



FAMILY CAREGIVER NEWSLETTER MARCH 2012

Support Group and Event Information Inside

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

Home Alone

Evelyn, my grandfather's widow, was a very independent, strong-minded woman. As she got up in years, she insisted on remaining in the home they had shared. She accepted a little help with household chores, but she wouldn't hear of having a live-in companion. Family and church members worried about her and checked on her when they could. One winter day my mom and brother stopped by to see how things were, and they found her lying on her back porch, where she had died. She apparently tried to take out the trash, fell on the stairs, and was unable to summon help or return to the house. Some people felt guilty for allowing her to be alone, for not taking out her trash, for not coming sooner, etc. Were they guilty of wrongdoing?

Lila, 70 years old, lives with her husband Lawrence, a retired professor. For the last year Lawrence has been experiencing periods of disorientation. Once, while driving the car, he stopped in the middle of the road, "to let the little children cross." There were no children, and the driver behind them barely avoided an accident. Another time he left the house in the middle of the night. When Lila found him down the street, he said he was trying to catch up with "the children". Both times, he was back to his usual, intelligent self in a short time. Lawrence finally had a thorough neurological evaluation and was diagnosed with Lewy Body Dementia. Lila has been with Lawrence day and night since the diagnosis. She has become very depressed and sometimes thinks she's going crazy. She desperately wants to get together with a friend for lunch, and attend a Caregiver Support Group. Can she leave Larry home alone for an hour or two? He says he'll be just fine, and protests against anyone else coming to "babysit" him.

There is often no clear answer to whether or not a care receiver can safely live alone or be left alone. There are several factors to consider when making such a decision. Armed with knowledge of risks and possible solutions, you'll make the best decision you can, given your circumstances.

Concerns with leaving a care receiver home alone fall into three major categories: hazards in the home environment, the person's strength and mobility, and the presence of dementia (deficiency in mental functioning severe enough to interfere with daily life). Here are some questions a caregiving family will want to ask when deciding whether or not to leave their loved one alone:

- Can she summon help when needed? *If she were ill or injured, could she reach and use the phone?*

- Could he escape in an emergency? Is there a clear way out in case of fire, and is he mobile enough to leave quickly?
- Is she strong and steady on her feet? Can she walk without assistance or use a walking aid safely?
- Is he able to access and prepare nutritious food and fluids? Does he have nutritious food in the house? Can he reach cooking utensils? Is he losing weight? Does he seem dehydrated?
- Can she take medications safely and accurately? This requires dexterity to open and handle the meds as well as knowing when and how much to take.
- Does he use appliances in a safe manner? Does he use power tools recklessly or leave the stove on?
- Is she likely to wander (i.e. leave home and become lost)? Over 60% of people with dementia do wander at some time, and we never know who or when. Indications that wandering may be a very high risk include: restlessness, attempting to engage in former activities e.g. going to work, expressing a desire to “go home”.

Here are a few suggestions that may help being home alone safer for some people:

- ❖ **An easy-to-use cell phone** can put a person in touch with help. *He would need to be able to keep the phone with him at all times, make calls successfully, and keep the battery charged.*
- ❖ **A Personal Emergency Response System** (e.g. Lifeline) She can summon help when needed by pushing a button. (Some systems can detect most falls and call help even if the user is unable to push a button). *She would need to remember to wear the device at all times.*
- ❖ **Adaptive equipment** can make the environment safer. Handrails and grab bars reduce the risk of falls. A walker or cane can help steady one’s balance. Gadgets like long-handled “reachers” can make day-to-day tasks less hazardous.
- ❖ **Devices for dispensing medications** are available. Some pharmacies dispense medication in “bubble packs” where each dose is in a separate, easily accessible compartment. Medication reminder and dispensing devices may be purchased or rented from medical equipment providers and some home health agencies. *All of these require the user to be alert and oriented and able to follow directions.*
- ❖ The **Meal on Wheels** program provides a warm meal to homebound seniors, and the delivery volunteer can see whether the senior seems to be OK. If not, the office is notified and a family member contacted.
- ❖ **Family, friends, or volunteers** can call or come in to check and provide companionship. They could organize a care team - a group of people committed to working together for the well-being of a person who needs help. Some older people can thrive in their own homes longer if they are checked on several times a day.
- ❖ **Appliances can be disabled.** *For example a stove could be unplugged or the controls removed.*

Such changes to the environment may not be enough to make it safe for your loved one to be alone. In fact, **if you are concerned with a family member being alone, it’s time to start making an alternate plan now.** You may eventually need to make arrangements so someone else is always present. That person can’t always be YOU. You’ll need help! Here are some options:

Have your loved one attend a daytime respite program e.g. Adult Day Services (see Community Resource Directory) or Harmony Club (262-898-8900).

