

DOCUMENT RESUME

ED 356 851

PS 020 650

AUTHOR White, Helga I.; Olson, Philip  
 TITLE Reducing Barriers to Participation in Family  
 Caregiver Training: Respite Options for Caregiver  
 Training.  
 INSTITUTION Missouri Univ., Kansas City. Center on Rural  
 Elderly.  
 SPONS AGENCY Kellogg Foundation, Battle Creek, Mich.  
 PUB DATE 90  
 NOTE 54p.  
 PUB TYPE Guides - Non-Classroom Use (055)

EDRS PRICE MF01/PC03 Plus Postage.  
 DESCRIPTORS Adult Day Care; \*Demonstration Programs; \*Educational  
 Gerontology; Educational Principles; \*Family  
 Caregivers; \*Nonschool Educational Programs; Older  
 Adults; Program Descriptions; Rural Education; \*Rural  
 Population; Social Services  
 IDENTIFIERS Barriers to Participation; \*Caregiver Training;  
 \*Elder Care

ABSTRACT

This manual for professionals who offer, or are interested in offering, educational programs for family caregivers identifies obstacles to offering such programs and describes effective practices for dealing with these obstacles. The document's emphasis is on the process of providing educational programming, and not the content of the programming. The first of the manual's four chapters includes information about the scope of the caregiving experience and caregivers' needs for education and training. The second chapter highlights three models of effective practices for educational programs that increase attendance and provide respite for family caregivers of elderly family members while the caregivers are receiving the educational programming. The third chapter extracts some general principles from these and other successful models. Finally, the fourth chapter, which is designed specifically for rural practitioners, offers four case studies that demonstrate how the general principles from the models can be implemented in rural settings. Three appendices offer a bibliography of caregiving literature, a list of educational programs for caregivers, and a list of self-help resources to which families can be directed. (HOD)

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# Reducing Barriers to Participation in Family Caregiver Training:

• Respite Options for Caregiver Training

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# Reducing Barriers to Participation in Family Caregiver Training:

Respite Options for Caregiver Training

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Philip Olson

Center on Rural Elderly

This publication is supported by a grant from the W.K. Kellogg Foundation

## ACKNOWLEDGEMENTS

This manual is the product of several dozen persons who contributed ideas, suggestions, material, and support:

The three professionals who prepared the respite models: Cynthia Higbea, Lee Memorial Hospital, Fort Meyers, FL; Susan Tebb, Veterans Administration Hospital, Topeka, KS; and Jill Boyd, St. Louis Alzheimer's Chapter, St. Louis, MO.

The four professionals who prepared the rural case studies: Virginia Bell, University of Kentucky; Vera Guise, Alzheimer's Association of Western North Carolina; Phyllis O'Hara-McGuane, Franklin County Home Care Corp., Turner Falls, MA; and Lois Oliver, Cedar Acres Adult Day Center, Janesville, WI.

Those professionals who participated in the focus groups at GSA and NASW: Lisa Gwyther, Duke University; Raymond Coward, University of Florida; Marjorie Cantor, Fordham University; Karen Roberto, University of Northern Colorado; Carol Schultz, University of Missouri; Amy Horowitz, The Lighthouse; Ellie Brubaker, Miami University; Robyn Stone, National Center for Health Services Research; Alice Day, Population Studies Center; Eleanor Stoller, SUNY Plattsburg; Tim Brubaker, Miami University; Julie Malloy, Benedum Geriatric Center; Gary Nelson, University of North Carolina, Chapel Hill; William Pollard, Grambling State; Kathy Reed, Benedum Geriatric Center; Ira Colby, University of Texas-Arlington; Emelia Martinez-Brawley, Pennsylvania State University.

Those professionals who answered questions, provided ideas, suggested names of other professionals, sent materials, brainstormed with us, and in countless ways contributed to this manual: Rhonda Montgomery, Wayne State University; Robert Jackson, University of Nevada-Reno; Vicki Schmall, Oregon Cooperative Extension Service; Nancy Hooyman, University of Washington; Lynn Osterkamp, University of Kansas; Angela Heath, AARP; Debbie Anderson, Overland Hospital, Bellevue, WA; Joyce Prothero, NW Gerontology Center, WA; Leah Eskenazi, Good Samaritan Hospital, Portland, OR; Karen Miller, VNA, Washington, D.C.; Zelda Menuskin, Senior Companion Program, CO; Enid Cox, University of Denver; Carol Farran, Rush Presbyterian Hospital, Chicago; Ann Zimmer, Brookdale Foundation, NY; Susan Martin, Good Samaritan Hospital, WA.

The Center on Rural Elderly acknowledges the assistance of all of the above named persons, but in no way implies that any of them are responsible for the contents of the manual or its overall objective.

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## INTRODUCTION

This manual is created for professionals who offer, or who are interested in offering, educational programs to family caregivers. The purpose of the manual is to address the **process** of providing educational programming, not the content. The "how" will be examined, not the "what". Additional resources are included as appendices to this guide which can provide help with content. It is hoped that the manual will help professionals offer educational programs in a way that will both address the needs of the caregivers and make it possible for them to attend workshops. The goal is to identify the obstacles to offering educational workshops, concentrate on one of those obstacles and attempt to locate model programs whose "best practices" can be shared by way of this manual. This activity is a result of the mission of the W.K. Kellogg-funded Center on Rural Elderly, which is to collect and make available detailed information to professional educators on educational training programs in family caregiving.

During the work of the Center on Rural Elderly, it has been apparent that professionals face a number of obstacles to the implementation of successful educational programs. The Center set out to discover the most serious obstacles with the view of developing a set of "best practices" guides for practitioners that would assist them in overcoming these obstacles. The first step of the Center in identifying obstacles was to contact a sample of people who had developed educational programs. Twelve program developers were contacted, including persons from the United State Department of Agriculture Cooperative Extension Service; private practice social workers; university professionals and staff, including psychologists and gerontologists; registered nurses and staff at the American Association of Retired Persons. These professionals named sixteen (16) obstacles to successful educational programming for caregivers.

