

# Family Caregiver Newsletter

Newsletter Date October 2013

## 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.

## The Person at the Center

Hello! I'm Tony. I'm an engineer. I'm a wood carver. I'm the husband of Theresa, father of Julie and Brad, and grandfather of beautiful, bubbly 3-year-old Alana. I'll soon be 70. I have Multiple Sclerosis (MS for short). I like listing the MS *last*, but it seems to be front and center for most people who talk to me. In the last few years it seems that no one has asked me about much of anything else. "How's the new wheelchair, Tony?" "Can you speak louder, Tony?" "Tony, can you go to the bathroom now?" "How are the legs working today, buddy?"

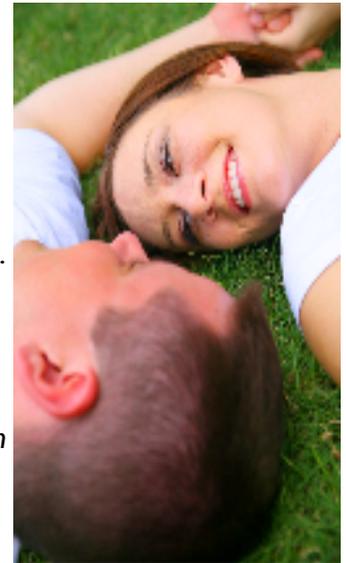
Theresa was my lovely bride 40 years ago. We worked hard and provided our family with a comfortable and loving home. We took good care of our children as they grew. Diaper changer, little league coach, driving teacher...I've done it all. Oh, and I carved all those authentic, detailed figures you see in this room. I won quite a few prizes, too! I volunteered at the local food bank, and I was on the city council for many years. Now people want to talk about my wheelchair and my urinary routine!

Theresa is my *caregiver* these days. She feeds me, takes me to the bathroom, helps

me get up and down, drives me to medical appointments and a thousand other things. Besides all this, she still does the cooking, cleaning, and laundry and lately all the outdoor work, bill paying, and arranging for home repairs. She refuses any help. She looks exhausted, and she often has a backache. There isn't much hugging or hand-holding anymore, just the "care taking," as some call it (like I'm a shrub instead of a husband). I guess, along with all the losses MS has brought, we've lost romance in our everyday life.

Alana is always delighted to see me. To her I am an awesome "Pappa." Even now... an awesome Pappa and wood-carver and storyteller who happens to sit in a wheelchair. When she's not around though, I feel like I've lost my very self.

I try to cooperate with things, but sometimes I feel angry, left out, and useless. When these feelings take over, I refuse to let Theresa touch me or give



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me medication. Sometimes I shout (as best I can) and even swear. Then I feel sorry. Theresa tells the doctor and a few days later I begin to feel groggy. I think they're giving me some pills to "calm me down." I need something more than pills.

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Hi, I'm Theresa, caregiver for my husband Tony. He's had Multiple Sclerosis for the last fifteen years. At first he did most of his regular activities, but now he needs help with everything. I take care of all his needs – lifting him in and out of bed, the car, and his chair; assisting him in the bathroom; helping him dress; taking care of his medication and on and on. I try to use the gait belt the way they showed me in the hospital, but still my back hurts most of the time. Sometimes the bed sheets get soaked with urine. Those are my worst days. My back hurts worse from carrying laundry to the basement. I feel overwhelmed, and I get grouchy. I just don't know how I'll get everything done that I have to do. Now there are leaves to rake, and soon, of course, snow to shovel.

People tell me there are classes and support groups for family caregivers. HA! How would I ever fit anything else into my schedule? My children tell me to get some help at home. Well, I could never afford that, and I don't want strangers in my house. Besides, I'd have to plan my schedule around when they are coming, and they'd never be able to give Tony the kind of care I do. Plus I would feel so guilty having anyone else take care of him. He was such a good husband and father.

"Get out of the house," my friends say. "You used to bowl and golf and make beautiful jewelry. We hardly know you anymore." Well, they just don't understand, and I don't want to bother them with my problems.

Sometimes Tony refuses to let me help him. The other day he told me to "Keep your damn hands off of me." That really hurt. I told the doctor that he's been acting like that, and he gave me an

anti-anxiety medication to give him with his medicine every day. He hasn't gotten too insulting since then, but he is getting harder and harder to help with transfers, and I have to feed him now.

I've been having splitting headaches lately, and I've lost my appetite. I hardly sleep at night for worrying about things. Sometimes I just sit down and cry for a long time. Then I feel guilty because the housework isn't done. It's just a vicious cycle. I don't even feel like myself anymore.

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How can Tony and Theresa find themselves, the essence of who they are as individuals and as partners through these years when Tony needs help with his daily care?

