



FAMILY CAREGIVER NEWSLETTER
FEBRUARY 2013

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

HELP, HELP!

Helen is a 64-year-old retired school teacher who cares for her husband Larry because he has Parkinson Disease with dementia. Helen has had rheumatoid arthritis for many years and meeting Larry's physical needs is becoming more and more difficult for her. She also has high blood pressure, for which she takes medication. Helen has always been very independent and proud of it. She is devoted to Larry, and she adjusts her expectations of herself frequently as his needs increase. His medications are often changed, so there are many trips to the doctor and pharmacy, which are difficult because of Larry's mobility problems and sometimes his behavior. He is not able to assist with his transfers like he used to, and Helen is exhausted and in pain much of the time. Still she tells her children and her friends that she is "doing just fine." She has no plan for getting help because "Larry wouldn't want other people coming into the house."

It may seem obvious to you that Helen is blinded by her expectations of herself and that she desperately needs help. This month's issue of the Family Caregiver Newsletter asks you to take a look at your own situation and make a plan for the help YOU need.

Deciding whether or not you need help with caregiving is really not complicated. You have a family member who needs care now and for the foreseeable future, and whose care needs will increase as time goes on. You have other roles and commitments in life. You must tend to your own health and well-being. OF COURSE you need help! Family caregiving is not an individual sport. It takes a team. The questions are: What specific help do you need now?; How will you ask for it? What are family and friends willing and able to volunteer for?; and, What help will need to be purchased? The Caregiver Worksheet will walk you through the principles of getting the help you need in your situation.

What help is needed? Respite (time away from caregiving) is by far the most desired form of help for caregivers. This can be someone to stay with your care receiver while you get away; a day respite program like Harmony Club or adult day care; or even overnight coverage while you take a trip or just rest. All caregivers need respite time, including you!!

Help with physical care tasks e.g. bathing and lifting is also commonly needed. This may require the expertise of a Personal Care Worker or Certified Nursing Assistant and usually needs to be purchased. You can hire someone from an agency or a private care provider. Some families hire a live-in caregiver. If your care receiver qualifies for Medicaid (Title XIX), funding is available to provide ongoing help in the home (see *Community Resources*).

Then there are your everlasting responsibilities like yard work, snow removal, car and home maintenance, endless errands, medical appointments, and the list goes on. These are tasks which may be carried out by family members or friends. Do not feel guilty when you think about how nice it would be to have help. Planning for help is a sign of caregiver strength.

Some Sources of Help

There are probably people you know who would be willing and able to help in some way if they were asked. You may have family, friends, neighbors, and people from church, or other organizations who would like to help you if they knew how. Some caregivers have been greatly helped by a Share the Care Team., whereby a group of people are committed and organized to meet the needs of a caregiving family. Call or have a friend call Ruth at 833-8764 to find out more about this innovative model.

Sometimes help is in the form of streamlining the things we get used to doing every day. For example, with medication changes and refills, you may have a lot of trips to your pharmacy, as well as the responsibility of keeping all the doses straight. For a very reasonable fee, you can find a pharmacy that delivers medications to your home all sorted out in individual doses. That is quality help that is affordable and doesn't feel like asking for favors.

Hospice services provide help and support to you and your loved one and are covered by Medicare. This care is not just for the very end of life. Talk with a hospice agency and/or your doctor to determine when this might right for your situation.

Transportation programs can provide great relief to caregivers, especially in difficult weather. The Paratransit Program provides a low-cost way to medical appointments, Harmony Club, and adult day care. For a little higher fee you can have more personalized service through the Independent Transportation Network of Racine County or Skill Bank.

Options Counseling from the ADRC will help you sort out all the options available and decide which services are best for you.

Barriers to Getting Help

When you think of getting help, you may seem to run into a wall of resistance in your mind. All caregivers encounter some barriers to making this change. Surprisingly, we may have helped build some of those barriers ourselves. Some hurdles to overcome are:

- ❖ Self-expectation: (“I should do it all.”) Don't “should” on yourself!
- ❖ Denial: (“I don't have it so bad.” or “He will get better soon.”)
- ❖ Objections of care receiver: (“He doesn't want anyone but me.”) Your loved one has a disease. You would like to make every moment comfortable and happy for him or her. That's compassionate but not realistic. There will be times when he will have to adapt to things he doesn't particularly like. He can adapt to the help you need, if you let go of expecting yourself to make everything all right for everybody.
- ❖ Cost: – If your care receiver has assets, they may need to be used for his or her care needs, even though it was planned that they would be passed down to heirs. A disease that requires long-term care happens to the whole family and may change plans for inheritance. For care receivers who don't have more than \$2,000 in assets, there is public funding available (see *Community Resources*).