Next, the Center gathered additional professionals together in a group context to discuss the issues in detail. At the 1988 annual meeting of the Gerontological Society of America, a group of eight professionals with expertise in gerontology and caregiving were convened in a focus group format. A similar group of eight experts was also convened at an 1988 annual meeting of the National Association of Social Workers. Issues were prioritized by both groups by how much they created an obstacle to implementing an educational workshop. The program developers who were contacted, as well as both focus groups were unanimous in their choice of one obstacle as the highest priority: **caregivers may not be able to attend a workshop if they have no respite to allow them to take time from the actual caregiving duties.**

The last step in developing this manual was to identify programs which had developed successful strategies, or "best practices", for providing respite during educational workshops for caregivers. Since it would not be feasible to do a national survey of all the possible professionals who might be offering respite with

educational programs, another sampling method was chosen as more productive. Beginning with the professionals who attended the focus groups, a nonsystematic, snowball sampling was conducted to identify models. Each person was called and asked to identify model programs or identify other professionals in the field who might know of model programs. Contacts represented states from California and Washington to Pennsylvania and North Carolina. Several models were chosen for inclusion in this manual. This kind of educational programming is not often evaluated by its developers and uniform evaluation measures are not available, so the programs were chosen for more informal reasons. The persons who operated the model programs presented in this manual found that the method they used for offering respite **worked** so that caregivers could attend the program. More caregivers attended the program than when respite was not offered and the caregivers themselves, in all three cases, expressed the sentiment that they would not have been able to attend otherwise. While this is a more tenuous method of choosing models, it does recognize "what works" for program developers in the real world. These models are not intended to represent all of the possible variations and methods for providing respite during educational programming, but they do provide a springboard for discussing some of principles which others have found increase attendance and address an obstacle to providing valuable educational programming to caregivers of the elderly persons.

The manual is designed for experienced as well as beginning practitioners.

- Chapter 1 is a general introduction to the manual which includes information about the scope of the caregiving experience and caregivers' needs for education and training.
- Chapter 2 highlights three "best practice" models for dealing with the caregivers' need for respite during educational programs.
- Chapter 3 extracts some general principles from these and other successful models.
- Chapter 4 is designed specifically for those rural practitioners and offers some additional case studies which provide opportunities to see how the general principles from the "best practice" models may be implemented in rural settings. This chapter on rural settings reflects the Center on Rural Elderly's original mission to assist rural practitioners in their task of addressing the needs of elders and their caregivers.

Three appendices offer a bibliography of caregiving literature, a list of educational programs designed for use with caregivers, and a list of self-help resources to which families can be directed.

## CHAPTER ONE

# CAREGIVING

Being confronted with the need to help an aging parent has become a common experience for adult children today. The need to provide care also confronts many older spouses, who find themselves taking care of a husband or wife in the later years. In fact, studies have shown that it is families who provide between seventy percent (70%) and eighty percent (80%) of the care older persons receive. A recent survey has shown that four out of every five older Americans who suffer from physical or mental disabilities which impair their abilities to function independently, avoid being placed in an institution because of assistance provided by family members or friends.<sup>1</sup>

### The Scope of Caregiving

The assistance provided by family members is most often related to either managing a household or providing direct personal care.<sup>2</sup> As the elderly persons' needs increase, so does the need for more intensive care. Studies done by the American Association of Retired persons (1987; 1988) give an indication of the number of families providing help with tasks of daily living. In a study of caregivers in the workplace;<sup>3</sup>

- over fifty-five percent (55%) of caregivers said that they provided help with transportation, house-hold chores, and companionship
- thirty-four percent (34%) helped the elder manage finances
- twenty-seven percent (27%) provided financial support

In a national survey of caregivers taken one year later,<sup>4</sup> it was reported that nearly all caregivers assisted with at least one "instrumental activity of daily living" (IADL). The IADLs include managing finances, grocery shopping, housework, meal preparation, transportation, or administering medications. In addition, two-thirds (2/3) of the caregivers provided help with one or more "activities of daily living" (ADLs), which include walking, dressing, toileting, bathing and feeding the older person.



1 AARP and Travelers Insurance Company, 1988

2 AARP and Travelers Insurance Company, 1988

3 Health, 1987

4 AARP and Travelers Insurance Company, 1988



Caregivers may also have to provide a certain level of medical care to the elder. This may include learning the symptoms of a condition, learning techniques such as catheter care, blood pressure and pulse monitoring, or diabetes testing and injection of insulin.

## The Need for Education

These activities represent a great deal of care being provided by caregivers, and yet, family caregivers do not have training in the skills needed to give this care, and must improvise on the job.<sup>5</sup> In fact, family caregivers have been compared to new employees<sup>6</sup> who enter an unfamiliar setting with new tasks to perform. Yet, whereas new employees receive not only job descriptions but some training in their job skills, caregivers do not have the advantage of a defined set of tasks, nor in many cases, do they have any skills training. It has been noted that "our society does little to prepare families for this nearly universal role of caregiver to older relatives. Compared to the extensive child rearing literature, guidelines on how to care for an older relative, to get support, or to cope with ambivalence about caregiving responsibilities are scarce".<sup>7</sup>

A number of people interested in studying caregiving have noted the critical need to educate caregivers.<sup>8</sup> In a review of the literature concerning educational and support programs for caregivers,<sup>9</sup> it was found that, while not all tasks seem amenable to skills

development and training, certain tasks seem to be. The authors of a study of informal home care for rural elders<sup>10</sup> felt that the care of elders may be improved with the training of caregivers. The National Council on the Aging (no date) has published a guide to assist national voluntary organizations in recognizing and addressing the needs of caregivers, and one of the suggestions given to such organizations is to develop education and training programs for caregivers.

Education can be particularly valuable to families faced with a serious dementia, such as Alzheimer's Disease. The Atlanta Chapter of the Alzheimer's Disease and Related Disorders Association has suggested that education can serve the following purposes:

- assist families in recognizing the disease in a relative
- allow families to help an older person compensate for some of the losses they are experiencing
- help families relieve guilt
- empower caregivers and give them a sense of self-confidence in making decisions
- possibly prevent abuse caused by the stresses of giving care
- inform caregivers of methods to address their own needs

5 Troll, 1986  
6 Springer and Brubaker, 1984  
7 Hooyman & Lustbader, 1986 p. 5  
8 Troll, 1986, Archibald, 1982, Hooyman & Lustbader, 1986,  
Newhouse & McAuley, 1987, Clark & Rakow, 1983  
9 Clark & Rakowski, 1983  
10 Newhouse & McAuley, 1987

As these efforts suggest, many service providers have recognized the necessity of providing training and education to family caregivers. Caregivers face varied and extensive duties in caring for a frail relative, and this affects them both emotionally and physically. The goal of education is to help alleviate some of the stress caregivers undergo and to help in providing the elder with a higher quality of in-home care.



