

Family Caregiver Newsletter

Newsletter Date May 2014

The Powerful Caregiver

This column is named after the class "Powerful Tools for Caregivers," a six-session workshop on helping caregiving families thrive (not just survive). It is offered in Racine County several times a year.

DIAGNOSIS: Caregiver Burnout

Roger is a 72-year old caregiver to his wife Maggie who lives with multiple sclerosis. He has built a ramp, installed grab bars in several rooms, put in a walk-in shower, and made many other changes to accommodate Maggie's changing needs. As time goes on, Maggie's contribution to household duties has diminished. Roger is doing his best to cook nutritious meals, keep up with laundry, manage Maggie's medications, assist with her bathing and dressing, take her to medical appointments and maintain the house and yard. He has high blood pressure, is borderline diabetic, and needs a knee replacement. He is in pain most of the time. He is exhausted every night, but he has trouble sleeping and is still exhausted in the morning.

Roger is proud of the good job he's doing. He and Maggie have had a long marriage and enjoyed their children. Maggie always took good care of Roger and the children, and now he's glad to return the favor, but lately he has been losing patience, and feeling like he can't do this anymore. Sometimes Roger is noticing a heavy feeling of impending disaster. He feels profoundly sad as he sees Maggie losing abilities. At times he feels so angry he could yell or punch something. On top of everything else he is worried and fearful about finances. He has

many questions about what would happen if.....?

The other day Roger was waiting on the phone to speak with a "real person", and Maggie was asking for help. He kept asking her to wait a minute, hoping to get his question answered. Maggie lost control and her clothing got soiled. Roger hung up in disgust and yelled at her. Then they both cried for a long time. Roger apologized to Maggie, but he felt terrible. Now he feels so sick and discouraged that he's afraid he will die, and then who will care for his dear wife?

Although "burnout" isn't an official diagnosis, the term Caregiver Syndrome is becoming more common in the health care community. Neurologist Jean Posner defines this as a debilitating condition triggered by unrelieved, constant care of someone with chronic illness coupled with the burden of loss and grief. Others have described it as a "depressive, exhaustive state" resulting in "deteriorating emotional and mental



Self Care and support helps to fuel a "steady flame."

Inside this issue:

Diagnosis: Caregiver Burnout	1
Community Resources	3
Support Groups for Family Caregivers	4
Caregiver Opportunities	4



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continued from front page

health.” It is accompanied by an elevated level of stress hormones – the level designed to help us outrun predators for a few minutes. During a chase or a fight, these hormones shut off important functions (like fighting off disease or keeping the internal organs nourished) so that the body can concentrate on immediate survival and then recover normal function. Caregiving can keep this stress system going and going and g-o-i-n-g... until the body is no longer able to keep up with essential tasks. It’s like an oil lamp that has run dry and lost its flame.

Have a Burnout Prevention Plan

The time to start thinking about Caregiver Burnout is before it happens.

When we take on the role of a caregiver (whether by choice or catastrophic incident), we need to develop a plan to prevent burnout, as surely as we need preventive measures to avoid other illnesses.

Here are some suggestions for your Burnout Prevention Plan:

- **Tend to your own health.** Maintain healthy habits of diet, exercise, and socialization. Have regular medical check-ups, and make sure your health care providers know you’re a caregiver and how that impacts your life.
- **Gather and share information** from reputable sources about your loved one’s condition and about caregiving.
- **Accept your feelings and have someone to talk about them with.** Keep in touch with Caregiver Support persons and with other caregivers in person, by phone, and/or online.
- **Let go** of ideas like “I have to do it all” and “It has to be done my way.”
- **Insist on and accept help.** Keep a list of tasks you can delegate when

people offer. Say “I need help with...” Say this often!

- **Accept that systems are imperfect.** Phone calls and “red tape” of bureaucracy can be maddening. This is difficult for many caregivers. It has been called “institutional stress.” Try not to confuse the system with the people who may be able to help you.
- **“Keep calm and carry on!”** Practice relaxation techniques such as deep, slow breathing and just focusing on the present moment, and keep up with other relationships and activities in your life.
- **Practice changing negative thoughts to positive ones.** Instead of dwelling on “My sister only helps once a week,” trying saying to yourself, “I’m glad she comes every week. It’s good to have her help.” Take time to remember the benefits of caregiving, too. Caregivers who thrive have been shown to score higher on physical performance and memory tasks than non-caregivers their age. There are also emotional, psychological and spiritual rewards, e.g. developing more confidence in your abilities and have better relationships with those close to you.

How can you recognize impending burn-out? Here’s an early sign:

Someone said that “the first symptom of burnout is euphoria.” In other words, if you find yourself thinking that you can “do it all” and “don’t need help,” you may well be headed down Caregiver Burnout Highway! Some other symptoms to watch for are: exhaustion; change in eating or sleeping habits; irritability; neglecting your own health; feeling hopeless; thinking that “no one cares;” losing interest in things you once enjoyed; and pervasive sadness.

It is difficult to identify these symptoms in oneself. It’s important to pay attention to others when they express concerns about you.

