

Wisconsin Alliance

for *Family*

Care

GIVING



## Caregiving Relationships Curriculum - Off to a Terrific Start

By Caregiver Relationship Steering Committee

This spring, the Wisconsin Alliance for Family Caregivers coordinated a special training on the Caregiving Relationships curriculum. Seventy-five people attended the training on Thursday,

March 25th, in Wisconsin Rapids. These individuals represented county/tribal aging offices, UW – Extension services, interfaith programs, senior centers and other social service agencies.

Feedback about the training was very positive; over 80% of the individuals who completed the training evaluation form indicated that the material presented during the training would be of immediate use to them. Twenty-three individuals indicated that they are interested in becoming master trainers! The Caregiving Relationships Steering committee has already received requests to coordinate another training!

Caregiving Relationships curriculum is made up of six different modules ranging in topics from mixed emotions to maneuvering through the social service maze. Rachel Schwarzendruber and Amy Griswold, from the University of Illinois Extension, are authors of the curriculum and presented the material. This curriculum can be used during a one-on-one conversation with caregivers or in a group setting like caregiver support groups or classroom training. Session participants stated they plan on sharing the curriculum with other staff as a resource in addition to sharing it with family members, friends and neighbors.

To learn more about the Caregiving Relationships curriculum or to contact a class leader in your area, go to the Wisconsin Alliance for Family Caregivers at <http://www.uwex.edu/ces/flp/caregiving/relationships/index.html>

## Training for *Caregiving Near Life's End*

As many of you know, the Alliance has established a steering committee to implement another family caregiving curriculum entitled *Caregiving Near Life's End*. It is a versatile curriculum that has 9 modules on end of life issues such as completion and closure, life affairs, personal relationships, love of self and others, finality, and the meaning of life and bereavement. The Wisconsin Alliance for Family Caregiving received funding from Rallying Points to help underwrite the cost of bringing the authors of this curriculum to Wisconsin.

A Master Training session will be held August 3-5, 2004 in Stevens Point for 50 individuals. Individuals will be selected to participate in the training after completing a Master Trainer application. A Master Trainer is expected to teach the curriculum two times to family caregivers and then to provide training to others throughout the state. So if you're interested in being a Master Trainer, please contact Melanie Ramey at:

[melr217@aol.com](mailto:melr217@aol.com)

Please include your name and contact information so a letter and more information can be mailed to you. Applications are due June 15, 2004.

If you can't participate in this training, there will be other training opportunities as the steering committee hopes to have regional training later this year or in early 2005.

# What's a Class Leader To Do

Betty M. Quinn, LPC -  
Cornerstone Counseling Inc.

You've been leading Taking Care of You...Powerful Tools for Caregiving classes for two or three years and, perhaps, feeling as though you've experienced all the curves that can possibly be thrown at you in a class setting. You're a competent, seasoned, empathetic class leader. Comfort zone...yes. Not. Expect the unexpected.

Consider this scenario: You're beginning the fourth class of a group of caregivers you've come to know and enjoy. You become aware of the fact that one of the group members is under the influence of alcohol, as she exhibits unusual behavior that is disruptive to the class. You try a variety of "tools" any seasoned class leader would have at hand and nothing is successful in getting the focus off the individual and her disruptive behavior, and on the class material at hand. You don't feel you can send the person home, as you don't want her driving under the influence. You feel the frustration of other class members because the material isn't being covered and their needs aren't being met. You don't want to unduly embarrass the person under the influence. What's a class leader to do?

Since about 12% of caregivers sometimes turn to alcohol to cope with the stress of caregiving, it's a challenging scenario that any of us could experience. Remember that caregivers may have had a very difficult few days, or just made a major decision, such as placing their family member in a care facility, that is making them feel guilty. It may be helpful to acknowledge that the caregiver is going through a difficult time right now (especially, if one wants to keep the door open to the person coming back into the group. They may feel embarrassed by his/her behavior, and thus, feel uncomfortable in returning). It is important to remember that

some caregivers who are depressed may turn to alcohol as a way to "lift their spirits," but of course, it really does not since alcohol is a depressant. As you deal with the caregiver, it is important to recognize and acknowledge what is happening in their lives while at the same time taking a firm stance that their current behavior is not acceptable. Here are some thoughts and ideas for your consideration:

