



Aging & Disability  
Resource Center

of Sauk County

Issue 1  
July 2010



# the caregiver

news support

## INSIDE THIS ISSUE

- 
- ARE YOU A CAREGIVER?
  - FEATURE ARTICLE *STICKS AND STONES*
  - SPOTLIGHT STORY: *DAVE*
  - CAREGIVER STATISTICS
  - A SPECIAL SHOUT OUT
  - VOLUNTEER OPPORTUNITIES

**CAREGIVER?** When the people we love need help, who do they turn to?

Many people don't think of themselves as caregivers, because "it's just what you do for family," but it doesn't matter if care is provided out of love or obligation, if you are providing basic assistance to someone who is frail, disabled or ill and needs help~

**YOU'RE A CAREGIVER!**

**GETTING STARTED** Aging & Disability Specialists are trained to provide you with the information you need to make informed choices about long-term care options. Sometimes an assessment will be done to help identify needs and funding options. The assessment includes a review of your loved one's personal history, preferred lifestyle and goals for the future. It also includes looking at functional limitations and capacities, and their financial situation.

The information you receive will be timely, accurate, thorough, unbiased and appropriate to your situation.

**WHAT WE DO** Aging & Disability Specialists provide caregivers and their loved ones with useful information about all of the long term care options available, and they will assist people who need help in navigating systems and accessing resources or benefits.

- Finding someone to help you're loved one meet their basic needs (dressing, bathing, cooking)
- Locating a facility that could provide the type of care your loved one needs
- Understanding the rules regarding publicly funded long term care services
- Finding a support group
- Linking to services when your family member has been a victim of abuse or neglect by others

ADRC is open Monday-Friday 8:00 a.m. - 4:30 p.m.

**STICKS AND STONES**

As family caregivers, the best support we can offer our loved ones usually occurs when we see ourselves as full and equal members of his or her professional care team. That certainly makes sense and is quite easy to say, but there are many differences to overcome between family and professional caregivers once we receive that phone call in the middle of the night telling us that something is amiss with a loved one.

One difference in particular is, of course, that the professional caregivers on your loved one's team have many years of practical experience and education in their chosen field. We, on the other hand, get about a minute to collect our thoughts and start our new lives as family caregivers. This means that we are destined to be playing catch-up as many new words become crucial elements of our new language of caregiving.

Unfortunately, many of the words and concepts can have unjustifiably negative connotations which they do not deserve. For example:

**HOSPICE**

Don't feel too bad about not immediately understanding the value of hospice care since many professionals (including doctors) do not fully understand hospice either. The first thing to realize is that hospice is not a place, but a concept. Hospice care can take place in a stand-alone facility, in a nursing home, a hospital, and even at home. And contrary to any misinformation that is out there, investigating hospice care does not in any way mean that you or your medical team has "given up." Some of the best and most supportive care I have witnessed for ill friends and family members, as well as their loved ones, has been with hospice care.

**SUPPORT GROUPS**

Many of us would rather have a root canal performed than think of going to a support group meeting. That is quite understandable until you realize that a well-run support group can be a vital link in receiving the information and support you need as a family caregiver. Think of it as a board of directors meeting where you can openly discuss anything that concerns you as the CEO of Caring for My Loved One, Inc. No matter what piece of the puzzle you are looking for with regard to your loved one's care, most likely someone in the group has already found a solution for themselves that can work for you as well, and is more than willing to share it with you. It is also important to have a place to share those feelings that only other family caregivers can appreciate. One other thing about support groups—if appropriate, they can be a blessing for your loved ones as well. After my dad's diagnosis of bone marrow cancer in the early nineties, the last thing this proud Marine (once a Marine, always a Marine) would agree to would be joining a support group; so my surprise was justified when I saw him in a Tom Brokaw news piece on support groups. Dad loved that group and they loved him. In fact, every member of the group was front and center at his funeral six months later. It only made sense, as they had become important members of his extended family. And for that, I am eternally grateful.

-Gary Barg  
(founder of caregiver.com)

SPOTLIGHT DAVE

Dave has Huntington's Disease, which doesn't require "skilled medical care." It does require over \$600.00 monthly in medication, food via the feeding tube, and help to bathe or dress. We live on Social Security and I use the food bank and other charities to provide for my family which includes two teenagers. I have lost my home and am \$40,000 in debt. I have been made to prove his feeding tube was inserted for "other than cosmetic reasons." I have dealt with some of the rudest people through social service programs who have suggested I divorce him.