### Educational Programs

Families can get information and skills training from a number of sources. They can get information face-to-face from a physician, hospital discharge planner, social worker or counselor. They can get information from self-help books and materials. Families can also get information by attending workshops or classes, directed by professionals, designed to educate and train caregivers.

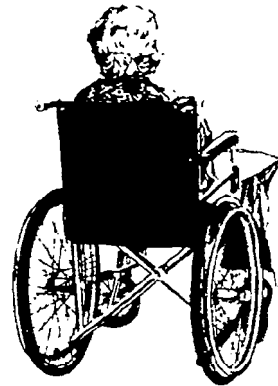
These workshops are similar to school classes or continuing education, and may meet in formats such as several hours in one day, several hours a day for a week, several weekends in a row, or once a month. The information given to caregivers in the workshops may address normal aging processes, legal and financial issues, community resources, mental disability and senile dementias, reducing stress, nursing care, managing medications, or communication skills. Examples of agencies that sponsor such programs include hospitals, social service agencies, Cooperative Extension Service offices, universities, or Alzheimer's Association chapters. The time families spend in the classes or workshop sessions may include lectures, role playing, discussion, expert speakers, or skills demonstrations.

In many cases, the professionals directing these workshops develop written materials which can help other professionals carry out the same type of workshop. (A listing of manuals which have been developed appears in Appendix B.) These written materials most often include a manual for the facilitator. This manual provides information such as how to plan the program, where to hold the workshop, and how to obtain publicity. It may also include outlines for lectures or full curriculum materials for the presentations. In some cases, a manual is

developed for participants of the workshop which includes handouts and written information they can take home as references.

As in the case of many services or interventions, professionals may encounter obstacles when trying to implement these workshops. As described in the introduction to this manual, a number of professionals interested in the needs of caregivers were surveyed; they identified some of the major obstacles that are faced in trying to deliver and implement these educational programs for family caregivers. When asked, "what are the obstacles you faced in implementing educational programs for family caregivers," issues mentioned included:

- the families' need for transportation to the workshop
- the families' belief that they should not accept help from "outsiders"
- the difficulty in reaching those families that may need the information.



However, the most frequently mentioned barrier to successfully implementing educational programs was the need by primary caregivers to have someone care for the elder family member while they attend the educational program. The caregiver is actually prevented from seeking any assistance because of the daily, and sometimes twenty-four hour per day, nature of caregiving. The same tasks which caregivers want information or training about may prohibit them from getting that training. The purpose of this manual is to identify ways that educators have sought to solve this problem.

## CHAPTER TWO

# STRATEGIES FOR PROVIDING ELDER CARE DURING EDUCATIONAL PROGRAMS

Respite has been defined as "short term in-patient or out-patient care delivered to an elderly person in lieu of his or her regular support."<sup>11</sup> Respite involves some substitute care for an elderly person in the temporary absence of a primary caregiver.<sup>12</sup> Most important in the definition of respite is the emphasis on a **temporary** time frame, though this time frame may range from a few hours to several weeks.

Formal respite care may be provided in an institution, such as a hospital or long term care facility; in the home; or in a community-based day program, such as an adult day care facility or a free-standing respite facility. However, respite is also commonly provided by informal sources, such as other family members, friends, and neighbors.<sup>13</sup> In addition, respite can be seen as service itself, provided by formally organized providers or informal helpers, or it can be seen as a byproduct of other programs and services.<sup>14</sup> Even in the cases in which respite is the byproduct of another service which the frail elder may be receiving, such as homemaker service, the primary beneficiary is the

caregiver, who is given time off or relief from the caregiving duties.

Service providers have recognized this need to offer respite in conjunction with educational workshops and have used a number of strategies to provide this relief for families. A second, follow-up survey of professionals revealed a number of these strategies. Three of the "best practices" or successful strategies are presented here. These particular models were chosen because the program's sponsors reported that caregivers who otherwise would have been unable to attend, utilized the respite in order to attend the workshops.



11 HHS Definition  
12 Gwyther and George, 1986  
13 Lidoff, 1983  
14 Lidoff, 1983

**MODEL #1.**  
**"FOR THOSE WHO CARE"**  
**LEE MEMORIAL HOSPITAL**  
**FORT MEYERS, FLORIDA**

*The first strategy is to coordinate with existing community agencies and formal respite providers to offer several respite options to participants of workshops.*

The Older Adult Services Department at Lee Memorial Hospital in Fort Meyers, Florida offers a free monthly caregiver education and support program called, "For Those Who Care." The program is designed to provide education, skill development and emotional support for families and individual caregivers to meet the responsibilities the caregiving role demands. Topics covered in the program are:

- responsibilities and role changes
- understanding aging
- chronic illness and behavior changes
- doctor-patient communication and medication management
- personal care of the older adult
- safety and emergency measures
- communication skills
- facilitating communication
- caregiver feelings
- community resources
- making decisions for the future

The educational program meets for five consecutive days, four hours per day. Graduates of the educational program can attend a monthly support groups, which continues the

relationships and support gained from the class sessions.

The format of this particular workshop necessitates that caregivers make some respite arrangements, since they will be attending for five consecutive days. The facilitators stress that one of the program's goals is to encourage caregivers to see that the time off provided by respite is important to their own physical and emotional health. The content of the workshop supports this goal by exploring some of the community resources available and by addressing the emotional and psychological issues caregivers face in leaving elders with another person. The week spent in the workshop also gives caregivers an opportunity to try respite services and experience how the care receiver relates to another caregiver or another environment.

To support these goals, the organizers of the workshop have coordinated with community agencies and programs to offer several respite options to attendees. A coordinator in the Older Adult Services Department maintains ongoing contact with families and can arrange the best respite alternatives for each family, as they make the decision to attend the workshop.

**The first option is available for workshop participants who are also clients of the Senior Friendship Center.** The Senior Friendship Center is a multi-service agency and community care state Medicaid waiver program. While the Senior Friendship Center normally provides up to four hours per week of

respite care for its clients, those clients wishing to attend Lee Memorial's educational program will receive respite services for the entire week of the program.

The second option is provided by an adult day care in the community. The adult day care has donated funds and utilizes those, in part, to offer day care services to some workshop participants.