1. As class leaders, our first obligation is to the group and the material they are prepared to cover. Since it is unreasonable to think we can deal rationally with someone under the influence while in group, the first necessary step is to have one class leader take over the group and the other leader respectfully and assertively tell the individual it would be best to discuss some issues privately in a different room.
2. When in private, share with the person that you cannot allow her to continue in the group today since she is under the influence of alcohol. You can explain that your first obligation is to the whole group and the assigned topics, and that her current needs, while under the influence, cannot be adequately addressed in class today, without disrupting the entire class schedule.
3. We also have a responsibility to see that the person gets home without compromising her, or others, safety. Therefore, share that you cannot allow him/her to drive home for safety reasons, and discuss ways they might get home safely. Some options you could present are calling a friend or family member or calling a cab

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for her. But driving home is not an option. Recognize that you will need to be assertive with the individual during this discussion while at the same time NOT coming across as judgmental. Exhibiting care and compassion for the person during the discussion will be helpful. For example, how one tells a person “I cannot allow you to drive yourself home” can either cause a person to become aggressive or instill calm. We need to provide some “face saving,” while at the same time addressing the concern of them driving while under the influence.

4. There’s certainly a chance the individual could become belligerent or aggressive. Should that occur, it may become necessary to communicate that you really do not want to call the authorities, but that it is an option, if it’s the only way to get her home safely. Obviously, this approach should be used only if circumstances require it. It may be wise to discuss this option with your local law enforcement to see what suggestions they have and what they would recommend in this situation.
5. Finally, it’s important to let her know she is welcome back to the next class, as long as she is not under the influence. It would be appropriate to call her the next day repeating this message and allowing her an opportunity to talk if she so desires. This gesture reinforces that you care about the individual and want them to continue being a part of the class.

Yes, expect the unexpected and be ready to put to use the many skills you’ve gained as a class leader. If you have experienced similar or other challenging situations as class leader, please feel free to share them with the Alliance, as well as what has worked for you. Then, perhaps, we won’t be faced with the question of “What’s a class leader to do?”

## Caregiver Relationships Sharing Session - Mark Your Calendars

Caregiving Relationship Class Leaders are invited to share their experiences of using the new curriculum on August 9, 2004 from 1:30 to 3:00 p.m. All you have to do is dial 608-316-0022 (Toll Number), or 888-677-9189 (Toll Free Number), and when prompted, put in the pass code number, 4876# and join the conversation. We hope everyone can join us!

## Research Project Needs Your Help!

The University of Missouri-St. Louis is conducting an eight Midwestern state study of men who are providing care to a family member with memory loss. The Dementia Caregiving Skills Program provides skills to men living with a family member who has memory problems. The program uses proven ways to help with the family member’s difficult behaviors, like repeated questioning, embarrassing behaviors, losing control of bladder or bowels, as well as bathing, dressing, toileting, or sleep troubles. Participating men will receive all information by mail or by telephone. The no-charge training is done either by instructional guide alone (group one), or by video series and telephone coaching (group two). Eligibility requirements include willingness to be assigned, by chance, to either of the two groups. This study is funded by the Missouri Alzheimer’s Disease and Related Disorders Research Board, and is directed by Judith R. Gant, Ph.D., Assistant Research Professor, Dept. of Psychology, University of Missouri-St. Louis. Participation is completely voluntary and confidential. The study is funded for men from eight Midwestern states, including Wisconsin. For more information, please call (314) 516-4395 or toll-free 1-866-669-7140. The e-mail address is [gantj@umsl.edu](mailto:gantj@umsl.edu)

# Flexible Respite Options That May Facilitate Caregiver Participation in Training and Support Activities

By Dana Cyra, Resource Services Director at Portage County Department on Aging

Over the past year, the Portage County Department on Aging has experienced significant growth in Caregiver Support Programs, much of which may be attributed to offering the *Taking Care of You: Powerful Tools for Caregiving* curriculum on a consistent basis. Of course, getting caregivers to commit to a six-week training requires some advanced planning to eliminate barriers to participation. One of the biggest barriers to participation is respite care. Some family caregivers haven't used respite in the past and don't know of anyone they can ask to provide respite. Others have used respite but are reluctant to pay for additional respite in order to attend a training. Finally, there are those who have barely left the side of the person they care for since assuming caregiving responsibilities. These people are simply uncomfortable being away from the person they care for, for any length of time. Sometimes relinquishing caregiving responsibilities is an emotional struggle for the caregiver and in other instances, the care recipient is reluctant to let another person provide assistance.

