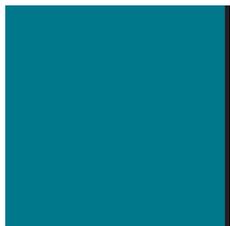


CAREGIVER  
EDUCATION  
AND SUPPORT  
PROGRAMS:  
BEST PRACTICE  
MODELS

RONALD W. TOSELAND, Ph.D.

DECEMBER 2004



**FOA**  
FAMILY CAREGIVER ALLIANCE®  
*National Center on Caregiving*





FAMILY CAREGIVER ALLIANCE®  
*National Center on Caregiving*

Founded in 1977, Family Caregiver Alliance serves as a public voice for caregivers, illuminating the daily challenges they face, offering them the assistance they so desperately need and deserve, and championing their cause through education, services, researches and advocacy.

Long recognized as a pioneer among caregiver organizations, FCA operates programs at local, state and national levels. FCA is the lead agency and model for California's statewide system of Caregiver Resource Centers. In 2001, FCA established the National Center on Caregiving to advance the development of high-quality, cost-effective policies and programs for caregivers in every state in the country. Visit [www.caregiver.org](http://www.caregiver.org)

(800) 445-8106

[www.caregiver.org](http://www.caregiver.org)

CAREGIVER  
EDUCATION  
AND SUPPORT  
PROGRAMS:  
BEST PRACTICE  
MODELS

**RONALD W. TOSELAND, Ph.D.,**  
Institute of Gerontology, School of Social Welfare  
State University of New York at Albany  
Albany, NY

DECEMBER 2004



**FAMILY CAREGIVER ALLIANCE®**  
*National Center on Caregiving*

180 Montgomery Street, Suite 1100  
San Francisco, CA 94104

© 2004 Family Caregiver Alliance

## **ACKNOWLEDGEMENTS**

This monograph was reviewed by Michelle S. Bourgeois, Ph.D., Professor of Communication Disorders; Associate, Pepper Institute on Aging and Public Policy, Florida State University, Tallahassee, Florida.

Funded by the Archstone Foundation.

The opinions expressed in this monograph are those of the author and do not necessarily reflect the views of the Archstone Foundation.

# CAREGIVER EDUCATION AND SUPPORT PROGRAMS: BEST PRACTICE MODELS

## INTRODUCTION

An estimated 44 million people currently provide care to a chronically ill spouse, relative, or friend in the United States (National Alliance for Caregiving & AARP, 2004). A great deal of evidence has accumulated indicating that family caregiving can have a negative impact on caregivers' health, well-being and labor force participation (see, for example, Metropolitan Life Insurance Company, 1999; National Alliance for Caregiving & AARP, 2004).

*A growing body of evidence indicates that caregiver education and support programs can delay nursing home placement and reduce the health care costs of care recipients.*

At the same time, studies over the past two decades have shown that caregivers of frail older persons can benefit from participating in community programs that focus on education and support (for reviews, see Cooke, McNally, Mulligan, Harrison, & Newman, 2001; Gallagher-Thompson, et al., 2000; Schulz, 2000; Zarit, Gaugler, & Jarrott, 1999). A growing body of evidence indicates that caregiver education and support programs can delay nursing home placement and reduce the health care costs of care recipients (see, e.g., Brodaty & Peters, 1991; Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996; Peak, Toseland, & Banks, 1995; Toseland, Smith, & Banks, in press). Therefore, although caregiving can be stressful, its effects can be mitigated at least partially by participating in education and support programs.

Despite widespread agreement that caregivers of frail older persons can benefit from caregiver education and support programs offered in community settings, there is little consensus about which programs should be used by practitioners, or what programs are most effective. More research, particularly about the effectiveness of programs in community settings, is needed. Still, it is important for practitioners to have access to the best programs currently available.

The purpose of this report is to describe five widely used caregiver education and support programs that have empirical evidence to support their effectiveness. The report also presents information about how to obtain these programs and any limitations on their use.

There are a wide variety of ways to educate and support family caregivers. These methods include:

- community workshops and educational forums

*It is important to decide whether the program should reach out to all caregivers or whether it should target particular subgroups of caregivers.*

- lecture series followed by discussion
- support groups
- psycho-educational and skill-building groups
- individual counseling and training
- family counseling
- care coordination and management
- technology-based interventions.

It is not an accident that many different ways to educate and support caregivers have evolved over the years. Although the focus of this paper is on five highly developed and widely used psycho-educational support programs, these programs require caregivers to commit to a series of group meetings. Yet, caregivers are a very diverse group of individuals with a variety of needs and a wide range of abilities to attend community programs. For example, a half-day community educational forum focused on caregiver issues may appeal to a spouse caregiver who has never attended any type of caregiver support program and who does not like to go out in the evening. In contrast, an evening lecture and discussion series may have greater appeal to an adult child caregiver who works full time. To accommodate caregivers' needs and schedules, therefore, it is important for a range of caregiver education and support programs to be available in any community. The programs described at the conclusion of this report represent just some of the many ways that caregivers can receive education and support.

### **SELECTING A PROGRAM**

When selecting a program to recommend or present to caregivers, professionals in the aging network should carefully consider the characteristics of the caregivers they intend to serve. An assessment of the needs, characteristics and resiliency of caregivers planning to attend an educational or training program helps the facilitator ensure that the program meets caregivers' needs. In tailoring program components, it is important to consider the range of caregivers' needs for education on disease processes, coping skills, problem solving skills and support.

It is also essential to define the goals of the program to be offered to caregivers. It is important to decide whether the program should reach out to all caregivers or whether it should target particular subgroups of caregivers. Casting a broad net is appealing because it enables an organization to reach out to the largest possible group of caregivers. This may be the only option in communities that are sparsely populated or have

limited resources. Programs that invite broad participation, however, have to keep education and training activities at a general level in order to be of interest to all participants. They are less likely than specialized programs to provide education and training tailored to the individual needs of caregivers. Thus, targeting has important implications for program planning.