The third option involves Lee Memorial Hospital's home health agency. The Older Adult Services Department of Lee Memorial maintains a fund so that, if the family member cannot afford to pay for the home health care, those services can be purchased with money from the fund.

The fourth option came about when the hospital became a host site for a Senior Companion Program, which will train seniors as respite workers. Senior Companions will be available to provide respite to any caregivers, particularly those who attend the educational and support program. In addition to these four options, facilitators of the program encourage caregivers to utilize informal supports, such as other family members, friends, neighbors, or church groups and church resources.

Lee Memorial's Older Adult Services Department has been successful in both highlighting the need for respite among caregivers, and in providing some options for that respite. Statistics from the Older Adult

Services Department show that approximately 50-70% of attendees utilize those respite options the whole week, and a higher percentage (about 75-80%) use those options at least one day. Although it has been much more difficult to find and recruit families willing to attend the five day, four hour per day format, evaluations have shown that participants feel that the use of respite in that format was very important.



For more detailed information about this program, contact:

Cynthia Higbea, M.A.  
Manager, Older Adult Services  
Lee Memorial Hospital  
P.O. Drawer 2218  
Fort Meyers, FL 33902

**MODEL #2.  
CAREGIVER SUPPORT UNIT  
COLMERY-O'NEIL VETERANS  
ADMINISTRATION MEDICAL  
CENTER  
TOPEKA, KANSAS**

*The second strategy is to coordinate with one specific agency to provide respite to workshop participants.*

Coordinating with other community agencies is a common theme among successful strategies. The Colmery-O'Neil Veterans Administration Medical Center represents one variation on this theme by forming a collaborative effort with one agency, the American Red Cross, to provide respite, rather than offering a list of several respite options.

For the past two years, the Caregiver Support Unit at the Medical Center has offered an annual, full-day educational workshop for caregivers. The most recent workshop was entitled, "Hands On", and provided a variety of experiences for caregivers, including dance, exercise, and massage techniques to reduce tension and stress. In addition to this educational program, the Caregiving Support Unit provides family and individual counseling, as well as support groups.

The American Red Cross has also addressed its services to the needs of caregivers by offering trained volunteers to:

- provide companionship to elderly persons who are isolated or lonely;
- to provide relief to family members by staying with elderly persons while the caregiver takes time off.

The service provided by the American Red Cross is free and is funded by mill levy funds; however, contributions are requested.

These two organizations have cooperated to provide caregivers with a more complete range of services that has allowed caregivers to get the kinds of learning experiences that will assist in their caregiving tasks. Staff in the Caregivers Support Unit have felt that the offer of respite for family members wishing to attend the educational forum was very important. Although the caregivers who used respite expressed a number of reservations, including the difficulty and concern over having a stranger in the home taking care of the elder, they could not have attended without respite.

For more detailed information about the programming, contact:

**Susan Tebb, MSW  
Veteran's Administration Medical  
Center  
2200 Gage Blvd.  
Topeka, Kansas 66622**

**MODEL #3**  
**"HOW TO COPE WITH**  
**ALZHEIMER'S DISEASE"**  
**ST. LOUIS ALZHEIMER'S**  
**ASSOCIATION**  
**ST. LOUIS, MISSOURI**

*The third strategy for providing elder care during educational programs is to offer some respite service at the site of the program, so that family members may bring the frail elder with them.*

The St. Louis Chapter of the Alzheimer's Association offers an educational program entitled, "How to Cope With Alzheimer's Disease." The program is an eight hour training course offered in four two-hour sessions and addresses issues of:

- a medical overview, myths and facts
- communication: verbal and non-verbal ways of communicating
- activities of daily living: wandering, bathing, feeding, incontinence
- legal/financial resources and ways to approach nursing home placement.

The course is designed for family caregivers as well as health care providers of Alzheimer's patients.

As a result of other programs the chapter coordinates, a list of agencies providing home health services in the St. Louis area is maintained. The facilitators of "How to Cope" chose a sitter from one of those agencies and while family members participate in

the workshop in one room, elders are provided with companionship by the sitter, in a different room. The sitter is available to visit or talk, to walk up and down the hall, or to join the elder in looking at magazines. The sitter does not provide any medical care, even though he or she may be a nursing assistant.



Facilitators stress the importance of continuing to make that elder care available. While not every session has had someone who took advantage of the respite service at the site, it has been vital in allowing some families to attend. For more detailed information about the program, contact:

Alzheimer's Association  
St. Louis Chapter  
9374 Olive Street Road  
Suite 110  
St. Louis, Missouri 63132



## CHAPTER THREE

# PRINCIPLES FOR SUCCESSFUL ELDER CARE DURING EDUCATIONAL PROGRAMS

The agencies and programs described in Chapter 2 represent three of the "best practices" in providing care to elders while family caregivers attend educational programs. Descriptions of the programs were presented briefly, with the realization that it is the reader who will take this information and apply it with their skill to their individual setting. To assist in using the model programs to generate successful programs in new areas, five general principles can be drawn from these case studies that can be helpful to anyone wishing to coordinate elder care for workshop participants. It should be noted that they do not constitute a "formula" for success, but are simply principles which can be applied to a unique setting to increase the success of providing respite to workshop participants.

**Establish and maintain ongoing, cooperative linkages with other community agencies and organizations.**

The general concept of coordinating and cooperating with other community agencies has been stressed by the developers of educational programs as

well as the developers of respite programs. Developers often recommend that a task force of community agencies be formed to assist in the implementation of the educational program. When a task force is formed, this provides an opportunity to learn of other agencies who could provide respite for the workshops.

"For Those Who Care," the program at Lee Memorial Hospital, the developers recommend that a task force of community agencies be formed. This program is described by its facilitator, Cynthia Higbea, as a community project. By networking among the agencies involved in aging in the Fort Meyers area, various options can be offered to caregivers. The agencies donate services or funds, which allowed caregivers to benefit, and the agencies benefit by the increased exposure to their services. Additionally, other community groups, such as Kiwanas or Rotary, are involved and give resources to be used for caregivers who do not have the finances to obtain respite on their own.

An additional key to this community cooperation is illustrated by the Colmery-O'Neil Medical Center. The medical center chose to cooperate with

a community agency, the American Red Cross, which is well known through its other activities and ongoing contact with the public. The families feel comfortable using the service because of the visibility and credibility of the agency within the community.