In order to meet the respite needs of caregivers, we provide assistance and a variety of flexible options. Caregiver training and support activities are usually offered in the late afternoon/early evening hours when regular programming at our facility is winding down for the day. This allows us to offer on-site respite in our Adult Day Center after the day program has closed. Depending on the number of requests for on-site respite, one or two

of our Adult Day Center Aides stay later to accommodate the need for respite. Offering on-site respite for caregiver training and support activities has proven to be a good outreach tool for Adult Day Center services and a great way to encourage caregivers to use supportive services. Those who participate in on-site respite have an opportunity to get to know the facility and some of the staff within the context of a smaller group, and on a more personal level. This seems to increase the level of comfort the caregiver and the care receiver feel when considering Adult Day Center services as an option available to meet ongoing needs.

For those who are not interested in using on-site respite, one of the first things we ask is whether they have someone to provide respite in order for them to attend. If they already have someone they feel comfortable leaving their loved one with, we offer to assist in paying for the respite provided while attending caregiver training or support groups. Sometimes people have a family member, friend, or neighbor who has been helping but they are reluctant to ask for another favor. Being able to offer some financial compensation as "part of the package" may help them to feel more comfortable asking. Others may be paying for substitute care already but need financial assistance to support the additional hours of service needed to attend training or support activities.

In the event that a caregiver is not interested in on-site respite and does not have someone to provide in-home respite, we explore other options for respite. We talk about what the care receiver is likely to need during that period of time. Depending on the specific needs, we talk about Home Health agencies, Supportive Home Care agencies, and private providers who have been screened and met the criteria for a list of Chore Service Providers maintained by our agency. We continue to assist the caregiver, as needed or requested, to locate an in-home respite provider. Sometimes we provide very little assistance; the caregiver or

a family member simply wants a list of agencies or people who can provide the services and they get everything set up. At the other extreme, agency staff are actually setting up and facilitating meetings between the family and potential providers. Once a suitable respite provider is located, we again offer financial assistance to pay for respite, if needed.

In regard to financial assistance, we have found that flexible options help to preserve the dignity of individual caregivers. On-site respite is available at no cost to caregivers. The amount of financial assistance is typically an agreed-upon hourly rate which is based on the needs of the person receiving care. We typically assist families at a rate of \$10.00 per hour of respite but the amount may vary. It may be higher if the care receiver has skilled nursing needs or lower if the caregiver has already established a lesser rate with a provider. Some caregivers indicate they are able to pay something toward the cost but not the full amount. In that case, we would pay the difference between what they can afford and the actual cost. In other words, the amount of assistance is based on what it takes to meet the needs expressed by the caregiver.

In terms of how financial assistance is provided, caregivers have two options: (1) direct payment to the provider; or (2) reimbursement to the caregiver for payment they've made to the provider. In either case, we've developed a simple form that is to be completed by the person to receive payment. The form and a self-addressed, stamped envelope are given to the caregiver upon arrival at our facility. Since we do ask the caregivers to submit a receipt from the provider, we are able to provide a generic receipt which the respite provider can sign indicating the amount she/he received for providing respite. This allows the caregiver to receive financial assistance without having to inform the provider. When payment is made directly to the provider, the caregiver's signature is required to verify the receipt of services on the dates and times indicated.

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Those of you who are exploring respite options are probably wondering where the funds come from to support respite for caregiver activities. As a County Aging Unit, we have access to a variety of funding sources to support caregivers. National Family Caregiver Support Program dollars, administered by County Aging Units, are available to pay for respite services for the person (of any age) who is the caregiver for someone 60 or older. Alzheimer's Family Caregiver Support Program Funds may, depending on the budget submitted by the county's lead agency, be used to support respite for people of any age who are caring for an adult who has been diagnosed to have Alzheimer's or another form of dementia. A county's Elder Abuse allocation may also be a funding source, since Elder Abuse funds can be used to support prevention and intervention. A county's long term care unit may also choose to approve funding for additional caregiver respite for those caring for people who receive public funding for long term care via such programs as COP, CIP, or Family Care. Whether or not you have, or are able to, access such funds likely depends on whether you are the designated lead agency for that funding source, whether you have a good working relationship with the agency responsible for administering those funds in your county, and whether the program budget includes, or can be adjusted to include, funding for such activities.

In summary, any caregiver expressing an interest, or even the willingness, to attend caregiver training or support activities, is really ready to take that first step toward, "Taking Care of You..." As professionals, whatever we can do to eliminate any potential barriers to taking that step will likely benefit both the caregiver and the care receiver. If you have any additional questions about the options presented in this article, please feel free to contact me by email at [cyrad@co.portage.wi.us](mailto:cyrad@co.portage.wi.us).

