

Family Caregiver Newsletter

Newsletter Date June 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.

Obstacles on the Road to Balance

Alice and David are both retired teachers, age 69. David was diagnosed five years ago with Multiple Sclerosis (MS). David and Alice have both determined to live life to the fullest as long as they can, and over the last five years they have hiked, biked, travelled and spent many happy hours with family and friends. Now David's needs are increasing. Biking is out of the question, hiking is done with a walker slowly, around the block, and travelling presents many challenges. Alice is exhausted. Each day seems like an endless stream of responsibilities, many of which she has no time or energy to address. Nights are often sleepless. Alice's friends comment that she appears pale, is losing weight, and seems always sad. They complain that she doesn't respond to their invitations for outings. They encourage her to get some help, but David says he doesn't need that, at least not yet, and he won't allow strangers in the house. Alice realizes that she isn't as patient with David as she used to be. She appeals to his son and daughter to spend time with him, but they are "just too busy."

Alice talks with a Caregiver Support

Specialist who says:

- Get help.
- Don't try to do it alone.
- Caregiver stress can damage your health and your relationships.

This is good advice, of course. Nevertheless, as Alice tries to navigate toward healthy, balanced caregiving, she finds obstacles strewn in the roadway.

First, there is a big orange barrel with graffiti in David's handwriting: "I don't need help." "I don't want help." "No strangers in my home." "I only take help from the best: Alice."

"Hired help is too expensive."

Around the next corner sits a huge boulder rolled into the road by family members declaring: "We're too busy." "We want to remember our Dad the way he was." "You married him, so it's your job." "We don't trust service providers." "Don't spend Dad's money on things you could do yourself."

Then Alice encounters a stone wall. Graffiti on it reads: "I want to do it



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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](mailto:marilyn.joyce@goracine.org)



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all.” “I’m the only one who can do it right.” “I would feel so guilty letting anyone else take care of him.” “I’ve heard horror stories.” “If I spent the money now, how would I live later?” “I don’t want him to feel uncomfortable.” “No one else will do it like I do.” She suddenly realizes that she has built that wall herself! She has a choice: dismantle the wall or fall down a ravine!

Let’s look at these very common obstacles that can prevent caregivers getting enough help in time.

First - David’s barrel of objections:

They are all very understandable; none of us would choose to be in David’s shoes. However, they are based on the caregiver relationship being one-sided. Alice gives and David receives. There is a better model for this arrangement: a partnership. Both David and Alice have challenges. Neither of them wants David to have the disease. It’s a cruel blow. Nevertheless, Alice can’t take away all discomfort, inconvenience, embarrassment, sadness, etc. that comes along with it by sacrificing her own health.

There are many ways to relieve stress for a caregiver. There are day respite opportunities that provide socialization for the person who needs care as well as relief for the caregiver. So David and Alice need to think of themselves as a pair of Care Partners, sharing difficulties, challenges, and good times as they come. If Alice gets the help she needs, she’ll be able to support David through this journey in more important ways than doing endless errands and chores. David may also feel better about being a Care Partner rather than a Care Receiver.

Then comes the boulder of family objections:

In this case, Alice needs some assertive communication techniques and a

duck suit!

Here are some brief suggestions. First, Alice may find “I” messages effective in warding off arguments from unhelpful family members. “I can’t...” “I’m not able to...” “I’m willing to do (this) but not (that.)” Another good answer is: “My doctor told me I must slow down or I’ll be very ill.” (No doubt Alice’s doctor will tell her that after hearing her story.) Being specific in what needs to happen without blaming anyone has a good chance of being effective. One brochure says that the best way to ask for the help you need is to simply say, “I need help with....” So Alice could say something like: “I need someone to stay with David for two hours on Wednesday mornings.”

And the duck suit? You need one in your wardrobe to help criticism, insults, and guilt feelings roll off your mind like water off a duck’s back. Call 262-833-8764 for your own little rubber duckie if you need a reminder not to absorb negativity – yours or anyone else’s.