These illustrations suggest several agencies that might be possible collaborators in offering respite. The New York State Office for the Aging, which developed a course for caregivers entitled, "Practical Help",<sup>15</sup> suggests cooperating with other groups such as the Junior League, the League of Women Voters, church leaders and high school principals and guidance personnel, all of which may have some volunteer respite provision program. Other community agencies that may be available include in-home service providers (e.g., visiting nurses & homemakers), family service agencies, hospital social service departments, community mental health centers, other mental health service providers, protective services and crisis intervention service providers, case management agencies, volunteer service organizations, area agencies on aging, adult day care programs, senior centers, churches and synagogues, and the Cooperative Extension Service.<sup>16</sup>

**Develop ongoing contact with the caregivers to overcome some of their resistance to services such as respite.**

In the Colmery-O'Neil Medical Center, staff of the Caregiver Support Unit have ongoing contact with families and

can encourage the use of education as well as respite. This is also the case at Lee Memorial Hospital. Staff at the medical center have learned that the key to getting families to accept the use of respite is to have continued contact with those caregivers. The staff of the Lee Memorial's Older Adult Services Department gets referrals from the medical unit of the hospital which allow them to develop a relationship with the caregivers by checking with them periodically, telling the families about new resources, or being available to counsel with families. These relationships can overcome barriers and promote the use of education and various support services by the families.

**Educate caregivers on the value of respite, as well as other formal services and education.**

The educational and support program, "For Those Who Care", addresses the need for and use of respite during the educational workshop. In the text of the leader's manual common excuses by the caregiver for not using respite are listed. In response to the excuse, "I don't have time" the suggestions include, "Make time. Time for yourself is just as important as medication for a loved one's illness. You don't have time to become ill - emotionally or physically. Time for yourself is your prescription." Many other educational programs include a workshop or class on finding and utilizing community resources. Some programs may invite a guest speaker from the community to present some of

<sup>15</sup> NY State Office on Aging, no date  
<sup>16</sup> Lad-ff, 1985

the specific services available in that area to the caregivers.

**Design the format of the workshop so that it encourages and facilitates the use of respite.**

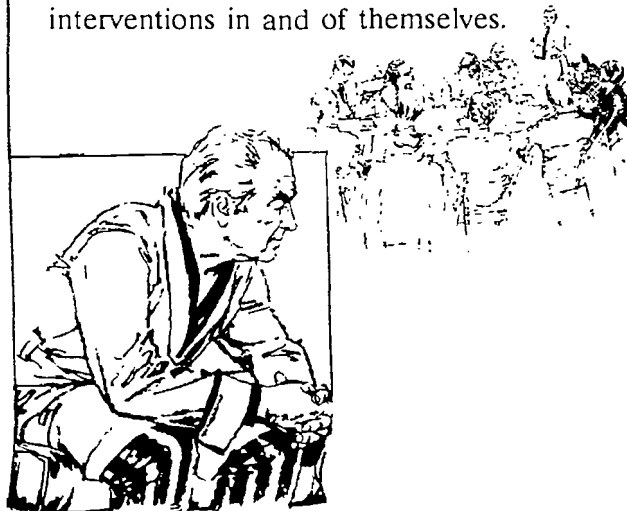
Caregivers may be more likely to use respite services if the educational workshop, or support group, requires a regular and long-term commitment. If the respite is needed only for a couple of hours one day, it may be more difficult for caregivers to find a respite provider, to qualify for assistance if that is necessary, and to feel comfortable with a "stranger" in the house. In those cases, caregivers may rely more heavily on informal supports, such as another family member or a neighbor. "For Those Who Care", at Lee Memorial, is an example of a program which necessitates the use of respite by a time-intensive format of four hours per day for five consecutive days.

**Make respite services as convenient and easy to obtain as possible.**

The complications and "red tape" that can exist in any social service delivery system are unfamiliar to many family caregivers, who may never have sought assistance of that kind. Programs such as the St. Louis Alzheimer's Association relieve families from having to negotiate that delivery system by providing the respite assistance on-site during the educational program. In both the case of Lee Memorial and

Colmery-O'Neil, family members had the option of in-home respite. Some families may prefer this type of arrangement, since it frees them from having to get the elder ready to go somewhere and relieves the transportation problem of getting the care receiver to a community facility or program.

As another example, many providers holding support groups, such as the Good Samaritan Hospital and Medical Center of Portland, Oregon, have learned the value of dual support groups for caregivers and the elders. The dual support groups allow the care for the elder to be convenient and easy to obtain. Good Samaritan noticed that some caregivers brought the care receivers to the support group meetings, which lessened the caregiver's ability to focus and forced families to talk about problems or feelings in the presence of the care receiver, possibly creating conflict. In the case of Good Samaritan, facilitators lead both support groups. Many providers also feel that dual support groups are viable interventions in and of themselves.



## CHAPTER FOUR

# SUGGESTIONS FOR RURAL PRACTITIONERS

The primary message of each of these successful models has been the need to cooperate and collaborate with other agencies who provide formal respite services, when offering respite to families who wish to attend educational programs. While the needs of elders and their families in rural areas may be quite similar to those in urban areas, research has shown that rural areas often lack the resources and personnel to provide many of the formal services available in urban areas. Because of the mission of the Center on Rural Elderly to address the concerns of practitioners in rural areas, four additional case studies have been included.

Four persons, recognized nationally as experienced in respite options for rural areas, were invited to write case studies for inclusion in this manual. Each author was asked first, to describe the rural area in which the program was operating and second, to give an overview of other formal respite resources available in their rural area. The authors also offer some comments on how educational programs and respite alternatives have operated in their rural communities.

These chapters are not designed to be additional case studies of model

programs of respite connected with educational training in family caregiving. Rather they are intended to help the reader think through the difficulties and options of providing respite for caregivers in rural areas who may want to attend educational workshops. No prescriptions are offered, no formulas for success are put forth. These four case studies should empower the reader with additional information about the subject of respite being offered with educational programs. Each of the studies reflects a different geographic area of the U.S., type of rural setting, mix of population, history, and cultural lifestyles.