There are at least two advantages to targeting specific caregiver subgroups. First, it enables the trainer to impart specialized information and knowledge to caregivers of persons with particular health problems such as Alzheimer's disease. Second, it enables the trainer to engage caregivers who might otherwise not participate in a more general caregiver education and support program. When developing education and training programs for caregivers of persons with specific disorders, trainers should consider doing so in partnership with local chapters of national organizations such as the Alzheimer's Association, the American Cancer Society or American Heart Association. These organizations can help with educational content and provide insight into the support needed by persons who suffer from these disorders.

Another targeting criterion is the extent of the care recipient's disability. For example, caregivers of those with severe disabilities may respond better to programs delivered in their homes by teleconferencing, the internet, or in-person one-on-one meetings, whereas those caring for persons with milder disabilities may be more able to avail themselves of community-based programs, and may welcome the opportunity to socialize and have a respite from caregiving.

The relationship of the caregiver to the care recipient can also have an impact on the content of education and support programs. Adult children, for example, often have different needs and issues than spousal caregivers. Adult children are more likely to bring up issues of sibling rivalry and family conflict, work-related conflicts, and the impact of caregiving on their relationship with a spouse, children, or their own parents. The caregiving experience is less normative for adult children than for spouses, so they are more likely to bring up misgivings about being in the caregiving role. Thus, although it is possible to serve spouses and adult children caregivers together, consideration should be given to limiting participation to one group or the other, especially in caregiver programs designed to address psychological and emotional issues.

Gender is another characteristic that should be considered when targeting subgroups of caregivers. In our clinical work with caregiver support groups, for example, we have found that the character of the discussion changes in mixed-gender as compared to same-gender groups. In general, our observations are that the character of the discussion is richer and franker in same-gender groups. At the same time, members of mixed-gender groups say that they appreciate learning about the viewpoints of members of the opposite sex. Thus, those who are organizing groups need to think carefully about whether they will limit participation to males or females, or encourage caregivers of both genders to participate.

Race, ethnicity and socio-economic status are other factors that should be considered when targeting subgroups of caregivers. Practitioners who serve caregiving families should be aware that caregivers' racial and ethnic backgrounds can affect the caregiving situation. The extent of acculturation, for example, can affect how Latino caregivers respond to caregiving interventions. Ramos, B., Jones, L., and Toseland, R. (in press), for example, describe how levels of acculturation can affect perceptions of illness and the responsibilities of caregivers. They also emphasize the importance of bilingual staff, the translation of materials into Spanish, and the pace and timing of interventions.

Older persons from minority groups are a rapidly growing segment of the population. Whereas minorities constituted 20% of elderly population in 1980, and 26% of elderly population in 1995, they are projected to represent 33% of the population by 2050 (Markides & Miranda, 1997). Also, their needs for service are often greater than the overall population. For example, on most health status indicators, African American and Latino elderly are less healthy than white elderly (Agency for Healthcare Research and Quality [AHRQ], 2004; Stump, Clark, Johnson, & Wolinsky, 1997). Nevertheless, relatively little attention has been paid to minority caregivers, and their utilization of community services and participation levels in intervention studies has been low (Cox, 1999; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Toseland, Smith, & McCallion, 2001). Therefore, greater attention to the needs of minority family caregivers by those in the aging network is urgently needed.

Sexual orientation also has an important impact on the use of caregiver support groups. Lesbian, gay, bisexual and transgender (LGBT) caregivers may need special assistance and support to encourage them to attend caregiver groups. These individuals' experience with discrimination often cre-

ates barriers to service utilization (Coon, 2003). They may be reluctant to join a group or to self-disclose once they are in a group because of fears about the intolerance and outright hatred some people display toward LGBT individuals. Organizational and system barriers, including problems with medical insurance, can also affect service use. Coon (2003) lists a number of ways these barriers can be overcome. Fundamental to all of these recommendations is treating each LGBT person as an individual without stereotyping or assumptions about their caregiving status based on sexual orientation. He points out that older LGBT caregivers often have had much different experiences with discrimination, prejudice, intolerance and ability to “come out” than younger LGBT caregivers, and these experiences should be taken into account when engaging and working with this group of caregivers. Staff sensitivity training and careful attention to alleviating organizational and system level barriers are other important aspects of working with LGBT caregivers.

#### **PREPARING TO IMPLEMENT A PROGRAM**

There are many issues to consider when planning and implementing caregiver education and support programs. Some of the most important are:

- training needs
- recruitment strategies
- screening of participants
- monitoring program implementation
- evaluating program impact.

One of the first things to consider is the need for training in how to deliver the intervention. Although the programs presented in the following section of this report are clearly described, all of the programs' authors recommend that leaders get some training before implementing a caregiver program. Individuals who have no prior experience leading groups might consider, for example, reading an article on group dynamics such as one by Toseland, Jones, & Gellis (2004), or an introductory textbook on working with people in groups (see Toseland & Rivas, 2005, or Yalom, 1995).

Leaders who have done psychotherapeutic work with a group of people before but who have not worked with older people in groups might benefit from reading a recent article focused on what is different about working with older people in groups by Toseland and Rizzo (in press), or a book on group work with older adults (see for example, Burnside & Schmidt, 1994; Toseland, 1995).

*Training programs can help even experienced leaders learn about the nuances of the program and the best way to present the content while encouraging interaction and participation on the part of all members.*

The caregiver psychoeducational support programs described later in this report have training programs available. These training programs are highly recommended, even for seasoned practitioners who have had experience working with groups of older persons in the past. Training programs can help even experienced leaders learn about the nuances of the program and the best way to present the content while encouraging interaction and participation on the part of all members. They can also teach leaders to present material effectively, and how to work with challenging group members who may have very complicated caregiving situations. The training manuals and other materials supplied by these programs also help to ensure treatment fidelity when the programs are implemented in diverse settings.

### **RECRUITING PARTICIPANTS**

A second consideration when implementing a program is how participants will be recruited. Program planners and practitioners frequently ask about effective strategies to involve caregivers in education and training programs. A variety of strategies can be used including:

- contacting caregivers directly
- mailing and posting announcements
- preparing television and radio announcements and appearing on television and radio programs, and
- issuing press releases and contacting feature writers of local newspapers.

