Carson

In memory of **John F. "Jack" Walsh**

by Carlo and Margaret Valenti

Donald and Marilyn Gosselin

Mary E. Laubenstein

Paul D. Richardson

Roberta and Pat Ward

Rona Cooper

Elaine and Douglas Arnold and Family

Yvette M. Giarrusso

Mary R. Regan

In memory of **Bernard Weinstein**

by Dot and Hank Benedict

Lou Carson

Iris T. Abel

Phyllis and Lester Schreier

Evelyn Cheslow

Phyllis and Kal Lazear

Francine Giannattasio

Emily, Rana, and Katie Singh

Roseanne Diegnan

In memory of **Louis Weinstein**

by Harriet Adelstein

Lindy Adelstein

In memory of **Alice Wickham**

by Bill and Thelma Boyle

Theodore and Catherine Main



Meetings in Collier County

Education Meeting

The first Tuesday of the month at 11:00 a.m.
First Presbyterian Church, 250 Sixth Street South

Tuesday at Ten and Thursday at Ten Discussions

each Tuesday (except the first) and **each** Thursday

10:00 - 11:30 a.m.

at the **Caregivers' Resource Center**, 660 Tamiami Trail North, Suite 21
(Program for loved ones in another room)

Ask the Expert Series

during the Tuesday or Thursday meeting. Please call for schedule

Caregiver Workshops

during the Tuesday or Thursday meeting. Please call for schedule

Marco Island Support Group

meets the 3rd Friday at 10:00 a.m. at Bank of America

Adult Children of Alzheimer's People

meets the 1st and 3rd Wednesdays at 5:30 p.m. at the Caregivers' Center

Daughters of Mothers with Dementia Group

meets the 2nd and 4th Wednesdays at 5:30 p.m. at the Caregivers' Center

Facility Issues Group

meets the 2nd Friday at 10:00 a.m. at the Caregivers' Center

Day to Day Coping Group

meets the 3rd Thursday at 2:30 p.m. at the Caregivers' Center

Bridge from Grief Group

meets the 3rd Friday at 10:30 a.m. at the Caregivers' Center

Male Caregivers' Group

meets the 4th Friday at 10:00 a.m. at the Caregivers' Center

Early Stage Groups

Please contact the Caregivers' Center (262-8388) for details

***For the latest information on Support Groups in Lee County
call the Alvin A. Dubin Alzheimer's Resource Center at 437-3007***

Support Groups