CASE STUDY 1  
LEXINGTON/BUEGRASS ALZHEIMER'S ASSOCIATION  
LEXINGTON, KENTUCKY

Written By: Virginia Beil, M.S.W.,  
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A significant proportion of Kentucky's elderly population resides in rural areas. Compared to the national average of 25.5% rural elderly, Kentucky has 46.5% or 190,538 elderly persons living in rural areas.<sup>17</sup> Many rural elderly in Kentucky, particularly in the 49 counties making up the Appalachian region, are subject to deprivations that research has suggested are characteristic of the rural elderly including low incomes, sub-standard housing and limited access to social programs. In addition, 13.3% of all elderly in this region have households without a telephone. On the other hand, the elderly in rural Kentucky enjoy some advantages including being known in the community, having community-based social support available, and having a lower crime rate.<sup>18</sup>

Respite is not a household word in general in Kentucky and certainly not in rural areas. Traditionally, families have taken care of their own at any cost - physically, emotionally and financially. Child day care is becoming accepted more in rural areas but adult day care is basically a new concept and there are few models for the rural elderly to view.

Respite services are very limited in Kentucky, especially those convenient

for the rural elderly. This is complicated by the fact that Kentuckians are dedicated and loyal to their county, which is a hub for shopping, trade and entertainment and many rural elderly refuse to go beyond their county for services, posing a challenge to providing respite services. Of the nineteen licensed day health care programs in Kentucky all but two are in the largest cities and none are located in communities of less than 2,500. Other respite programs based on a social model have received funding from the Commonwealth of Kentucky to serve persons with dementia and their caregivers, but these are spread out too far to serve more than just a few rural communities. Adult day care centers of all types serve only a small percent of families who could benefit from this type of respite.

The Lexington/Bluegrass Alzheimer's Association, a non-profit group founded in 1981, provides patient and family services, offers information and referral, sponsors educational programs, and raises money for research. It is an affiliate of the national Alzheimer's Disease and Related Disorders Association, and is closely related to the Alzheimer's Disease Research Center (ADRC) at the University of Kentucky, one of twelve such centers funded by

<sup>17</sup> U.S. Bureau of Census, 1980

<sup>18</sup> Lee and Lassey, 1980; Rowles, 1984

the National Institute on Aging.

The ADRC and the Alzheimer's Association worked closely in the early 1980s to develop badly needed respite services for caregivers of persons with Alzheimer's Disease. This effort resulted in the Helping Hand respite program, founded in March, 1984, and today operated by the Lexington/Bluegrass Alzheimer's Association. The program has both in-home and day care components and provides respite from the often 24-hour day of caregiving facing families. In addition, the Helping Hand has won wide acclaim for its innovative use of volunteers, who work one-to-one with persons with dementia to build self-esteem through creative activities. Currently, the Helping Hand is one of nineteen programs to receive a major grant from the Robert Wood Johnson Foundation to be part of a four-year study of dementia-specific respite care. While the Alzheimer's Association only offers respite care in the Lexington area, the Association's service area also includes all of the Appalachian Kentucky. Thus, the Association has actively worked with respite care programs and support groups in a number of rural settings.

Homecare through the Kentucky Division of Aging Services also gives respite on a limited basis for families who qualify. This agency serves two and one-half times more rural than urban elderly. Yet, there is often an extensive waiting list for services under this program and the requirements for an initial assessment before services

are rendered make Homecare an impractical solution for occasional respite services.

In general, Kentucky, has made great strides in offering respite care services. Yet, these services tend to be concentrated in more urban areas. Clearly, there are not adequate formal respite services available in our regional to care for an older family member, particularly services which would offer respite while the caregiver attends and educational seminar.

However, there are several principles which do characterize the successful respite programs in rural settings. First, transportation is a critical need. Without transportation, many elderly cannot get their loved ones to a respite program. One respite program in Somerset, Kentucky found that their census increased significantly when a van was donated to pick up clients. Second, programs need to recognize that families are often very protective of their loved ones and do not necessarily rush to utilize services. Programs must work to educate the families about their services and lay a firm foundation by working with local support groups, churches, and the medical community. Third, programs must strive to protect confidentiality; in a small community, if a client's behavior in a respite program is discussed by staff or volunteers, the effects can be devastating. Finally, programs should market the respite services as being good for the client, not just the family. By showing the families that social stimulation and creative activities can enrich the client's life,

families can overcome guilt or hesitation which can be associated with placing their loved one in a respite program.

The challenges to offering respite care in a rural setting to families attending an educational workshop can be enormous. As previously discussed, few formal respite programs currently serve most rural settings. Agencies which do offer respite for the rural areas may have intake and assessment requirements that make "one-shot" respite difficult to justify.

Second, it is critically important for program planners to recognize that caregivers are often under great strain and stress. They may say "I cannot come to an education program because no one can look after my husband," when in fact there are many friends or family members who could help. In this case, because of guilt, embarrassment or denial the caregiver may not be ready to seek help. The rural practitioner must recognize that a foundation must be laid even before an educational program can be offered. By working with the family one-on-one, encouraging them to attend a support group, and by educating the caregiver to understand that respite can enrich their loved one's life, resistance to seek help can be overcome.

With this caution, there are strategies for offering respite during educational programs which a program planner can employ. **First**, if there are agencies providing respite services, they could

be invited to co-sponsor the educational program. As a co-sponsor, the agency might be willing to bend their usual intake procedures and perhaps ask staff to volunteer a few hours to provide respite for the special event.

**Second**, program planners should take advantage of one of the greatest strengths of a rural setting, the often **strong social network of friends, church, county extension agents, services clubs, and other groups** who can be asked for help. These volunteers could go into the home to provide care, or staff a day program. With this strong community network, a program planner may find that it can actually be easier to organize respite care for a one-time program in a rural community, than in an urban setting.



Notes

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CASE STUDY 2  
ALZHEIMER'S ASSOCIATION OF WESTERN NORTH CAROLINA  
ASHEVILLE, NORTH CAROLINA

Written By: Vera Holland Guise  
Founder and Executive Director

Alzheimer's Association of Western North Carolina, Inc.

The Alzheimer's Association of Western North Carolina has had a continued commitment to provide services which address the needs of Alzheimer's victims, ease the burden of caregivers, and provide models which can be replicated in other communities. The services provided by the Association, which are discussed in this manuscript, have been developed in the western part of North Carolina, an area comprised of some 25 counties or one-fourth of the state, with a mixed topography of the Piedmont flat lands to the peaks of the Appalachians and Blue Ridge mountain range.