Some evidence suggests that direct contact with potential clients is the most effective recruitment method (Toseland & Rivas, 2005). When potential group members can be identified from agency records or from caseloads of colleagues, providers may wish to set up initial appointments by letter or by telephone. Providers can then interview prospective members in the office or at their home. However, person-to-person contact, particularly in-home contact, can be quite expensive in terms of staff time, and therefore may not be feasible.

Brief, written announcements are useful for recruiting caregivers but they must be sent to the correct audience. To be effective, mailed and posted announcements must be seen by caregivers or potential referral sources. Therefore, careful targeting of the audience is essential. Too often, providers rely on existing mailing lists developed for other purposes or post announcements where they will not be noticed by the target group. Computerized record systems are widely available and can be useful in identifying and targeting individuals who may need a particular service. If providers have a list of

potential members, announcements can be mailed directly to them. Providers may also mail announcements to other social service agencies likely to have contact with potential group members. Experience suggests that a follow-up phone call to those who have received announcements increases the probability that referrals will be made. Announcements can also be posted on community bulletin boards, in senior housing, public gathering places and local businesses. In rural locations, announcements can be posted at firehouses, church halls, schools, general stores and post offices. Providers can ask that announcements be read at meetings of community service groups, church groups, business associations and fraternal organizations.

The Internet offers increased access to caregiver education and support groups. Announcements can be posted on local area networks and community computer bulletin boards, or e-mailed directly to caregivers. Also, organizations within the aging network can, of course, create their own web pages that are accessible to millions of persons who may be interested in learning more about particular services.

Providers might make information about a group available through public speaking and through local television or radio stations. Many civic and religious organizations welcome guest speakers. A presentation on the need for the group, its purpose, and how it would operate can be an effective recruitment tool. Many television and radio stations broadcast public service announcements deemed to be in the public interest, and the proposed caregiver program might be eligible for inclusion in such broadcasts.

Commercial television and radio stations also frequently produce their own local public interest programs, such as talk shows, public discussions, special news reports, and community news announcements. Although public access cable television channels generally have smaller audiences, they can also be used to describe a group service and to invite members to join.

Press releases and newsletter articles are another way to recruit members. Many newspapers—particularly smaller ones—publish a calendar of events for a specified week or month; brief announcements can be placed in the calendar. An article in the features section of a newspaper can reach many caregivers who might be interested in attending a particular program. Newspapers frequently publish stories about new group services or particular social problems. Providers should consider whether the group is newsworthy and, if so,

contact a local editor to request an interview with a reporter. It is particularly helpful if the group's subject matter ties into a news event of the day, for example, a relevant new book has received much publicity, or a notable public figure has announced he has Alzheimer's. Clinical experience suggests that feature newspaper stories are excellent for recruiting caregivers.

### **SCREENING PARTICIPANTS**

When recruitment is complete—but before the program begins—it is important, if possible, to screen potential participants. Sometimes participants are not appropriate for a program because of an untreated psychiatric problem, because they are socially inappropriate, or because they may have difficulty sharing the leader's time with other participants. In most cases, a screening interview will enable the leader to identify individuals who might not be appropriate participants and refer them to alternative sources of help.

In some situations screening interviews may not be possible. In other situations, the screening interview may fail to identify a person whose needs can't be met in the program. For example, sometimes individuals who are very talkative do well in a screening interview, but then dominate discussion time when they participate in the caregiver program. The leader may attempt to intervene by reminding the talkative member of others' desire to speak, or by using other techniques described in Toseland and Rivas (2005). Still, the person in question may dominate the group discussion. When this occurs, leaders should keep in mind that their responsibility is to all the caregivers who are participating in the program. Therefore, leaders should consider meeting after the program with the person whose needs are not being met to help this person find a more suitable source of support.

### **MONITORING PROGRAM IMPLEMENTATION**

As has been pointed out, although much attention has been focused on planning caregiver education and training programs, little attention has been paid to ensuring that they are implemented correctly (Bourgeois, Schulz, & Burgio, 1996). It is essential to build in ongoing monitoring and supervision for those implementing the program. Experience in implementing structured psychoeducational programs for caregivers suggests that even seasoned clinicians can benefit from supervision. We have found audio-taping or video-taping group sessions can be effective in helping leaders to improve their program implementation skills. Training manuals also help leaders to implement programs effectively.

Program evaluation should be a routine part of any caregiver education and training program. At minimum, caregivers should be asked to evaluate the instructor, the usefulness of the program, what features were least and most helpful, and what uncovered issues should be included in future programs. More extensive evaluations can include assessments of the impact of a particular program on members' knowledge and skills, their ability to problem solve or to cope with pressing problems, or their well-being. The choice of outcome measures should be guided by the goals of the program.

### **FIVE SELECTED PROGRAMS**

The caregiver educational and support programs described below were selected after a careful review of the literature and discussion with experts in the field. The programs that were selected have been widely used, have at least some research evidence for their effectiveness, are available for distribution from a source that is likely to remain available for the foreseeable future, and contain well developed ready to use training materials.

The programs are presented in alphabetical order. Because they have not been compared to each other, it is not possible at this time to state with any certainty whether one program is superior to the others. Programs should be selected based on a thoughtful evaluation of the needs of caregivers who are likely to participate in the program. When making a decision, factors to consider include the length and duration of each program, and program content. Special circumstances should also be considered. For example, only one of the programs is designed for Chinese caregivers, two are intended exclusively for caregivers of persons with dementia, one has a version that can be delivered by telephone, and one has versions for caregivers of medically ill persons and for persons with dementia.

#### **PROGRAM #1**

#### ***American Red Cross Family Caregiving Program***

**Description:** The Red Cross Family Caregiving Program is an interactive modular program targeted to caregivers who care for a relative or friend at home. Leaders who have attended a group orientation or completed a self-study facilitate the program's nine modules.

**To order:** Contact the publisher, StayWell, or your American Red Cross chapter. Locate your local Red Cross chapter through [www.redcross.org](http://www.redcross.org) or the white pages of your telephone directory.

