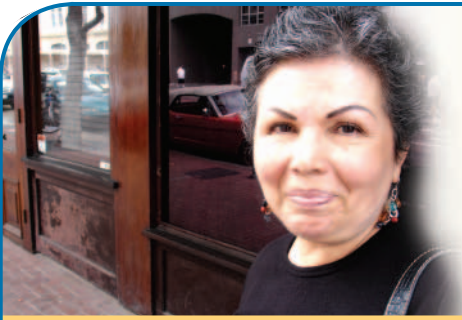


# The League of Experienced Family Caregivers

**SHARE BECAUSE YOU CARE!**



## News from the LEFC Project Team

Welcome to the latest edition of the LEFC newsletter. Together with our partner organizations, care managers, and members of the LEFC National Advisory Board, we have been making progress on a number of projects and new initiatives. The League of Experienced Family Caregivers would not be able to exist or move forward without your ongoing interest and support, and the project team would like to thank all of the organizations and care managers who continue to support our work. By encouraging family caregivers to participate in the program, handing out brochures, and posting information on websites, your help has allowed us to continue to expand the registry.

In the last issue of the newsletter, we told you about the new name for our process, UCARE, which stood for “Uniform Caregiver Assessment and Referral.” After much consideration (and consulting our lawyers), we have come up with a new name for UCARE – *T-Care*, or “Tailored Caregiver Assessment and Referral.” Although the name has changed, we are pleased to report that the process, tools, and user manual all remain the same. In fact, we’ve been working hard to improve all facets of the program as we continue to expand the protocol into new states. In this edition of the LEFC newsletter, we are excited to update you on what we have done, what we are currently working on, and what’s in store for the future. Like LEFC itself, this publication was designed with you in mind. But it is also a work in progress - so we welcome your feedback and input as we move forward.

*Appreciably,*  
**Rhonda Montgomery**

## Not Familiar with LEFC?

It is a growing registry of family caregivers from around the nation who are helping the project team at the University of Wisconsin – Milwaukee to improve service delivery for all family caregivers by sharing their unique insights and experiences that come with caring for a loved one. These insights are helping our project team create assessment tools and care management protocols that will provide caregivers with the resources they need.

## New Alzheimer’s Grant

The UW–Milwaukee Office of Applied Gerontology has recently received a \$240,000 grant from the Alzheimer’s Association (with \$337,000 of in-kind support from the endowed chair committee, which was funded by the Helen Bader Foundation). The grant will assess the impact of an evidence-based care management protocol as it relates to family caregivers and organizations. The 30-month study will include 80 care managers and 400 family caregivers from Georgia, Michigan, and Washington, and will focus on the health and well-being of family members caring for individuals with dementia, in addition to the use and costs of support services by caregivers. The care management protocol being studied is grounded in Dr. Montgomery and colleagues’ Caregiver Identity Theory, which examines the type and extent of caregiver distress being experienced and provides recommendations for assistive services. It is our hope that the project will contribute to a growing body of knowledge about effective caregiver interventions by increasing knowledge for tailoring services to unique circumstances, beliefs, and needs of family caregivers.

*To learn more about the project and how you can get involved, please call the UW–Milwaukee Applied Gerontology Office at (414) 229-3289.*



## T-Care Training Activities

This has been an exciting and busy year for the T-Care team, as we have moved the protocol into the field. The team has piloted training content, materials, and teaching formats with a number of organizations in Florida, Georgia, Wisconsin, Michigan, and Minnesota.

Early piloting of the T-Care training process with our partners in Florida yielded new insights about necessary adaptations in content, delivery methods, and the overall length of initial training sessions. T-Care is a complex process that mirrors the complexity and diversity of individual caregiving experiences. Care managers need experiential opportunities to fully understand how to use the protocol. We have found that small group interaction and discussion of case summaries tailored to actual families that care managers assist are most effective. Additionally, individual and group technical assistance are key elements to helping care managers understand how to apply the protocol with their own clientele.

With these lessons in mind, the team has piloted and subsequently implemented a four-step training process:

- **Introductory seminars** designed to provide information to and gain support from administrators, program supervisors, and care managers of prospective partner organizations.
- **An initial two-day intensive training session** for care managers designed to introduce core concepts of the protocol and provide experiential opportunities for trainees to apply each step of the process. (Time 1)
- **A one-day follow-up training session** six-to-eight weeks later designed to reinforce core concepts and commitment at the organizational level and to develop an implementation plan. This third day of training targets care managers who will use the T-Care protocol, in addition to agency administrators, supervisors, information system coordinators, and resource specialists. (Time 2)
- **Ongoing case-based learning and technical assistance** is available to care managers via web-based seminars and individual conference calls.