- ❖ Anxiety about asking for help: – This is one of the most difficult things caregivers do. The first time asking for help (especially volunteer help) is like an initiation. See the Caregiver Worksheet and get support from a friend or other caregivers.
- ❖ Fear of losing control: – Sometimes you may need to realize that others may not do things as you would. If the care they provide is safe, you'll need to let go of making sure it's "perfect."
- ❖ Guilt feelings: – Real guilt is for when you have done something deliberately to hurt somebody. Guilt feelings arise when we are unable to meet unreasonable demands we place on ourselves. You did not cause your loved one's disease nor can you take away all suffering. It's OK to feel compassion, sadness, and sometimes regret. But don't let these emotions stand in the way of taking care of yourself.

Helen continues to care for Larry by herself. As time goes on, she gets little sleep and has constant flare-ups of her rheumatoid arthritis. She takes more pain medicine and pushes on, having no time to see her own doctor. One fateful day Helen suffers a major stroke, which causes lasting damage to her physical and mental functioning. Now she can no longer care for Larry at all. Furthermore, she and her family and friends will miss out on the many things she planned to do with them "someday."

Consider the price of help versus the price of no help!! Can you think of a better ending for Helen's story...and yours?

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 (638-833-8777) or www.adrc.racineco.com)

The Alzheimer's Association and the Veterans' Administration have a grant to provide free respite to Veteran caregiving families dealing with dementia. You can qualify for a several hours a week of respite time, and priority is given to caregivers who wish to attend support groups or classes. The Veteran can be either the care receiver or the caregiver. Call the ADRC (833-8777) or a Caregiver Support Specialist today!

Publicly Funded Long-Term Care Programs – If your care receiver qualifies functionally (needing a certain level of care) and financially (being eligible for Medicaid (Title XIX), you can get plenty of help with respite, physical care, transportation, and an other services even while your loved one lives at home. Call the ADRC (833-8777) and ask for Options Counseling. An Information and assistance specialist will help you determine if this is a good fit for your situation.

Support Groups for Family Caregivers

First Thursday 10:30AM-12Noon

Alzheimer's Association Group — FEB. 7

For Families Dealing with Alzheimer's and other Dementias

Lincoln Lutheran Office Building, 2000 Domanik Drive, 4th Floor

First Friday 12N-1PM **FEB. 1**

“Caregiver Connection” Telephone Group

Call 262-833-8762 to pre-register.

Second Tuesday 1:30-3:00 pm **FEB. 12**

Yorkville United Methodist Church

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

Second Saturday 10:30AM–12N **FEB. 16**

Atonement Lutheran Church, 2915 Wright Ave., Racine

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

Third Wednesday 1:30-3:00 PM **FEB. 20**

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

Third Thursday 6:00-7:30 PM

Alzheimer’s Association Group **FEB. 21**

For Families Dealing with Alzheimer’s and other Dementias

Atonement Lutheran Church, 2915 Wright Avenue, Racine

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

Other Events for Caregiving Families

From the Alzheimer’s Association

Understanding Dementia – Three sessions beginning Feb 21

Orientation to Early Memory Loss – Feb. 26 9:30 AM

Please see accompanying flyers for descriptions and registration information

Paulette Kisse, Outreach Specialist, will be available for two **family consultations** on
Wednesday, **Feb. 23rd** between 2 and 4 pm.

at the Racine County Ives Grove County Offices, 14200 Washington Avenue, Sturtevant

For an appointment call **Felicia Elias, 262-833-8761**

Caregiving Relationships

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

Three Saturdays 10:30AM-12:30 PM, beginning March 16th.

Call Marilyn at 262-833-8764 for more information.

Marilyn Joyce, Caregiver Support Specialist,
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