*Mail:* Attn.: Order Entry Dept., the StayWell Company, 780 Township Line Road, Yardley, PA 19067.

*Telephone:* StayWell Customer Service, (800) 667-2968, Monday through Friday from 9:00 a.m. to 8:00 p.m. Eastern Time.

*Fax:* Fax your order to the StayWell Order Entry Department (877) 297-8525.

*E-mail :* [orders@staywell.com](mailto:orders@staywell.com)

**Description of Materials:** Family Caregiving offers nine modules that help participants provide better care and gain an understanding of safety, nutrition, and general care, legal and financial issues. In addition, a scripted leader curriculum is provided to facilitate the module presentations.

*Participant Booklets:* 10/pack for \$26.50

- Home Safety Participant's Booklet (StayWell Stock No. 653989)
- General Caregiving Skills Participant's Booklet (StayWell Stock No. 653988)
- Positioning and Helping Your Loved One Move Participant's Booklet (StayWell Stock No. 653987)
- Assisting with Personal Care Participant's Booklet (StayWell Stock No. 653985)
- Healthy Eating Participant's Booklet (StayWell Stock No. 653990)
- Caring for the Caregiver Participant's Booklet (StayWell Stock No. 653986)
- Legal and Financial Issues Participant's Booklet (StayWell Stock No. 653993)
- Caring for a Loved One with HIV/AIDS Participant's Booklet (StayWell Stock No. 653991)
- Caring for a Loved One with Alzheimer's Disease or Dementia Participant's Booklet (StayWell Stock No. 653992)

*Family Caregiving Video* (VHS Stock No. 653983 or DVD Stock No. 653984) contains required video segments used for each module. Cost is \$45 each.

*Family Caregiving Leader's Guide* - Obtain from your local chapter or [www.redcross.org](http://www.redcross.org). The scripted guide is used to facilitate the modules, reviewed in a Leader's Group Orientation or downloaded and used in a self-study format.

**Whom the Materials Are Designed to Serve:** The facilitator materials are used by Family Caregiving Leaders who have attended a group orientation or followed a self-orientation. The

Leader conducts the Family Caregiver presentations in their local communities providing and reviewing the participant booklets with class attendees. The classes are interactive and viewing caregiving skills and information on a video stimulates participant conversation. The nine modules include information that can be used in many different types of caregiving situations.

**Other Languages:** English only at this time.

**Training Available:** Local American Red Cross chapters conduct the leader training, which consists of a group leader orientation to the materials, review of video segments and review of leader role and responsibilities. The orientation takes approximately 2.5 hours. Upon completion, leaders facilitate the module information to groups of caregivers through one-hour presentations for each of the nine modules. The modular concept is flexible and leaders may elect to teach one or all the modules. The leader group orientations can be conducted at your location or at the Red Cross chapter. Chapters can also elect to deliver the modules directly to caregivers through scheduled presentations conducted in the community.

**Cost of Training:** The cost of the Leader's Orientation is usually about \$80 but varies slightly by Red Cross chapter and includes all materials to facilitate the modules.

**Restrictions on Use of Materials:** The materials are copyrighted and cannot be duplicated.

**Research Supporting the Curriculum/Program:** Prior to curriculum development focus groups and a telephone survey were conducted with caregivers. This information was used to guide program development.

**Description of Use:** The program recently has been released to 900 Red Cross chapters nationwide. Chapters report strong interest from caregiving community based organizations that wish to become leaders and several chapters have received grant funding to deliver the presentations.

## PROGRAM #2

### ***Caregiver Health Education Program***

**Description:** The program is designed to help professionals lead education and support groups for caregivers of frail older persons with chronic disabilities. A version of the program has also been developed specifically for caregivers of persons with dementia. There is also a version of the program de-

signed to be delivered by teleconference. This latter program is particularly useful for reaching out to rural caregivers and those who do not, or cannot, attend face-to-face groups.

**To order:**

Institute of Gerontology, University at Albany, State University of New York, 135 Western Ave., Albany, New York 12222

*E-mai:* [plaverty@albany.edu](mailto:plaverty@albany.edu)

**Cost:** \$20.00 for postage and handling.

**Materials Included:** Leader manual, 130 pages; workbook, 40 pages

**Description of Materials:** The leader manual contains introductory material, 20 session agendas (eight weekly meetings and 10 monthly meetings) speaker handouts and supporting materials. The workbook contains outlines and educational material for each session and handouts used during the program.

**Whom the Materials Are Designed to Serve:** The training manual is intended for professionals such as social workers, nurses and psychologists who want to lead a caregiver support group. The participants workbook is intended for the caregivers who participate in the program. The program itself is designed for all individuals caring for persons with chronic disabilities. There is a special version of the program designed for use over the telephone (teleconferencing support group protocol), and a version of the program specifically for caregivers of persons with dementia.

**Other languages:** Program materials will be translated into Spanish.

**Training Available:** Training workshops are available upon request.

**Cost of the Training:** \$700 for a one day workshop, plus travel and per diem expenses.

**Restrictions on Use of Materials:** Those who use the program are free to copy the workbook and any of its contents. The training manual should not be copied without the permission of the author.

**Research Supporting the Curriculum/Program:** The program has been used in a variety of research studies, testing both face-to-face groups and the telephone program.

**Description of Use:** The program has been used in a variety of medical and social service settings, primarily in the Up-state New York region. The program has included caregivers of persons with many different types of chronic health problems. A special version of the program has been developed for caregivers of those with dementia.

**Publications:**

Toseland, R., Rossiter, C., & Labrecque, M. (1989a). The effectiveness of three group intervention strategies to support caregivers. *American Journal of Orthopsychiatry*, 59(3), 420-429.

Toseland, R., Rossiter, C., & Labrecque, M. (1989b). The effectiveness of peer-led and professionally-led groups to support family caregivers. *The Gerontologist*, 29(4), 465-471.

Toseland, R., Rossiter, C., & Labrecque, M. (1989c). The effectiveness of two kinds of support groups for caregivers. *Social Service Review*, 63(3), 415-432.

