

Family Caregiver Newsletter

Newsletter Date March 2015

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.

Decisions

Fred is an 82-year-old caregiver to his wife Anita. She has Parkinson's Disease. Fred has cared for Anita since her diagnosis 12 years ago. He's very proud of having tended well to her ever-increasing needs. His own health, however, has declined during that time, and he now has congestive heart failure, macular degeneration, and clinical depression. Fred's children are insisting that Anita go to live at a care facility. Fred has always wanted to care for his beloved at home for the rest of her life. Now his doctor tells him that without help he is likely to die before her, leaving her in the hands of strangers and without a husband to be a companion and help manage her care. He is faced with a very difficult decision: can he get enough help in the home so that Anita could stay there? Should he ask her to move to a facility that can provide for her physical care? If so, which facility?

Sally's father is 84 years old and has dementia. One of Sally's concerns is that he still drives. He insists that there is no problem because he always has his wife

in the car to help him navigate and make decisions. Sally is very worried about this situation. She is pondering what to do: try to have her dad's license revoked, forcibly take the keys away, disable the car, or let the situation ride for now?

It's a tremendous responsibility to make decisions on someone else's behalf. Caregiving decisions are especially complicated because they involve not only the caregiver and care receiver, but often other family members as well. Here are some key thoughts on decision-making for caregiving families:

- Any decision you make will likely have both positive and negative consequences.
- Sound, compassionate decision-making involves the risk that you might make mistakes.



Considered decisions can help to open doors for both caregiver and care receiver.

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Contact:
Marilyn Joyce
Caregiver
Support
Specialist

Aging and
Disability
Resource
Center of
Racine County

262- 833-8764
marilyn.joyce@goracine.org



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- Mistakes can provide important information to guide further decisions.
- The health and well-being of the primary caregiver is one of the **MOST IMPORTANT** factors to consider when making plans for family caregiving.

The Caregiver Helpbook suggests the following model for making caregiving decisions. Notice that decision-making is an ongoing process, not a “one-shot deal.” This takes away the pressure and fear that a “wrong” choice will be made permanently. Here are the recommended steps:

1. **Define the problem.** Be factual and as specific as possible, e.g. “Dad’s driving skills are affected by his dementia. My health problems are being affected by lifting and lack of sleep, and constant stress.”
2. **Gather Information.** Get facts about the care receiver’s health and level of functioning AND the state of the primary caregiver’s health. Find out what services are available and affordable. Talk with other caregivers, explore online resources, ask experts like the ADRC or the 24/7 Alzheimer’s Association Helpline.
3. **Make a list of options.** Have a brainstorm with other helpful people. Make a list of all ideas for solutions to the problem. Don’t stop to discuss or “over think” any options. Just keep the ideas flowing.
4. **Evaluate the options.** List the benefits and the limitations for each idea. Usually there is no “right” or “perfect” course of action. Many times the best solution is to blend two or more ideas from your list.

5. **Create a plan.** A good plan meets the care receiver’s needs in as comfortable an environment as possible AND it doesn’t unduly burden a family caregiver. At times it may seem as though you must choose the “least worst” option, but it may be the best plan available to you at the time.

6. **Act on Your Plan.** What are the first steps? Who will carry them out and when? Make a timeline for putting the plan in place. Decide on a trial period e.g. “We will revisit the situation in a month to see how well the plan is working.”

7. **Reassess the plan and make necessary changes.** – Are the needs of the care receiver and the family being met? Does anything need to be tweaked? Should a different option be tried? Who will initiate changes? Flexibility is decision-making at its best!!

Include your loved one in decision making as much as possible and always consider his/her feelings. Unless the person has been deemed incapacitated* or incompetent,** decisions need to be made with (not about) him or her. Plans made without the care receiver often backfire! For instance, help hired may well be fired, and decision making begins all over again. Your long time knowledge of your loved one will guide you. For instance, for a person who has been a bird lover, a facility that has a birds might be the best choice if it can also provide for other needs.

You may feel guilty if a decision also serves your need for relief from stress. However, it’s important to consider YOUR well-being as well as that of the person you are taking care of. You

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need to remain healthy enough to provide what's most important to your loved one - your presence, your companionship, and your love.

Finally, when making a decision, give yourself time. In Daily Comforts for Caregivers Pat Samples says "...the harder I push myself to decide, the more confused I get." She suggests doing something else until one's mind clears or having some quiet time to "turn to my intuition or my Spiritual Power for insight." We often refer to this as "sleeping on it," and that is wise advice.

We don't know what decisions Fred and Sally will make in their present

situations. But we do know that as conscientious caregivers, they have the **wisdom** to gather information and make a plan, the **courage** to carry it out, and the **flexibility** to modify it if necessary. That's really all they need.

*Incapacitated means unable to make decisions regarding one's health care. This is determined by an activated Power of Attorney for Health Care, which was completed when the person was in better health.

**Incompetence is determined by a court of law involving guardianship.



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

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.

Alzheimer's Association Happenings in March

As always, there is a **24 hour helpline** that you can contact with any questions you may have relating to someone who is living with an irreversible dementia like Alzheimer's. They can talk about programs, services, managing behavior and much more. Many caregivers describe the helpline as a "lifesaver."

800-272-3900

Understanding Dementia

This course will be offered in Kenosha at the Public Library. Tuesdays March 3, 7, 10 from 1 pm to 3 pm.

The Kenosha Public Library is located at 7979 38th Ave (approximately 14 miles

from downtown Racine). It will be held in the Conference Room.

The course is free and you can register by calling Deborah Klement at the Alzheimer's Association of Southeastern WI at 414-479-8800.

Help Fellow Caregivers

The ADRC is planning a seminar (later this year) for those who balance family caregiving with employment. The planners would like you to tell us "What I Wish I'd Known." Please help us make this workshop more helpful by giving Marilyn your answer by mail, phone, or email (see contact information on the left side of page 2.)

Thank you for sharing your wisdom.





14200 Washington Ave
Sturtevant, WI 53177

Caregiver Opportunities

Please note that the **Caregiving Relationships** course that was promoted in the February edition of the newsletter has been postponed until later in the year. Apologies for any inconvenience. Please watch for the new date in the future, or call if you would like to be put on a contact list about this program. Marilyn 262-833-8764.

At the Golden Rondelle:
“Alive Inside” A Story of Music and Memory
Thursday March 12, 2015
7:00 to 9:00 p.m.
1525 Howe St, Racine
RSVP to 262-260-2154



Support Groups for Family Caregivers

First Thursday 10:30 am-12 Noon March 5th
Alzheimer’s Association Group

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

First Friday 12 Noon-1pm “Caregiver Connection”
Telephone Group March 6th
Call 262-833-8762 to pre-register

Second Tuesday 1:30-3:00 pm March 10th
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 March 14th
Atonement Lutheran Church
2915 Wright Ave
Park and enter in back of building (on South side)

Third Wednesday 1:30-3:00 pm March 18th
Burlington Senior Center, Eppers Room
209 N Main St

Third Thursday 6:00-7:30 pm March 19th
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)