Regarding the stone wall we sometimes build ourselves:

When my husband Bryan was ill, I had all of the thoughts on Alice’s wall. When people came into the house, I felt vulnerable, inconvenienced, and exposed. I even felt embarrassed that my house was such a mess. I thought that this was never going to work. My Caregiver Support friends, listened, heard my dilemma, and encouraged me to continue accepting help. When I finally decided to lay my misgivings aside, it was like jumping into deep water. But I survived!

When someone comes in to help, you become a **Care Manager**. Be honest with staff. Be the eyes and ears for the agency. Report discomfort or evidence of substandard care or inappropriate behavior. Do it for the good of your

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family, the agency, and people who will need help in the future.

Another means of stress relief is a day program (e.g., Harmony Club or Adult Day Programs). These can provide the person who needs care with an outing and some socialization as well as good, safe care and respite for the caregiver.

Some thoughts on the “too expensive” concern:

Think of paid services as an investment in the health and well-being of the care partners and the whole family relationship. Some things are exponentially more important than dollars – sense for one, in fact!

When the care receiver’s funds are near depletion, there are publicly funded long-term care programs available. How to go about finding the right resources to meet the needs of both the care receiver and the caregiver contact the Aging and Disability Resource Center and request:

Options Counseling

There are many choices when it comes to resources, services, and programs. That’s why the ADRC offers Options Counseling meetings with staff who are especially knowledgeable about what is available and how best to access what is needed in your particular situation. These Information and Assistance Specialists can meet with you in your home or at the ADRC office. They will listen to your story, clarify what your needs are, and support you in your decision-making. They will explain various levels of services provided by agencies and residential facilities. They can also give you information about publicly funded long-term care (Family Care, Partnership, IRIS), Medicaid and other information on topics such as Spousal Impoverishment Protection. They also refer families for Caregiver Support if requested.



Begin building a new bridge for your road.

*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.

Consider supporting your caregiving relationship by attending a class. Here is the schedule:

2015 Class Schedule:

Stepping On

A class to help prevent falls and promote health. Call Felicia at 262-833-8761

1). Aurora Wellness Center, Burlington **August 7th - Sept 18th** 1:00 p.m. – 3:00 p.m.

2). Sealed Air YMCA **September 3rd – October 15th** 1:00 – 3:00 p.m.

Powerful Tools for Caregivers

Providing caregivers with information and resources. Call Marilyn at 262-833-8764. Atonement Lutheran Church 2915 Wright Ave, Racine. **August 3rd - September 14th** 1:00 to 3:00 p.m.

Caring for someone with a dementia? Check out the Alzheimer's Family Caregiver Support Program (AFCSPP). Call Felicia at 262-833-8761.





14200 Washington Ave
Sturtevant, WI 53177

Caregiver Opportunities

Caregiver Consultations:

Tasha Orr-Holmes of the Alzheimer’s Association will provide care consultations for families dealing with any type of dementia.

Tasha has openings for Thursday June 18 from 10:00 a.m. - 12:30 p.m. We will schedule 2 one hour appointments. To schedule an appointment with Tasha contact Felicia at 262-833-8761.

Summer Seminars at the ADRC

June 9th - **Balance between Caregiving and the Workplace**

June 12 - **Housing Options**
June 26th, the popular—**Guardianship and Power of Attorney Seminar** is back
Call 262-833-8777 to register.



Support Groups for Family Caregivers

First Thursday 10:30 am-12 Noon June 4th
Alzheimer’s Association Group

For Families Dealing with Alzheimer’s and other Dementias
2000 Domanik Dr, 1st Floor United Way conference room

First Friday 12 Noon-1pm “Caregiver Connection”
Telephone Group June 5th

Call 262-833-8762 to pre-register

Third Tuesday 1:30-3:00 pm June 16th

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 June 13th

Atonement Lutheran Church
2915 Wright Ave
Park and enter in back of building (on South side)

Third Wednesday 1:30-3:00 pm June 17th

Burlington Senior Center, Eppers Room
209 N Main St

Third Thursday 6:00-7:30 pm June 18th

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)