Labrecque, M., Peak, T., & Toseland, R. (1992). The long-term effectiveness of a group program for caregivers of frail elderly veterans. *American Journal of Orthopsychiatry*, 62(4), 575-588.

Toseland, R. (1990). Long-term effectiveness of peer-led and professionally-led support groups for family caregivers. *Social Service Review*, 64(2), 308-327.

Toseland, R., Labrecque, M., Goebel, S., & Whitney, M. (1992). An evaluation of a group program for spouses of frail elderly veterans. *The Gerontologist*, 32(3), 382-390.

Toseland, R., McCallion, P., Smith, T., Huck, S., Bourgeois, P., & Garstka, T. (2001). Health education groups for caregivers in an HMO. *Journal of Clinical Psychology*, 57(4), 551-570.

Toseland, R., McCallion, P., Smith, T., & Banks, S. (2004). Supporting caregivers of frail older adults in an HMO setting. *American Journal of Orthopsychiatry*, 74 (3), 349-364.

**PROGRAM #3**

***Caring for You, Caring for Me: Education and Support for Family & Professional Caregivers, Second Edition***

**Description:** The 10-hour program, conducted in five two-hour modules, addresses the needs of family and professional caregivers by bringing them together in a relaxed setting to discuss common issues, share ideas, and gain a better understanding of each other's perspective on what it means to be a caregiver. The goals are for caregivers to have the opportunity to:

- Gain information on various topics related to caregiving
- Learn ways of coping with the stresses and strains of being a caregiver
- Learn what resources are available locally, regionally and nationally
- Discover ways of working together to reduce frustrations and barriers in the caregiving experience
- Share common concerns and issues.

**To Order:**

**Mail:** Rosalynn Carter Institute for Caregiving,  
Georgia Southwestern State University, 800 Wheatley Street,  
Americus, GA 31709

**Web Address:** [www.RosalynnCarter.org](http://www.RosalynnCarter.org)

**Phone:** (229) 928-1234

**E-Mail:** [jenny@rci.gsw.edu](mailto:jenny@rci.gsw.edu)

**Cost:** \$50

**Materials Included:** Program Guide

**Description of Materials:** The Program Guide contains a scripted narrative of the content and suggested activities; handouts for program participants; mock-ups of overhead transparencies and a CD containing slides to support presentation; written material explaining the philosophy, organization and appropriate use of the program; and appendices with supplementary information.

**Whom the Materials Are Designed to Serve:** The Program Guide is designed for health care and human service professionals who lead groups and/or conduct educational or training programs for caregivers across diseases/disability groups throughout the lifespan.

**Training Available:** A one-day Leader Preparation Workshop is available from the Rosalynn Carter Institute for Caregiv-

ing (RCI). The workshop has been approved for 5.5 hours of continuing education credit by the National Association of Social Workers (NASW), National Board of Certified Counselors (NBCC), American Nurses Association (ANA), and the National Commission for Health Education Credentialing (NCHEC). The workshop is offered through two means: (1) directly by the RCI in various locations throughout the U.S. (For a schedule visit the RCI website.); and (2) at the request of sponsoring organizations for a maximum of 30 participants per workshop.

**Cost of Training:** Although costs may vary depending upon specific circumstances, the fee for individuals to attend leader preparation workshops sponsored directly by the RCI is \$250, which includes one Program Guide. Workshops conducted at the request of other sponsoring organizations cost \$1,900, plus travel expenses of the program leader and program guides for participants.

**Restrictions on Use of Materials:** The Program Guide contains mostly copyrighted material; however, permission is granted to purchasers of the guide to copy handouts for participants in the program.

**Research Supporting the Curriculum/Program:** The program was developed as part of a demonstration grant funded by The Pew Charitable Trusts in the mid-1990s. Content information developed for the program was based on a 1993 research study conducted by the RCI, review of relevant literature and existing programs for caregivers, and information from a task force of professional caregivers, family caregivers, and academicians.

During the demonstration project, participant satisfaction evaluations were conducted and compiled for all programs offered. Additionally, pre and post program surveys were used to measure the perceived impact of the program on participants. When the New Jersey Department of Health and Senior Services conducted the program on an extensive basis in 1999-2001, an evaluative study was conducted by the Center for State Health Policy at Rutgers University (cited in section below).

**Publications:**

Haigler, D., Bauer, L., & Travis, S. S. (in press). Caring for you, caring for me: A 10-year caregiver educational initiative of the Rosalynn Carter Institute for Human Development. *Health & Social Work*.

Haigler, D., Bauer, L., & Travis, S. S. (2004). Finding the common ground of family and professional caregiving: The education agenda at the Rosalynn Carter Institute. *Educational Gerontology*, 30(2), 95-105.

Silberberg, M. (2002). Evaluation of New Jersey's "Caring for you, Caring for me" course. New Brunswick, NJ: State University of New Jersey, Center for State Health Policy.

Talley, R. C., & Travis, S. S. (2004). A commitment to professional caregivers at the Rosalynn Carter Institute for Human Development. *Geriatric Nursing*, 25(2), 113-114.

**Description of Use:** Materials have been distributed for use widely throughout the United States. More concentrated use of the program has occurred in the following states in which leader preparation workshops have been conducted: Georgia, New Jersey, Colorado, California, Kansas, North Carolina, South Carolina and Tennessee.

**Other Information:** The Second Edition of *Caring for You, Caring for Me* became available in 2004. The descriptive information about the program (above), except for development and historical use of materials, is based on the Second Edition.

**Contact for Additional Information:**

Laura Bauer, MPA  
Rosalynn Carter Institute for Caregiving  
(229) 931-6902  
E-mail: [laura@rci.gsw.edu](mailto:laura@rci.gsw.edu)

**PROGRAM #4**

***Coping with Caregiving***

**Description:** This is a train-the-trainer education program that focuses exclusively on self-care for dementia family caregivers.

