



## FAMILY CAREGIVER NEWSLETTER

### MAY 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.*

#### **"Information, Please"**

*Melissa is a college student in Arizona. Her parents and grandparents live in Racine County. Melissa's beloved grandpa has Alzheimer's disease. Her grandma seems frazzled and distant. The other night Grandpa tried to leave the house at 3 AM. Her parents don't know what to do next.*

*Will someone need to be with him all the time from now on? How will they pay for the care he needs? Is there any help for family members who feel so stressed, sad, and alone? In conversations with her family, Melissa senses that they need outside help and information but are too busy and stressed to reach out. Melissa takes out her computer and appoints herself the "Family Information Seeker." She will gather all the information she can about Grandpa's disease, his medications, services, the financial help available, and moral support for her caregiving family. She is glad to have a role in her family's time of need even though she's far away.*

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*Brad is a 35-year-old businessman who travels a lot for his job. Christine, his 56-year-old mother, lives with her mother Louise, 77, who has diabetes. Louise needs daily assistance, as she has many diabetic complications. She is legally blind, has neuropathy which hampers her mobility, and is now facing serious kidney disease. Christine has tended to her mother's needs for several years – monitoring her glucose levels, administering the correct dosage of insulin and other medications, helping her with personal hygiene, taking her to medical appointments, preparing proper meals, taking care of the house inside and out, and so on. Christine feels isolated and exhausted. She rarely has time to keep in touch with the rest of her family. Brad sees that his mother is exhausted and depressed. He wants to help her somehow, but his time at home is so limited, and he needs to spend most of it with his children. One day Christine asks him to find out what help there is in the community. This is something he can do even when he is away from home.*

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Information is power for caregiving families! Unfortunately many primary caregivers (those who handle the most responsibility) often don't have time or energy to gather facts and find the help they need. That's why caregiving families need an Information Specialist. In today's world that person can help the family from any location. If you are a primary caregiver, ask family members to gather information for you – especially if they say, "Let me know if I can do anything" or "I'd like to help, but I'm so far away." Write down questions and issues as you think of them, then pass your concerns on to your

information helper and ask for feedback in a reasonable time.

Here are a few examples of areas you'll need information about:

- **Knowledge about the care receiver's disease:** What is known about this condition? Does it get worse as time goes on? What are the possible complications? What medications and treatments are recommended? Where are health care providers who are prepared to treat this condition?
- **Facts about finances:** How will we pay for care and treatment? Does the care receiver qualify for Veterans' Benefits? Public assistance programs? Drug Discounts? What does Medicare cover? What is Medicaid (Title XIX)?
- **Help in making plans:** How do I prepare for the future financially, legally, emotionally? How do I find in-home health care or other in-home assistance? What if we need to have our loved one move to a care facility? How will we find a good place? How can we pay for care?
- **Support for caregivers:** How could I get in touch with other caregivers? Can I get away for a few hours or even a few days? How can I get reasonably priced help with outside work and home maintenance? Where can I get ideas for how to cope and stay healthy?

A family meeting is one good way to share information someone has gathered. That way everyone can be on the "same page." People who can't attend a family meeting in person can be present by phone, email, or Skype, etc. It's a good idea to document what you've learned. That way other family members can stay informed by email or Fax.

### **Every caregiving family needs at least one information seeker.**

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*Melissa begins her quest by googling "Racine County, WI Aging Services" where she finds the Aging and Disability Resource Center (ADRC). The ADRC website turns out to be a treasure trove of information. Melissa follows a link to the Alzheimer's Association Website, and finds a ton of information on dementia, caregiving, support groups, classes, and a 24-hour Helpline (800-272-3900). She calls the ADRC, describes the situation, and discovers even more - Senior Services' Caregiver Support Program and the day respite programs of Harmony Club and Adult Day Services. She also discovers that since her grandpa is a veteran, he may qualify for benefits to help pay for services as well as support for her grandma through the VA/Alzheimer's Project. She documents the information she has gathered and emails it to her parents. They schedule a family meeting via Skype, where they discuss what to do next and how Melissa can help.*

