



FAMILY CAREGIVER NEWSLETTER
OCTOBER 2012

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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, Decisions

Fred is an 82-year-old caregiver to his wife Anita, who has Parkinson Disease. Fred has cared for Anita since her diagnosis 12 years ago. He is 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 residential care facility. Fred has always wanted to care for his beloved wife at home for the rest of her life. Now his doctor tells him that 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 get enough help in the home 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 behalf of someone else. Caregiving decisions are especially complicated because they involve not only the caregiver and care receiver, but often other family members as well. Here are a couple of 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. Mistakes can provide important information to guide future 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. It has proved helpful to many families. It shows that decision-making is an ongoing process, not a "one-shot deal". This takes away the pressure of fearing that the "wrong" choice will be made permanently.

Here are the recommended steps:

- **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.”
- **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
- **Generate Options** – Have a Brainstorm! 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,
- **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. A viable option should NOT unfairly burden anyone.
- **Create a Plan**
A good plan includes three aspects. It meets the care receiver’s needs, preserves the greatest control and freedom for him or her, and doesn’t unduly burden the primary caregiver. Usually there is no one “right” plan and certainly no perfect one. At times it may seem as though you must choose the “least worst” option. If it meets these three criteria, though, it may be the best plan available to you at this time.
- **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.”
- **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? Does there need to be a conversation with a care provider? Should a different option be tried? Who will initiate changes? Making necessary adjustments is decision-making at its best.

Include your loved one in decision-making as much as possible, and always consider his or her feelings. Unless that person has been declared incapacitated or incompetent, you need to make decisions 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. Family members may need to have some discussions without the care receiver present, and then the need for change and the choices available can be presented to their loved one in a sensitive manner. Remember that, under the law, competent older people have the right to take risks. If a person has been declared incapacitated (unable to make decisions about health care) or incompetent (unable to manage any personal affairs), then someone must make decisions on his or her behalf. Looking back on that person’s preferences over time may help in making the best decision. For instance, for a person who has been a bird-lover, a facility that has a large cage of 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 need to remain healthy enough to provide what’s most important to your loved one: that is 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 “going with our gut”, and that very 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.

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)

Online organizations can provide information and connections with other caregivers. Some examples are: National Family Caregivers Assn. www.thefamilycaregiver.org ; Alzheimer's Association www.alz.org and Assist Guide Information Services for Caregivers www.agis.org

Disease-specific organizations can be gold mines of information. Many are listed in the *Community Resource Directory*.

You may call to the Aging and Disability Resource Center (262-833-8777) and schedule Options Counseling, where an Information and Assistance Specialist will meet with you and help generate viable ideas for your particular situation.

Caregiver Support Specialists at the ADRC can meet with you or offer phone support.

The following book is available in our Caregiving Library: *A Family Caregiver's Guide to Planning and Decision Making for the Elderly*, by James A Wilkinson, a lawyer and caregiver for his father. It can be checked out by calling: 262-833-8764.

Support Groups for Family Caregivers

First Thursday 10:30am-12Noon

Alzheimer's Association Group — OCT. 4

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

First Friday 12Noon-1pm OCT. 5

"Caregiver Connection" Telephone Group
Call 262-833-8762 to pre-register.

Second Tuesday 1:30-3:00 pm OCT. 9

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

Second Saturday 10:30am–12Noon

OCT. 13

Mount Pleasant Lutheran Church, 1700 S. Green Bay Road

Third Wednesday 1:30-3:00 pm

OCT. 17

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

Third Thursday 6:00-7:30 pm

Alzheimer's Association Group

OCT. 18

For Families Dealing with Alzheimer's and other Dementias

Mount Pleasant Lutheran Church, 1700 S. Green Bay Road

Other Events for Caregiving Families

Paulette Kisse, Outreach Specialist, will be available for two **family consultations** on Wednesday **October 24th**, between 2 and 4 pm. at the Racine County Ives Grove County Offices, 14200 Washington Avenue. Sturtevant For an appointment call **Felicia Elias, 833-8761**

Living Well with Chronic Conditions

A class in self-management of one's ongoing health problems.
Thursdays, Oct. 25 – Dec. 5 (No class on Thanksgiving Day)
(See accompanying flyer)

“The Heart of the Matter”

A special event for family caregivers
In Celebration of National Family Caregiver Month
(See accompanying flyer)

Halloween is coming! Find reasons to laugh and share the merriment of children. And don't forget to treat yourself!

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