Dr. Montgomery conducted a series of web-based informational seminars this year on Caregiver Identity Change as a foundation to the T-Care process for state-level program administrators, area agencies on aging, and service organizations in Washington, Michigan, and Minnesota. She and Dr. Mary Brintnall-Peterson have also been traveling throughout the state of Wisconsin this fall to conduct similar seminars.

Other members of the training team have joined Rhonda and Mary, conducting three days of intensive T-Care trainings with care managers in Georgia, Michigan, Minnesota and Wisconsin. Time 1 and 2 training sessions are also scheduled in November and December for care managers in Florida. To date, Jeannine Rowe and Dale Adler have presented twelve web-seminars for care managers in the previously mentioned states.



## Update on the Progress of Evaluating the Dementia Care Specialists

The Dementia Care Specialist Program (DSP) is a 15-hour training curriculum designed for nursing home and assistant living staff who provide direct care for residents with dementia. Using practice-based exercises, interactive activities, media, and dialogue focusing on understanding the effects of dementia on the individual, participants learn the skills necessary to ensure person-centered care. The goal of DSP is to improve the quality of dementia care provided by long-term care facilities by increasing knowledge and caregiver skills in nursing homes and assisted living centers. The project began in April, 2007, and has three phases:

1. Pretest questionnaire administered by the Alzheimer's Association focusing on dementia knowledge and attitudes.
2. Posttest questionnaire with same areas of focus as the pretest, with the addition of a program evaluation.
3. Three-month follow-up questionnaire collecting similar information and an extended program evaluation.

To date, we have received more than 300 responses for both the pretest and posttest, and our work on the three month follow-up is in progress. We are also sad to announce the departure of Dr. Chris Biga – who started a teaching position at North Dakota State University in August, 2007. While Chris remains active on the DSP team, his work will now be supplemented by Dr. Tom Fritsch, who also serves as the Associate Director of the UW–Milwaukee Center on Age & Community.

## New Collaborations

Following is a detailed description of two new collaborating partner organizations for the League of Experienced Family Caregivers. We encourage you to share these valuable resources with your organization and care managers.

**The National Family Caregivers Association (NFCA)** was founded in 1993 by two family caregivers – one who was caring for her husband with MS, and the other for her mother with Parkinson’s Disease. The friends realized they had many of the same questions and concerns in spite of the differences between their situations. In founding NFCA, they created an organization that reaches across the lifespan, diagnoses, and relationships to address the common needs of all family caregivers. Today, NFCA is America’s premier organization for family caregivers. Through education, support, and advocacy, NFCA empowers family caregivers to act on behalf of themselves and their loved ones, and works to remove the barriers that stand in the way of a family caregiver’s health and wellbeing. NFCA’s efforts provide practical information and education that family caregivers can use right away. To find more information, facts, and stories about caregiving, please visit NFCA’s website: [www.thefamilycaregiver.org](http://www.thefamilycaregiver.org).

**The Caregivers Marketplace** is located in Milwaukee, Wisconsin and is a program that provides caregivers nationwide with cash back on several over-the-counter healthcare products, that they may purchase for their loved ones at absolutely no cost to them. Caregivers simply mail in qualifying receipts with a completed cash-back form and wait for a check in the mail. Cash-back forms can either be completed on the Caregivers Marketplace website ([www.caregiversmarketplace.com](http://www.caregiversmarketplace.com)) or by calling their toll-free number (800) 888-0889 to obtain a form by mail. There is no limit to the number of cash-back forms a caregiver can submit – the more a caregiver sends in, the more money they will save. An additional benefit of the Caregivers Marketplace is the valuable caregiver resources they provide on their website. We strongly encourage you to visit the website and share this fantastic resource with your staff and the family caregivers you work with.