**To order:**

**Mail:** Older Adult and Family Center, c/o VA Medical Center and Stanford University School of Medicine, 795 Willow Rd., Menlo Park, CA 94025

**Web Address:** [www.oafc-menlo.com](http://www.oafc-menlo.com)

**E-mail:** [dolorest@stanford.edu](mailto:dolorest@stanford.edu)

**Phone:** (650) 400-8172

**Cost:** Fees include a two-day training workshop plus the

course materials. Materials are available only to individuals who complete the Class Leader training. Cost per individual at programs held in Palo Alto, CA is \$500. Group rates for up to 20 persons off-site are available at a discount.

**Goals:** Improving the self-care and self-efficacy of caregivers are primary goals. *Coping with Caregiving* focuses on the self-care needs of caregivers, not the care receivers. Classes emphasize the importance of taking care of one's own physical and mental health in order to better care for others. Practical skills for effective coping, stress reduction, improving self-confidence and communicating effectively are taught and reinforced in a group setting under the direction of Class Leaders.

**Description of Materials:** A 100-page scripted curriculum and accompanying materials are used to teach the *Coping with Caregiving* classes to family caregivers. Classes consist of several four-session "modules" of two hours duration each, held weekly, that are facilitated by pairs of trained class leaders. Materials include:

- Class Leader's Guide and Participant Manual
- Set of color overhead transparencies, back-up diskette
- All handouts and marketing materials on diskette
- Relaxation audiotape

**Whom the Materials Are Designed to Serve:** Pairs of trained class leaders use the materials to conduct *Coping with Caregiving* classes in their local communities. Classes involve a variety of didactic and interactive techniques to teach self-care skills to family caregivers. The course is designed specifically for caregivers of persons with dementia.

**Other Languages:** The Class Leaders' Guide and the Participant Binders are available in Spanish and Chinese.

**Training Available:** Class leader training consists of a high-quality, interactive two-day program provided by a team of three experienced Master Trainers. A significant amount of practice time is built into this training so that class leaders can work comfortably in pairs to deliver the *Coping with Caregiving* curriculum to family caregivers. Upon completion of training, class leaders are successfully prepared to teach groups of 10-15 caregivers a set of self-care skills. These may be done in four-session modules so that caregivers can be offered those skill training programs that seem most suited to their needs.

Training workshops are conducted on a regular basis at Stanford University, Palo Alto, CA. Arrangements can also be made to conduct a training workshop at a location of your choice. Fees for these trainings vary depending on the location and the number of individuals being trained.

**Cost of the Training:** \$500 per person; discounted rates available for training held in other locales for groups of up to 20 persons.

**Restrictions on Use of Materials:** Class leaders are licensed to use the materials. Material can be used outside the context of the program as long as appropriate credit is given regarding its source.

**Research Supporting the Curriculum/Program:**

The *Coping with Caregiving* program was developed as part of the Resources for Enhancing Alzheimer's Caregiver Health (REACH) project. REACH was a multisite, multicomponent study to see which interventions were most effective in reducing the stress and improving the health of caregivers for loved ones with dementia. Boston, Philadelphia, Memphis, Birmingham, Miami and Palo Alto were the six sites; each site had a different intervention component. The Palo Alto site had *Coping with Caregiving* classes. Pre and post data were collected from caregivers who reported high use of the tools taught in the series and significant improvements in self-efficacy, emotional well-being, and self-care behaviors. Currently there are three projects run by the Older Adult and Family Center at the Stanford University School of Medicine and the Department of Veterans Affairs Palo Alto Health Care System that use the *Coping with Caregiving* as the basis of their interventions. They are REACH II, the Stress Management Project, and the Chinese Caregiver Assistance Program. Interventions in the REACH II project are done one-on-one, while the Stress Management project uses the *Coping with Caregiving* in a support group setting. Both projects use an English version and have translated the classes into Spanish. The Chinese Caregiver Assistance Program has translated the Class Leaders' Guides and the participant manuals into Chinese.

Preliminary data collected at pre and post among caregivers in Northern California show the positive impact of *Coping with Caregiving* on participants' self-reported depression, vitality, self-efficacy, positive feelings about caregiving, ability to make time for themselves, ability to take care of their own health, number of relaxation activities, time spent in relaxation activities, time spent exercising, and reaction to care recipients' problem behaviors. In addition, the completed

REACH I study, as well as smaller sample randomized studies conducted with both Chinese and Hispanic caregivers, indicate the superiority of this psychoeducational approach over other approaches to which it has been compared: notably, support groups (similar to those led in the community) and/or telephone support (control) conditions. There have been four separate studies completed that all found similar results. Details of these studies are included in publications, below. The PI can also provide more information about each of them, upon request.

#### **List of Manuals:**

Gallagher-Thompson, D., Rose, J., Florsheim, M., Jacome, P., DelMaestro, S., Peters, L., Gantz, F., Arguello, D., Johnson, C., Moorehead, R.S., Polich, T.M., Chesney, M., & Thompson, L.W. *Controlling your frustration: A class for caregivers*. (1992). VA Palo Alto, CA Health Care System & Stanford University, School of Medicine. (Note: This refers to two English language manuals: a class leader and a class participant version.)

Gallagher-Thompson, D., Arguello, D., Johnson, C., Moorehead, R.S., & Polich, T.M. (1992). *Como controlar la frustración: Una clase para cuidantes*. VA Palo Alto, CA Health Care System and Stanford University, School of Medicine. (Note: This refers to two Spanish language manuals: a class leader and a class participant version.)

Gallagher-Thompson, D., Ossinalde, C., & Thompson, L.W. (1996). *Coping with caregiving: A class for family caregivers*. VA Palo Alto, CA Health Care System and Stanford University, School of Medicine. (Note: This refers to a fully revised English language manual for leaders and class participants.)

Gallagher-Thompson, D., Ossinalde, C., Menéndez, A., Fernandez, E., Romero, J., Valverde, I., & Thompson, L.W. (1996). *Como mantener su bienestar*. Una clase para cuidadores. VA Palo Alto, CA Health Care System and Stanford University, School of Medicine. (Note: This refers to a fully revised Spanish language manual for leaders and class participants.)