Having an orphan disease means there is little support. There is only one neurologist who takes Medicaid here, and he has never had a patient with HD. It is bad enough to watch someone you love die in slow pieces from a disease for which there is no cure. I have lost my best friend, my lover, my other half.

Everyday when I leave my forty-six year old husband of seven years in his narrow bed at the nursing home, he looks at me with sad brown eyes. With far fewer benefits I could have kept him at home where he wanted to be till the end. But the rules would not allow for that and I couldn't fight any longer. I know Dave doesn't want to live in a nursing home. I have no choice. Maybe now I can find some of the me I lost while caregiving.

-Carmen Leal



STATISTICS



Family Caregivers provide more than 80% of all long term care in the US.

MetLife Mature Market Institute

37% of adult caregivers are caring for their aging parents.

Opinion Research Group

**THANK YOU** Earlier this week I was in Sioux Falls presenting about caregiving. Three sorts of people were in the audiences: family caregivers, volunteer caregivers, and professional caregivers. I ended my talk as I often do, expressing words of appreciation to them as individuals and as a group. As I looked into their faces while speaking my feelings and thoughts, I saw tears in people's eyes. I believe that was because they were not used to having their dedication so publicly recognized, their work so honestly affirmed. My words to them that day were impromptu, so I cannot recreate my exact message. But this is the sort of thing I attempted to express then, and what I express to you now, you who are finding meaning in reading *The Thoughtful Caregiver*: The work you do as a caregiver is far from easy. It requires not just physical energy but mental discipline and emotional stamina. And not just occasionally but day after day. Much is asked of you: your positive attitude, your compassionate stance, your openness to feelings, your willingness to listen well. Much is needed from you: your nonjudgmental acceptance, your heartfelt honesty, your unashamed humility, the courage to be vulnerable, to be authentic, to be human. Sometimes it may seem that your work is never done. It may feel as if the responsibilities are much to bear. You may experience a loneliness that you wish you didn't. On top of all this, you may not hear many words of appreciation or be shown many signs of support. But know this: you are doing something very important, even if recognition of this is overlooked, even if gratitude is in short supply. You are making a difference in another's life, perhaps in more ways than you know. You are living out the meaning of love, even if that is not always obvious, or sure, or comfortable. So for all these reasons and many more, thank you. Thank you for all your caring in the past. Thank you for what you are doing and what you are standing for, right now, right where you are. Thank you for being ready to carry on tomorrow with every bit of determination that you can lovingly muster. Just this: thank you so very much.

*-James Miller  
(caregiver speaker)*

**GET INVOLVED** We know that volunteering a portion of our time is something we should do. There are reminders all around us that our help is needed. Other people will significantly benefit from any time we contribute. But that is not the only reason to volunteer. Here are 18 off the top of my head.

*-Mary Jane Percy*

1. To make new friends
2. To build personal and professional contacts
3. To build your self-esteem/confidence
4. To develop new job skills
5. To make a difference in the world
6. To increase personal satisfaction
7. To add experience to your resume
8. To develop people skills
9. To develop communication skills
10. To do something as a family
11. To explore career possibilities
12. To be needed
13. To share your skills
14. To be challenged
15. To do something different
16. To earn academic credit
17. To improve your health
18. To have fun!

## Meet Mary Jane!

Mary Jane Percy is our volunteer coordinator here at the ADRC in Sauk County. If you are interested in volunteering or caregiving options in the Sauk County area please contact her.

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C. FAMILY CAREGIVER ALLIANCE

## RESOURCES

### Broward Health

One of the ten largest public healthcare systems in the nation. 30 different healthcare facilities across the nation. [browardhealth.org](http://browardhealth.org)

### Medipack

The presorted prescription program. This site can help to manage you or your loved ones medication. [medipackrx.com](http://medipackrx.com)

### Institute for Neurodegenerative Disorders

One of the ten largest public healthcare systems in the nation. 30 different healthcare facilities across the nation. [indd.org](http://indd.org)

### The Living Trust Network

An informational website that allows you to communicate with doctors, attorneys, and other caregivers. [thelivingtrustnetwork.com](http://thelivingtrustnetwork.com)

### The Scooter Store

Great prices on electric scooters. Zoom Zoom [thescooterstore.com](http://thescooterstore.com)

### Partners In Healing

This site sells a DVD program aimed at teaching the art of massage to a caregiver to use on cancer patients. [partnersinhealing.net](http://partnersinhealing.net)

### Fisher Store

Adult diaper and home health care products. [fisher.directhme.com](http://fisher.directhme.com)

### Cindy Laverty Show

Great caregiving information. The site claims to be a caregivers best friend. [cindylavertyshow.com](http://cindylavertyshow.com)



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