## New Faces

To accommodate the continued growth and expansion of the UW–Milwaukee Office of Applied Gerontology and the League of Experienced Family Caregivers, we are pleased to announce the addition of several new staff members:

- Steve Bernfeld is a doctoral student in Counseling Psychology who will provide coordination and communication for LEFC and other projects
- Katherine O’Connell-Valuch is a Master’s - level Sociology student who is managing data collection and coordinating student interviewers for our new National Alzheimers Association Demonstration Study
- Ingrid Gomez is a Master’s-level Social Work student who is overseeing the LEFC interview process
- Sondra Russell, MSW, joined the team in October as our new Training Coordinator

## The “Learning From You” study investigates the impact of Powerful Tools for Caregivers on spouse/partner caregivers

The “Learning from You”: Powerful Tools for Caregivers (PTC) study examines the impact of psychoeducational programs on spouse/partner caregivers. PTC is a program for family caregivers that teaches a variety of coping strategies such as emotion management, effective communication, and self-care. The “Learning from You” study looks at how PTC affects the day-to-day caregiving relationship. This study moves beyond caregiver satisfaction and looks specifically at characteristics of caregivers who benefit the most from PTC. This information can help social service providers direct caregivers to services and programs that will provide them with the greatest benefit.

Members of the League of Experienced Family Caregivers are asked to participate in this study by sharing their day-to-day experiences of caregiving in the form of two questionnaires. The questionnaires ask for demographic information about caregivers and their spouses/partners, in addition to information on how caregivers view themselves and their relationships with their spouses/partners.

This study is funded by the Hartford Foundation’s Geriatric Social Work Faculty Scholars Program. It is conducted at the University of Wisconsin-Milwaukee in conjunction with the Wisconsin Alliance for Family Caregiving and Legacy Health Systems.

*If you would like to learn more or get involved, please contact Dr. Marie Savundranayagam, the principal investigator of this study, via phone: (414)-229-6034 or e-mail: [maries@uwm.edu](mailto:maries@uwm.edu).*

## Georgia AoA Grant Update

Work recently began on a new Alzheimer's Disease Demonstration Grants to States (ADDGS) Program on behalf of the Georgia Division of Aging Services. The goal of this project is to implement and assess the impact of a care management protocol, developed by Dr. Montgomery and colleagues at the University of Wisconsin-Milwaukee. The objectives of the project are to train care managers to use uniform caregiver assessment tools and implement a care management process, expand the array of caregiver resources appropriate for diverse caregiver needs, increase care manager knowledge of and access to enhanced caregiver services, increase the number of caregivers using services, and to evaluate caregiver burden, depression, and satisfaction with services. This project is moving ahead as planned, and we are enthused about the fact that the T-Care Protocol is being tested by four Area Agencies on Aging in the state of Georgia.

## Caregiver Roadshows Across Wisconsin

Dr. Montgomery and her colleague, Dr. Mary Brintnall-Peterson from the UW-Cooperative Extension Service, conducted a series of five two-part workshops on September 13 (in Green Bay, WI), September 14 (Waukesha, WI), October 4 (Eau Claire, WI), October 5 (Green Bay, WI), and October 10 (Madison, WI). The goal of these workshops was to give participants a better understanding of the diversity and changing nature of the caregiving experience and to provide participants with guidance in creating service-rich environments that can effectively support caregivers in a timely manner.

Training was sponsored by AgeAdvantAge, Bay, Dane, Milwaukee, Northern, and Southeastern Area Agencies on Aging, the Wisconsin Department of Health and Family Services, and the Bureau of Aging & Disability Resources. Through these workshops, we have exposed more than 200 participants from Area Agencies on Aging, Alzheimer's and Dementia Resource Centers, and other agencies to the T-Care protocol.

If you have any information that you would like to share or feel is important to include in the next newsletter, please contact Steve Bernfeld: (414) 229-2734 / [bernfeld@uwm.edu](mailto:bernfeld@uwm.edu), or Jessica Jacobs: (414) 229-3661 / [jjacobs2@uwm.edu](mailto:jjacobs2@uwm.edu). Thank you!



In partnership with UW-Extension  
Cooperative Extension Service

## New Developments: Looking to the Future

- The project team continues to work very hard, and it is our goal to double the LEFC registry by January 1, 2008. We can only achieve this goal with the continued support of care managers and organizations like you. **To learn more about LEFC and how you can help, please call (800) 410-2586 or e-mail [lefc@uwm.edu](mailto:lefc@uwm.edu).**
- The T-Care protocol is being incorporated into programs throughout the state of Washington, and we continue to move forward in our work with state programs in Michigan, Minnesota, and Florida.