The Alzheimer's Association of Western North Carolina has been involved in respite care since 1984. No conscious decision was made to become a respite care provider; rather caregivers who attended the Association's Support Groups began to proclaim, "If I had a sitter the Chapter had trained that I could depend on, I'd gladly leave my husband to play golf each week", or "The sitters the home health agency sent did not know the first thing about Alzheimer's and it was impossible for me to train them since they send a different one each time. I'd rather not be bothered with it since I'm too afraid to leave my wife with a stranger." As well, private duty sitters

began to come into the office asking for names and telephone numbers of caregivers, which we were unwilling to provide due the risks involved. We did not have sufficient staff to check references on sitters, and we wanted to guard against the impression of endorsement. Thus, the Rx for Respite Program was born.

Rx for Respite was formally established in January, 1986 on a private foundation grant of \$70,500 and \$10,000 in United Way grants. The program has three basic components:

- In-Home Respite Care for patients needing non-medical supervision and assistance with daily living tasks, e.g. dressing, eating, toileting, etc.
- Senior Companion Service provided through a cooperative agreement with ACTION and the Area Agency on Aging. Senior Companions are economically disadvantaged persons 60 years of age or over who provide trained companion services 20 hours per week for a nominal stipend.
- Contract Respite services requiring nursing skills or temporary nursing home or hospital placement. The Association holds contracts with a variety of home health agencies,

hospitals and nursing homes to which admissions can be made on a space available basis.

"Rx for Respite" has provided in excess of 80,000 hours of respite care to some 150 unduplicated families in 11 counties since its inception. Contrary to early research findings in other areas of the country that caregivers of dementia patients are reluctant to seek of accept help, we have experienced no problem with utilization of the service. One important discovery is that caregivers who attend support groups are more likely to ask for and use respite services of all kinds. Our conclusion is that caregivers reaffirm the right to have "time off" in the support group context, and they learn to trust services when they are told of them by others who share a common experience.

Mountain Geri-Care Adult Day Health Center, another source of respite and care, was established in July, 1986 in cooperation with Memorial Mission Medical Center, the major acute care hospital in the area. Funding came from a private foundation, United Way and from the hospital's foundation. Mountain Geri-Care has a full time staff of four (including a registered nurse), and a number of part time support staff and volunteers. While the Center is not a dementia-specific center, about 90% of its clientele do suffer from some memory impairment from mild to fairly advanced stages. The Center offers a unique program of therapeutic activities to meet the clients' needs and abilities. These

include music and art therapy, drama, travelogue series, gardening and adapted recreational activities. Medical monitoring, nutrition counseling, personal care (bathing, shampooing), are also provided. Dental hygiene is provided in cooperation with the local community college. Even the most confused clients are taken on field trips to the Farmer's Market, to ethnic restaurants during travelogue week, and to have sing-alongs with local nursing homes and pre-schools. Their crowning achievement has been a musical revue "History in Harmony" produced and directed by the Center and performed live in concert.

A second component planned for Mountain Geri-Care Center, is ElderPlace. It will be developed as a program component for the mildly impaired, providing for the separation of clientele by function as opposed to diagnosis. Again, the Association has drawn on other resources to make innovation possible. The Junior League has committed funds and volunteers to this effect.

Cross Anchor Respite Inn grew out of the "Rx for Respite" Program and "Mountain Geri-Care Center". When families have regularly scheduled quality respite care, their next request is commonly for an extended break, e.g. a week for vacation, two weeks to go visit the daughter on the east coast, or 6 weeks for surgery and recuperation. More than 700 days of temporary institutional care were underwritten by the Association in a single year, thus the concept of Cross Anchor Respite Inn

evolved. Cross Anchor Inn is a guest house for temporary 24-hour respite care to families with patients in early to middle stages of dementia. Start-up funds came from a private foundation, United Way and the Community Foundation. Technical assistance and additional financial support has come from the Asheville Kiwanis Club.

Cross Anchor Inn admitted its first guest on February 20, 1989. Guests are admitted for a minimum of three days and a maximum of thirty day stays. It appears, at least on the basis of this early experience, that serial visits provide the best continuity and adjustment for the guest, as well as the opportunity for planned quality respite for the caregiver. The reasons for admission have been

- Caregiver vacation
- Out-of-town business
- Out-of-town medical appointments of caregivers
- Family death/illness
- To attend out of town functions
- To enjoy being alone at home and off duty.

The Alzheimer's Association provides administrative and nursing supervision of the Inn. A supervisor-in-charge lives at the home and provides the first line of supervision. Additional staff and volunteers are scheduled as needed. It has been our experience thus far that an additional person is needed during the day time hours at least twice per week when more than three guests are present. When a guest is particularly agitated, an even

higher staff/patient ratio is required. The best adjustments to Cross Anchor Inn have been made by guests who had been involved in adult day health care or were accustomed to being cared for periodically by someone other than the caregiver. This finding underscores our hypothesis that regularly scheduled respite of all types provide maximum therapeutic value to the patient as well as the caregiver.

Cross Anchor Inn rates are \$35 per day for a private room and \$25 per day for a semi-private room. Although some state respite grant funds have been available to subsidize care, all families have indicated an ability and willingness to pay the full nominal costs of care. This finding indicates a real possibility of long range financial solvency. The most difficult problems have been:

- recruiting and holding live-in staff at a time when unemployment is at an all time low
- the constant problem of adjustment to a new and strange environment by an already confused person
- some reluctance of caregivers to schedule 3 day visits on a regular basis even when they do not have travel plans which mandate the respite
- the distance of the current facility from other Chapter operations.

Providing respite care services of any type is no easy task. It is fraught with problems, both administratively and

philosophically. Most families are reluctant to seek and use respite services if left to their own devices. Locally sponsored support groups; physician, nurse and social work education; feature stories about local caregivers in newspapers and call-in radio talk shows; and a speaker's bureau comprised of a mix of providers and caregivers have been found to be important tools in facilitating utilization.

Structured education for caregivers has not been successful in Western North Carolina and we have not determined why. A series of "Dementia Classes for New Caregivers" was held with very poor attendance. It has been our experience that caregivers must be touched in two basic ways if they are to become acclimated to a mutual caregivers association and to accept and use services:

- (1) Caregivers must leave the agency after the initial contact with a strong sense that the agency has sound knowledge and expertise about their problem
- (2) Caregivers must have their pain reaffirmed through identification with others who share a common experience.