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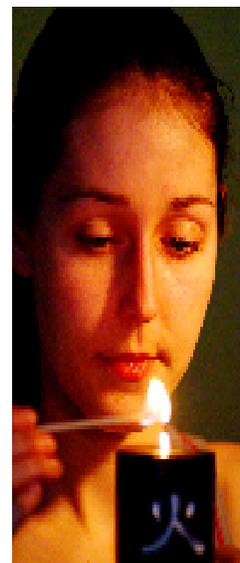
Rekindling your flame

- Call the ADRC (262-833-8777) and ask to speak with a Caregiver Support Specialist.
- Report your symptoms to your health care provider and remind him or her of your caregiving role.
- Express your feelings. Talk, write, email, sing, doodle, use a punching bag, or think of your own safe outlet. Some caregivers have gone out to the garage to yell.
- Look at the expectations you have of yourself, and begin to let go of some. A Caregiver Support Specialist can help you decide which ones are unrealistic.
- Insist on a break. Find out what af-

fordable resources there may be for you (call the ADRC).

- Change health habits as necessary. Make taking care of YOU your primary job!
- Trust yourself – How have you dealt with difficulties in the past?
- Re-engage in the parts of your life you have put on hold – relationships, social contacts, hobbies, a spiritual community, exercise opportunities, etc.

With help and rest and self-care, Roger can regain his physical and emotional health and enjoy his life again. He and Maggie can rekindle their partnership and hopefully some fun in the rest of their time together.



Community Resources

This column highlights some of the many resources in our community. [For more, see the Community Resource Directory](#) available from the Aging and Disability Resource Center (262-833-8777) or www.adrc.racineco.com.

Because We Care

http://www.aoa.gov/prof/aoaprogram/caregiver/carefam/taking_care_of_others/wecare/wecare.aspx Administration on Aging; An online resource guide for the growing number of Americans who are caring for an older family member.

Alzheimer's Association – Carefinder

<http://www.alz.org/carefinder/index.asp>

This interactive tool will give you recommended options and a list of questions to ask when screening a care provider.

AARP -Providing Care in the Home

http://assets.aarp.org/external_sites/caregiving/homeCare/index.html

Eldercare Locator:

<http://www.eldercare.gov/>

Long Term Care. Gov - helps consumers see long-term care planning options for their age group <http://longtermcare.gov/>

The National Alliance for Caregiving

<http://www.caregiving.org/resources/> has

partnered with **Lotsa Helping Hands**

<http://nac.lotsahelpinghands.com/eldercare/home/> to expand resources available to family caregivers. Through this website, visitors may create their own caregiving site to coordinate support needed for the caregiver and care recipient.

Other care sharing calendars:

Care Calendar:

<http://www.carecalendar.org/>

Care Together:

<http://www.caretogether.com>

E-Care Diary:

<http://www.ecarediary.com/>

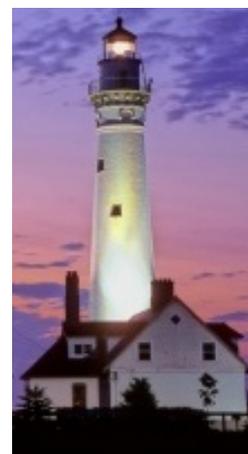
Share the Care:

A model program on how to create a unique caregiving family from friends, relatives, co-workers, neighbors and acquaintances. Visit the Share the Care website at:

<http://www.sharethecare.org/index.html>,

or contact the Aging and Disability Resource Center of Racine County.

*May I have...
Serenity to
accept the things
I cannot change,
Courage to
change the things
I can, and
Wisdom to know
the difference.*





14200 Washington Ave
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Caregiver Opportunities

I Remember Better When I Paint, Treating Alzheimer's through the Creative Arts, Tuesday May 6th 6:30 p.m. Sign up at the Golden Rondelle Theater 262-260-2154.

Mark Your Calendar!

Savvy Caregiver Training Program coming June 10th. Look for more details in the next newsletter, or on the <http://www.alz.org/sewi> website.

Mary Finley, Outreach Specialist from the **Alzheimer's Association**, will be available for family consultations on Wednesday, May 28th between 2 and 4 p.m. at the ADRC office located at 14200 Washington Ave (just west of I-94). This invitation is extended to those dealing with **any type of dementia**. For an appointment call Felicia Elias, 262-833-8761.

Support Groups for Family Caregivers

First Thursday 10:30 am-12 Noon
Alzheimer's Association Group

May 1st

For Families Dealing with Alzheimer's and other Dementias
Lincoln Lutheran Office Bldg, 2000 Domanik Drive, 4th Floor

First Friday 12 Noon-1pm

"Caregiver Connection" Telephone Group

May 2nd

Call 262-833-8762 to pre-register

Second Tuesday 1:30-3:00 pm

May 13th

Yorkville United Methodist Church

17645 Old Yorkville Rd (3 Miles West of I-94, Just N. of Highway 20)

Second Saturday 10:30 am-12 Noon

May 10th

Atonement Lutheran Church,

2915 Wright Ave

Park and enter in back of building (on South side).

Third Wednesday 1:30-3:00 pm

May 21st

Burlington Senior Center, Eppers Room,
209 N. Main St

Third Thursday 6:00-7:30 pm

May 15th

Alzheimer's Association Group

For Families Dealing with Alzheimer's and other Dementias
Atonement Lutheran Church, 2915 Wright Ave
Park and enter in back of building (on South side)