**Person-centered Care** is a relatively new philosophy among agencies who serve people with such ongoing needs. It's the idea that a person's basic identity (life story, likes and dislikes, relationships, personality, sense of humor, etc.) should always be honored and held above that person's deficits or disease. At the heart of person-centered care is the best friends approach. **Best Friends Approach**, which says simply to treat a person you are caring for as a best friend. Friends know each other's history and personality; they do things together; they communicate well and build each other's self-esteem; they laugh often; they are equals, working at a relationship.

Here are some components to a health sense of personhood:

**Comfort** – freedom from pain and pleasurable sensory experiences. Theresa could get control for her back pain and headaches. She and Tony could spend time outdoors, listen to music, or share other joyful moments..

**Identity** – a uniqueness that is known and accepted by others who can connect us with our past. Tony needs to be reminded that he always has been, and still is, an engineer, wood carver, and great husband, father and grandfather. Theresa also needs to be reminded of her non-caregiving roles.

**Inclusion** – being embraced as part of a group where we feel comfortable. Theresa could reconnect with her friends and Tony could bring some woodcarvings to Harmony Club.

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**Attachment** – intimate connection with someone with whom things seem familiar, not strange. *With more help and socialization, their marriage can grow again into a fond attachment*

**Meaningful occupation** – opportunities to do something useful. *Tony needs something useful and creative to do. He could perhaps help with simple tasks at home, but day programs like Harmony Club and Adult Day Care Centers are set up to provide such opportunities to people with varying abilities. Tony may choose to attend to support Theresa in gaining some time for her needs. He may find himself feeling embraced and comfortable there as well.*

In a family caregiving situation, personhood can be swallowed up in routine chores and overwhelming

responsibility. Through no one's fault, the physical care may take center stage, and “best friends” become simply “caregiver” and “care-receiver.” Care partners lose themselves and each other so gradually that they don't even realize it—until one day they're overcome with stress, worry, and often resentment. This is what Caregiver Support Specialists try to prevent!

Please dear caregiver, consider what can enhance the health, well-being, and personhood of yourself and your care partner, and your relationship with that person—even if it entails some inconvenience, money, and independent activities for both of you.



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

### Independent Living Center

Society's Assets

<http://www.societysassets.org/>

Serves Racine, Kenosha, Walworth, Jefferson and Rock  
Main Office - 5200 Washington Ave, Racine  
Call 1-800-378-9128 or 866-840-9761 TTY

You may not have heard about one of the most useful resources for caregiving families in Racine County—the Independent Living Center, housed at Society's Assets. Here you can find help with many of the challenges faced when a family member has a disability. Assistive technology (AT) holds solutions to many caregiving problems. It includes everything from a van with a wheelchair lift, a grab bar in the bathroom, to easy-grip spoons.

An Independent Living Specialist can visit your home and give suggestions, demonstrate how items work and may be able to loan you something to try. Occasionally AT items are donated and can be given to a consumer. The IL specialist can direct you to manufacturers, providers, and financial help if needed. Some examples of AT:

**Activities of Daily Living** (basic skills for daily care): modified eating utensils, clothing with easy fasteners, shower chairs, raised toilet seats, long-handled reachers.

**Mobility:** Walking aids, wheelchairs, scooters, gadgets for getting in and out of a car, ramps, chair lifts for stairs or other lifts for transferring from one place to another.

**Hearing and Listening** – devices to amplify sound, telephones with light up ringers, or phones that relay via computer.

**Vision and Reading** – talking clocks, magnifiers, flexible task-lighting systems, books on tape, and a radio station where materials are read aloud.

Call the Independent Living Center and pose a problem. You may be very surprised to find that there are many gadgets just waiting to lower your stress and help you meet the personhood needs of yourself and your family member.

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



**Aging and  
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## Caregiver Opportunities

Mary Finley, Outreach Specialist from the **Alzheimer's Association**, will be available for family consultations on Wednesday, October 23rd between 2 and 4 p.m. at the ADRC office located at, 14200 Washington Ave (just east of I-94). This invitation is extended to those dealing with **any type of dementia**. For an appointment call Felicia Elias, 833-8761.

**“Believe in Yourself,”** a gala event for Family Caregivers, will take place on Wednesday, November 13th, at Veteran's Terrace in Burlington. This is a FREE event with lunch for all and respite care for your care receiver. **Please see accompanying flyer, and call to register Today!**

## Support Groups for Family Caregivers

**First Thursday 10:30 am-12 Noon**

**October 3**

**Alzheimer's Association Group**

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

**First Friday 12 Noon-1pm**

**“Caregiver Connection” Telephone Group**

**October 4**

Call 262-833-8762 to pre-register

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

**October 8**

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**

**October 12**

Atonement Lutheran Church,

2915 Wright Ave

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

**Third Wednesday 1:30-3:00 pm**

**October 16**

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

**Third Thursday 6:00-7:30 pm**

**October 17**

**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)