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*In the air on his way to China, Brad learns more than he ever knew about diabetes from some health information sites (see Community Resources section on next page). He visits the ADRC website and finds the Community Resource Directory (see next page) with sources of help for caregivers, information on financial assistance, and services for the elderly in Racine County. Later he calls the ADRC, describes the situation, and learns that there may be some public funding for his grandma's long-term care right in her home. He sets up an appointment for Options Counseling, then assists his mother in applying for Family Care. Once the enrollment is complete, his mother Christine finally has some time away from caregiving. She reconnects with friends, spends time with her grandchildren, and participates in a Caregiver Support Group. She also finds that Skillbank is a community organization that can help her find assistance with outdoor work and home maintenance at a reasonable price. Brad has provided the impetus for major changes which will help his family cope with their situation for the long run.*

## **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](http://www.adrc.racineco.com))*

### **Useful websites for information seekers:**

[www.n4a.gov](http://www.n4a.gov) (stands for National Association of Area Agencies on Aging). From this site you can find local information about resources for the elderly in any county or tribal unit in the US.

[www.medlineplus.com](http://www.medlineplus.com) and [www.webMD.com](http://www.webMD.com) are sites filled with information about health conditions.

### **Aging and Disability Resource Center (ADRC) of Racine County**

This is the place to begin your search for specific services in Racine County. You can begin by visiting [www.adrc.racineco.com](http://www.adrc.racineco.com) for a general overview of services. Then call **262-638-6800**. An Information and Assistance Specialist will answer your questions and address your concerns. I & A Specialists are widely knowledgeable. They can discuss topics such as in-home care and respite opportunities, assistance for low-income families, transportation services, medical supplies and equipment, home-delivered meals and how to apply for public assistance for long-term care and much, much more. If necessary, they will schedule an appointment for Options Counseling. This is a more in-depth, face-to-face meeting to discuss resources that are best for your particular situation and help you plan for the future.

The Community Resource Directory is published by the ADRC. It is available in print form (call **638-6800**) and is also on the ADRC website (see below). Information is updated continually, and the most current will be on the website. Just a few examples of categories listed are: Diseases/Disability, Care in the Home, Food, Meals and Nutrition, Vision Impairments, and Assistive Technology. This directory is thorough, well-researched, and invaluable to caregiving families. You can also use the assist guide function (find a service) to search for various services available in the area.

To access it online,  
go to [www.adrc.racineco.com](http://www.adrc.racineco.com);  
select Resources on the left;  
select service directory from the drop-down menu; then  
select Community Resource Directory

## **Support Groups for Family Caregivers**

**First THURSDAY 10:30AM-12Noon - MAY 3**

**Alzheimer's Association Group**  
**For Families Dealing with Alzheimer's and other Dementias**  
Lincoln Lutheran Office Building, 2000 Domanik Drive, 4<sup>th</sup> Floor

**Second Tuesday 1:30-3:00 pm - MAY 8**

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

**Second Saturday 10:30AM–12N** - **MAY 12**

Mount Pleasant Lutheran Church, 1700 S. Green Bay Road

**Third Wednesday 1:30-3:00 PM** - **MAY 16**

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

**Third Thursday 6:00-7:30 PM** - **MAY 17**

**Alzheimer's Association Group**

**For Families Dealing with Alzheimer's and other Dementias**

Mount Pleasant Lutheran Church, 1700 S. Green Bay Road

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**COMING SOON: A support group by teleconference.**

**Call 262-833-8764 for more information.**

## **Other Events for Caregiving Families**

“The Heart and Soul of Caregiving to Loved Ones with Dementia:  
The Challenges and Joys” – A free program with lunch  
May 22, 9AM-Noon

and

“Understanding Dementia” – Educational Program for Family  
Caregivers

June 14, 21, and 28, 6:00-8:15 PM

**Please see accompanying flyers for more information**

**Marilyn Joyce, Caregiver Support Specialist,  
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