## A Caregiver's Story- Dale Bruhn

Excerpts from an article in the Wisconsin State Journal, March 14, 2004

It's only been two years since Dale Bruhn's wife, Norma, died after suffering from Alzheimer's for more than 15 years. Dale will tell you that "If you're going to help somebody, you have to let them know what you went through." So, when Dale speaks at his many public engagements, his voice is likely to crack and he will take a few moments to compose himself before going on. One reason Dale is so effective as a speaker/class leader is because the issues are so personal to him. Dale cared for Norma seven years at home and eight more years in a facility. He now helps both the Area Agency on Aging of Dane County and the Alzheimer's Association as a public speaker, doing one-on-one counseling, and leading *Taking Care of You: Powerful Tools for Caregiving* classes. Dale says you have to impress on caregivers how important it is to take care of themselves. "My mission in life now is to help others who are just beginning the role of a caregiver to understand, first of all, what they're going to face; secondly, how they can cope with it; and thirdly, impress upon them to take care of themselves. They're the key person in this whole triangle of taking care of somebody. It's the caregivers who too often don't take care of themselves." Dale is also a Lion's club member, serving his community by lining up volunteers to read prescriptions of donated eyeglasses and serving as driver for the Wisconsin Lion's Eye Bank. In Dale's words, "I just feel there's so much selfishness and so many people are so self-centered that we really have to learn how to help others, because we should be leaving this world a better place than it was when we arrived here. If we don't, then our civilization is doomed."

## New Class Leaders

Caregiving Relationships for People Who Care for Adults; March 2004, Stevens Point

Erica Anderson	Geri McKeon
Liv Arafat	Luane Meyer
Cheryl Ault	Linda Mezei
Donna Barron	Kathy Miller
Bonnie Baskett-Harvey	Becky Nelson
Barbara Bauknecht	Diane Niggemann
Diane Bluthardt	Debra Ninham
Jan Braby	Peggy Nordgren
Mary Brintnall-Peterson	Judy Olmanson
Judy Butcher	Lucia Patriitto
Claire Culbertson	Tammy Pence
Dana Cyra	Linda Pepping
Linda Dreyer	Susan Piazza
Judith Durkee	Judy Rank
Ken Eberhardt	Mary Reines
Karen Ehle-Traastad	Dianne Rhein
Dorrae Fietz	Mary Roberts
Candice Firgens	Barb Robinson
Gayle Fisher	Judy Roehm
Mary Beth Fumelle	Ruth Rotramel
Julie Genrich	Lynn Scheinoha
Ann Golueke	Julie Seeman
Renee Gross	Joan Severson
Aimee Henry	Donna Siedschlag
Nancy Holtz	Mary Sladich
Veronica Jeaunque	Mary Jean Smith
Carol Johnson	Sandy Smith-Dill
Patricia Johnson	Judy Steinke
Christine Kniep	Maurine Strickland
Sylvia Kriegl	Karen Swanberg
Diane Lanaville	Betty Tarabek
Joan LeFebvre	Beverly Tillich
Mary Fran Lepaska	Patricia Valentyn
Janice Lettenberger	John Wanserski
Dianne Lohse	Lisa Wells
Danielle Luethje	Diane Wiedenbeck
Carol J. Machek	Patricia Wilson
Gladys Mazanec	Heidi Zinda

**Powerful Tools; May, 2004, Manitowoc**

Nan Baumgartner	Chris Kniep
Carla Duket	Janice Lettenberger
Edie Felts-Podoll	Nancy Simenz
Carrie Gahan	Lynn Stanton
Terry Jochman	Pat Townsend

## Caregiver Collaborations on the Alliance Web Site

Family Caregiver Collaborations are being established throughout Wisconsin and nationally to collectively address the needs and concerns of family caregivers. We have added a Caregiver Collaborations page to the Alliance Web site. You will find it at:

<http://www.uwex.edu/ces/flp/caregiving/collaboration/index.html>

We want to list collaborations, (both local and state) on the site, so are you aware of any that should be added? It may be a local group that you participate in or are aware of, or a state group that provides resources and help to you in your caregiver role. Please contact Susan Meier at: [susan.meier@uwex.edu](mailto:susan.meier@uwex.edu) or FAX to (608) 265-0787 and give her the name of the group and a Web address or contact information. Thank you for helping add to this valuable section of the Alliance Web site!

## Marketing Tips

Have a local newspaper or radio station interview a caregiver who has taken the class  
(Contributed by Peggy Nordgren)