Enlist help from family members or friends who can provide care and supervision when needed.

Hire professional in-home helpers: companions, personal care workers, or Certified Nursing Assistants according to the needs of the situation. Caregivers can be found through a Home Health Care Agency or privately. (You’ll need to weigh the advantages and disadvantages with

each of these options.) There are agencies which provide live-in caregivers, a less costly options than hourly care around the clock.

Have your loved one move to a residential care facility where staff is on duty 24 hours a day, and the environment is designed for persons with special needs. This can be a very difficult decision for a family. However, it may be the best option available. The loved one still needs his family, - to visit, to share memories, to communicate with staff - but no one is on duty all the time.

You may well be thinking “This all sounds well and good, but how in the world do I get my care receiver to accept any of this?” It is true that anyone of sound mind, no matter how old or how frail, has the right to take some risks. It’s also true that most people balk at being asked to move or have strangers in their home. There are circumstances in which medical and legal professionals must decide that a person is no longer able to make decisions for his/herself. At that point someone else becomes empowered to make decisions about living arrangements. In a future article we’ll explore how to overcome resistance compassionately and what to do when a person may be incapacitated, incompetent, or a danger to self or others.

Caregiving involves some complicated and difficult decisions, doesn’t it? It may help to have someone to talk with about your situation as you weigh the pros and cons. You may want to start with your doctor or other health care provider, call the Alzheimer’s Association, or contact the ADRC.

Decision-making is one of the many skills caregivers add to their toolboxes. It helps to have help!

Evelyn was a lady who insisted on taking the risk of a mishap in order to live on her own terms. No one in the family did anything to intentionally hurt her. So although family members may wish some things had worked out differently, they each did the best they could under the circumstances. Rest in peace, Evelyn!

Lila and Lawrence never know when he will see “the children” or have other misperceptions of reality that may cause him to act unsafely. Therefore, after this, Lila and her friends and family work out a schedule where Lawrence is always with someone. They make each visit so friendly that, Lawrence enjoys this arrangement, a blessing for which Lila is exceedingly grateful.

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](#) (638-6800 or www.adrc.racineco.com)

Meal on Wheels – Provides meals to residents who are homebound and at least 60 years old.
Call **262-637-0727**

Center for Independent Living – has a loan closet for useful equipment. Independent Living Specialists will meet with you determine what would be helpful. Call **262-637-9128**.

This Caring Home – This website takes you through a virtual house and is chock full of tips on making a home safe, especially for someone with dementia. Go to: www.ThisCaringHome.org

Alzheimer’s Association Helpline 1-800-272-3900 – Call anytime with concerns related to any dementia.

Aging and Disability Resource Center (ADRC) of Racine County: Provides information and support in decision-making to caregiving families.. Call **262-638-6800**,

Tele-Care is a service for people who live alone and need contact with someone at least once each day. People are contacted once a day for a check-in and reassurance. Family members are called if a person cannot be contacted. (Call in **Burlington: 262-763-2473; in Racine: 262-687-4292**).

SUPPORT GROUPS FOR FAMILY CAREGIVERS

First THURSDAY 10:30AM-12Noon ****THIS GROUP FORMERLY MET ON FRIDAYS.**

Alzheimer's Association Group – MAR. 1
For Families Dealing with Alzheimer's and other Dementias
Lincoln Lutheran Office Building, 2000 Domanik Drive, 4th Floor

Second Tuesday 1:30-3:00 pm MAR. 13
Yorkville United Methodist Church
17645 Old Yorkville Rd.
(3 Miles West of I-94, Just N. of Highway 20)

Second Saturday 10:30AM-12N MAR. 10
Mount Pleasant Lutheran Church, 1700 S. Green Bay Road

Third Wednesday 1:30-3:00 PM MAR. 21
Burlington Senior Center, Eppers Room, 209 N. Main Street

Third Thursday 6:00-7:30 PM

Alzheimer's Association Group MAR. 15
For Families Dealing with Alzheimer's and other Dementias
Mount Pleasant Lutheran Church, 1700 S. Green Bay Road
1700 S. Green Bay Road

OTHER EVENTS FOR CAREGIVING FAMILIES

Caregiving Relationships

A workshop about caregiving issues, including stress, emotions, effective communication, problem-solving, decision-making, and more.

Saturday mornings, March 24, 31 and April 7th, 10:30-Noon

See accompanying flyer

From Alzheimer's Association:

Paulette Kisse, Outreach Specialist, will be available for two family consultations on March 28 between 2 and 4 pm. at the Ives Grove County Building, 14200 Washington Avenue. Sturtevant

For an appointment call **Felicia Elias, 833-8761**

**Marilyn Joyce, Caregiver Support Specialist,
Aging and Disability Resource Center of Racine County
262- 833-8764 marilyn.joyce@goracine.org**