Gallagher Thompson, D., Solano, N., McGee, J. S., Krisztal, E., Kaye, J., Coon, D., & Thompson, L. W. (2002). *Coping with caregiving: Reducing stress and improving quality of life*. VA Palo Alto, CA Health Care System and Stanford University, School of Medicine. (Note: This is a new manual for treating distress in family caregivers.)

Solano, N., Cardenas, V., Day, S., & Gallagher-Thompson, D. (2002). *Reduciendo su tension y mejorando su calidad de vida: Una clase para cuidadoras*. VA Palo Alto, CA Health Care System and Stanford University, School of Medicine. (Note: This is the Spanish language version of the caregiving manual. Authors listed are the translators of the material.)

Tang, P., Wang, P. C., Leung, L., Liu, A., Tse, C., Pu, C. Y., & Gallagher Thompson, D. (2002). *Coping with Caregiving: Reducing stress and improving quality of life*. VA Palo Alto, CA Health Care System and Stanford University, School of Medicine. (Note: This is the Chinese language version of the caregiving manual. Authors listed are the translators.)

#### **List of Publications:**

- Coon, D. W., Thompson, L. W., Steffen, A., Sorocco, K., & Gallagher-Thompson, D. (2003). Anger and depression management: Psychoeducational skill training interventions for women caregivers of a relative with dementia. *The Gerontologist*, 43, 678-689.
- Depp, C., Krisztal, E., Cardenas, V., Oportot, M., Mausbach, B., Ambler, C., Leung, L., & Gallagher-Thompson, D. (2003). Treatment options for improving well-being in dementia family caregivers: The case for psychoeducational interventions. *The Clinical Psychologist*, 7, 21-31
- Gallagher-Thompson, D., Arean, P. D., Rivera, P., & Thompson, L. W. (2001). A psychoeducational intervention to reduce distress in Hispanic family caregivers: Results of a pilot study. *Clinical Gerontologist*, 23 (1/2), 17-32.
- Gallagher-Thompson, D., Coon, D. W., Solano, N., Ambler, C., Rabinowitz, R., & Thompson, L. W. (2003). Change in indices of distress among Latina and Anglo female caregivers of elderly relatives with dementia: Site specific results from the REACH national collaborative study. *The Gerontologist*, 43, 580-591.
- Gallagher-Thompson, D., Haley, W., Guy, D., Rupert, M., Arguelles, T., Zeiss, L. M., Long, C., Tennstedt, S., & Ory, M. (2003). Tailoring psychological interventions for ethnically diverse caregivers. *Clinical Psychology: Science and Practice*, 10, 423-438.

Gallagher-Thompson, D., Lovett, S., Rose, J., McKibbin, C., Coon, D., Futterman, A., & Thompson, L. W. (2000). Impact of psychoeducational interventions on distressed family caregivers. *Journal of Clinical Geropsychology*, 6, 91-110.

Lau, A. & Gallagher-Thompson, D. (2002). Ethnic minority older adults in clinical and research programs: Issues and recommendations. *The Behavior Therapist*, 25 (1), 10-11; 16.

Thompson, L. W., Solano, N., Kinoshita, L., Coon, D. W., Mausbach, B., & Gallagher-Thompson, D. (2002). Pleasurable activities and mood: Differences between Latina and Caucasian dementia family caregivers. *Journal of Mental Health and Aging*, 8, 211-224.

**Description of Use:** *Coping with Caregiving* classes are being used by a variety of social service and healthcare organizations throughout Northern California.

## PROGRAM #5

### ***Powerful Tools for Caregivers***

**Description:** This is a train-the-trainer education program that focuses exclusively on self-care of family caregivers.

**To order:**

**Mail:** Mather LifeWays Institute on Aging, 1603 Orrington Avenue, Evanston, IL 60201

**Web Address:** [www.tools4caregivers.com](http://www.tools4caregivers.com)

**E-mail:** [srothas@matherlifeways.com](mailto:srothas@matherlifeways.com)

**Phone:** (847) 492-6810

**Cost:** Fees include a two and one-half day training workshop plus the course materials. Materials are available only to individuals who complete the class leader training. Cost per individual at programs held in Evanston, Illinois is \$895. Group rates for up to 20 persons off site are available at a discount.

**Goals:** Improving the self-care and self-efficacy of caregivers are primary goals. *Powerful Tools for Caregivers* focuses on the self-care needs of caregivers, not the care receivers. Classes emphasize the importance of taking care of one's own physical and mental health in order to better care for others. Practical skills for effective coping, stress reduction, improving self-confidence and communicating effectively are taught and reinforced in a group setting under the direction of class leaders.

**Description of Materials:** A 300-page scripted curriculum and accompanying materials are used to teach the *Powerful Tools for Caregivers* classes to family caregivers. Classes consist of six sessions, 2.5 hours each, held weekly, facilitated by pairs of trained class leaders. Materials include: class leader's guide; set of 76 color overhead transparencies, back-up diskette; all handouts and marketing materials on diskette; marketing and communications plan; the Caregiver Helpbook; the Dollmaker video; a Time for Healing relaxation audio-tape; carry bag.

**Whom the Materials Are Designed to Serve:** The materials are used by pairs of trained class leaders to conduct *Powerful Tools for Caregivers* classes in their own communities. Classes involve a variety of didactic and interactive techniques to teach self-care skills to family caregivers. The course is intended for family caregivers regardless of their caregiving situation or the living arrangements or medical conditions of care recipients.

**Other Languages:** The class leaders' guide and the Dollmaker video are available in Spanish.

**Type of Training Available:** Class leader training consists of a high-quality, interactive two and one-half day program provided by a team of three experienced Master Trainers. A significant amount of practice time is built into this training so that class leaders can work comfortably in pairs to deliver the *Powerful Tools for Caregivers* curriculum to family caregivers. Upon completion of training, class leaders are successfully prepared to teach groups of 10-15 caregivers a set of self-care skills through an engaging six-part course, based on weekly 2.5-hour classes.

Training workshops are conducted on a regular basis at Mather LifeWays, Evanston, IL. Arrangements can also be made to conduct a training workshop at a location of your choice. Fees for these trainings vary depending on the location and the number of individuals being trained.

**Cost of Training:** \$895 per person; discounted rates available for training held in other locales for groups of up to 20 persons.

**Restrictions on Use of Materials:** Class leaders are licensed to use the materials. Material can be used outside the context of the program as long as appropriate credit is given regarding its source.

**Research Supporting the Curriculum/Program:** The program was first developed and tested in Oregon. Pre, post, and six-month follow-up data were collected from 63 caregivers who reported high use of the tools taught in the series and significant improvements in self-efficacy, emotional well-being, and self-care behaviors. In northeastern Illinois, data were collected at pre, post and six-month follow-up among 205 caregivers. Results show the positive impact of Powerful Tools on participants' self-reported depression, vitality, self-efficacy, positive feelings about caregiving, ability to make time for themselves, ability to take care of their own health, number of relaxation activities, time spent in relaxation activities, time spent exercising, and reaction to care receivers' problem behaviors.

**Description of Use:** *Powerful Tools for Caregivers* classes are now offered through a variety of social service and healthcare organizations through trained class leaders in many states.

**Publications:**

Kuhn D., Fulton B.R., & Edelman, P. (2003). *Powerful Tools for Caregivers: Improving self-care and self-efficacy of family caregivers*, *Alzheimer's Care Quarterly*, 4 (3),189-203.

## REFERENCES

- Agency for Healthcare Research and Quality (2004 April). *Minority Health/Disparities Research*. AHRQ newsletter, Research Activities, April 2004, No. 284.
- Bourgeois, M., Schulz, R., & Burgio, L. (1996). Interventions for caregivers of patients with Alzheimer's disease: A review and analysis of content, process, and outcomes. *International Journal of Aging-Human Behavior*, 43(1).
- Brodsky, H., & Peters, K. (1991). Cost effectiveness of a training program for dementia caregivers. *International Psychogeriatrics*, 3(1), 11–23.
- Burnside, I., & Schmidt, M. (1994). *Working with older people: Group process and techniques* (3<sup>rd</sup> ed). Boston, MA: Jones & Bartlett.
- Cooke, D., McNally, L., Mulligan, K., Harrison, M., & Newman, P. (2001). Psychosocial interventions for caregivers of people with dementia: A systematic review. *Aging & Mental Health*, 5(2), 120-135.
- Coon, D. (2003). *Lesbian, gay, bisexual and transgender issues in family caregiving*. San Francisco: Family Caregiver Alliance. Retrieved October 10, 2004, from <http://www.caregiver.org/caregiver/jsp/home.jsp>
- Cox, C. (1999). Race and caregiving: Patterns of service use by African American and white caregivers of persons with Alzheimer's disease. *Journal of Gerontological Social Work*, 32 (2), 5-19.
- Gallagher-Thompson, D., Lovett, S., Rose, J., McKibben, C., Coon, D., Futterman, A., & Thompson, L. (2000). Impact of psychoeducational interventions on distressed caregivers. *Journal of Clinical Geropsychology*, 6 (2), 91-110.
- Markides, K., & Miranda, M. (1997). Minority aging and health: An overview. In K. S. Markides & M. R. Miranda (Eds.), *Minorities, aging, and health* (pp. 1-14). Thousand Oaks, CA: Sage.
- Metropolitan Life Insurance Company (1999). *The MetLife juggling act study: Balancing caregiving with work and the costs involved*. Westport, CT.: Metropolitan Life Insurance Company.
- Mittelman, M., Ferris, S., Shulman, E., Steinberg, G., & Levin, B. (1996). A family intervention to delay nursing home placement of patients with Alzheimer's disease. *Journal of the American Medical Association*, 276, 1725–1731.

- National Alliance for Caregiving and AARP. *Caregiving in the US*. Bethesda, MD: National Alliance for Caregiving.
- Peak, T., Toseland, R., & Banks, S. (1995). Impact of a spouse-caregiver support group on care recipient health care costs; *Journal of Aging and Health*, 7(3), 427-449.
- Ramos, B., Jones, L., & Toseland, R. (In press). Culturally competent social work practice with elderly of color. In D. Lum (Ed.) *Social work practice and people of color: A process stage approach*. (5<sup>th</sup> Ed.). Belmont, Ca: Brooks Cole.
- Schulz, R. (2000). *Handbook on dementia caregiving: Evidence-based interventions for family caregivers*. New York: Springer.
- Schulz, R., O'Brien, A., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *The Gerontologist*, 35, 771-791.
- Stump, T., Clark, D., Johnson R., & Wolinsky, F. (1997). The structure of health status among Hispanic, African American, and White older adults. *The Journals of Gerontology*, 52B (Special Issue), 49-60.
- Toseland, R. (1995). *Group work with the elderly and family caregivers*. New York: Springer.
- Toseland, R., Jones, L., & Gellis, Z. (2004). Group dynamics. In C. D. Garvin, M. J. Galinsky & L. Gutierrez (Eds.), *Handbook of social work with groups*, 13-31. New York: The Guilford Press.
- Toseland, R., & Rivas, R. (2005). *An introduction to group work practice* (5<sup>th</sup> ed). Needham Heights, MA: Allyn & Bacon.
- Toseland, R., & Rizzo, V. (in press). What's different about working with older people in groups? *Social Work with Groups*.
- Toseland, R., & Rossiter, C. (1989). Group intervention to support caregivers: A review and analysis. *The Gerontologist*, 29 (4), 438-448.
- Toseland, R., Smith, T., & Banks, S. (in press). The effectiveness and efficiency of a health education program in an HMO. *Research on Social Work Practice*.
- Toseland, R., Smith, G., & McCallion, P. (2001). Helping family caregivers. In A. Gitterman (Ed.), *Handbook of social work practice with vulnerable and resilient populations* (2<sup>nd</sup> ed.). 548-581. New York: Columbia University Press.

- Yalom, I. (1995). *The theory and practice of group psychotherapy* (4<sup>th</sup> ed.). New York: Basic Books.
- Zarit, S., Gaugler, J., & Jarrott, S. (1999). Useful services for families: Research findings and directions. *International Journal of Geriatric Psychiatry*, 14, 165-181.