Education or mutual sharing alone do not seem to provide incentive for a family to be able to establish rapport with an agency sufficient to support the respite relationship. It is the combination of education/information and emotional identification that makes

the difference. One of the enormous obstacles faced by agencies to develop services on a "mere shoestring". This places an enormous burden on staff and directing bodies for a continuous search for funds. Granting foundations traditionally give funds to start new programs, not to sustain them, thus the burden of increased funding must be taken seriously.

For Western North Carolina, one of the central issues is that we are one of the five leading retirement meccas in the country and face the task of demonstrating what services are needed and finding methods of delivery that work, despite limitations in funding, transportation, and personnel. We have learned that caregivers in Western North Carolina want and use a wide variety of services, since no one service meets everyone's needs all the time. Many service providers exist; however, they may limit their service to one town or county and programs or information and referral are rarely coordinated in any real way. Thus, families who do not know their way through the system often give up and fall through the cracks only to resurface with more urgent needs later on. Agencies must be sensitive to the economic and business environment and coordinate efforts with other providers. However, as long as solid sources of funds are not available to support services it is recognized that agencies, public or private, will have to be courageous enough to "take the mountains to Mohammed".

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CASE STUDY 3  
FRANKLIN COUNTY HOME CARE CORPORATION  
TURNER FALLS, MASSACHUSETTS

Written By: Phyllis O'Hara-McGuane, R.N.

Alzheimer Clinician

Franklin County Home Care Corporation

Turners Falls, MA

Franklin County Home Care Corporation is a local non-profit community agency providing a number of services for elderly citizens. Its catchment area includes the geographic area of Franklin County (approximately 750 square miles) plus four towns in western Worcester County. Included in the western part of Franklin County are several town where the ratio is one person per square mile. The over 60 population ranges from 9% in the towns which abut the five college area to 24% in several of the hill towns to the west and one in the Worcester County area. The state average for over 60 population is approximately 12.5% to 13%. It is an area where Italian immigrants settled having come here to build the Hoosac railroad tunnel, where the southern towns of the region carry the Polish and Lithuanian family names of the early farmers and where a number of towns were incorporated in the 1600s and early 1700s.

The Home Care Unit provides many services, including:

- needs assessment and case management
- home health aides, homemakers, personal care and chore services

- a loan closet which provides medical equipment on a loan basis
- transportation
- a nutrition unit which provides congregate and home-delivered meals
- the employment services, including a Senior Aide Program
- a housing relocation program, which provides assistance in locating clean and affordable housing
- the elder abuse unit
- the community services program, including the Good Life, a monthly 12-page newspaper
- the Adult Family Care Program, which provides community host families for elders who are frail and occasionally confused and who can no longer live independently in the community.

Respite services are provided to families of elderly individuals unable to care for themselves due to severe impairments. Respite care can be provided in-home by homemakers, home health aides, or companions, or out-of-home care arranged through the Elder Day Center or the Adult Family Care Program. The Elder Day Center is a health management program of the Franklin Medical Center, Greenfield (county seat of Franklin County). Respite monies available are allocated through the

Executive Office of Elder Affairs (a state agency) in Boston. One particular respite option, funded by the Alzheimer's Disease and Related Disorders Association (ADRDA) of Eastern Massachusetts, will be highlighted. The ADRDA formed the Partnership Project, designed to encourage professionals and family members to work together in identifying community needs and resources and to plan and coordinate services for Alzheimer patients. The Partnership project awarded a number of small grants to fund projects which would test innovative approaches to meet the need of Alzheimer patients and families in local communities and to serve as models for communities across the United States.

The Franklin County Home Care Corporation, in collaboration with the Franklin County Mental Health Association and the Athol Memorial Hospital, initiated an innovative volunteer-based, in-home respite program for Alzheimer patients and families called ADMIRE (Alzheimer's Disease, Memory Impaired, Resources and Education). The ADMIRE Program grew out of a study conducted by the Greater Franklin County Partnership which assessed the needs of Alzheimer patients. The study found that low-cost home-based respite care was a major need for families experiencing the stress and strain of daily care for dementia patients. The ADMIRE Program recruited and trained volunteers to provide free in-home respite care and conducted a public information

campaign to recruit and educate families coping with this disease. Three free public seminars on Alzheimer's disease, designed for families caring for a demented person, were conducted in three separate geographic towns of the FCHCC area.

By recruiting volunteers for a specific geographic area, it was possible to more readily obtain services in that area. Training included information on the disease process, common behaviors that accompany dementia, behavior modification techniques to help manage Alzheimer patients, and ways to provide emotional support to families and help them cope with the disease.

An unexpected but necessary first step in recruiting the families for the respite program was that of overcoming the families reluctance to accept public services. Many elderly residents of this largely rural region felt that accepting respite and other services was like taking "welfare". Many of those long time residents still remember the "Poor Farms" of the '20's and '30's. The proud "we can take care of our own" attitude is healthy in many circumstances, but can prevent people from receiving essential services and emotional support. Of vital importance in addressing this resistance was the fact that the director of ADMIRE has resided in the area for sixty years. Since many of the towns in the area were settled in the 1600's, she is considered "almost native", although it takes more years than that to be considered a "true native" in some rural hill towns. She has been able to visit in

homes and reminisce with the elderly about old families, old industries, old schools, and in doing so, make families more accepting of respite services and other support services available.

During the two years of the grant, ten families received respite services by volunteers in home; over fifty families received more specialized service, such as short-term counseling, legal referrals regarding conservatorship and guardian-ship, as well as assistance in obtaining medical evaluations. The average age of the patients served was 77.

In addition to ADMIRE, the existence of Councils on Aging have had a significant impact on the issue of addressing the needs of the elderly and their caregivers. Councils on Aging are departments of town government representing elders in the towns and interacting with other state and local groups on their behalf. Councils are responsible for assessing needs, and either providing programs and services to meet these needs or working with other agencies such as FCHCC to develop needed services. Some of these services include transportation, friendly visitors, preventive health screening and information and referral.

In our area, 26 towns have Councils on Aging. Councils on Aging have been described as "the community switchboard where elders can plug into direct services, information and related programs." Councils on Aging with Senior Centers become the "visible focal point for elders in the community."

The Greenfield Council on Aging and the Greenfield Senior Center worked with ADMIRE' to offer "Admiration Night"...a two hour period from four to six p.m. at the Center where families could leave their loved one, confident that there were trained personnel there who would participate in planned activities, music, and meal preparation as well as a period of reminiscing.

The Greenfield Senior Center is located on the ground floor of a reconverted hotel known as The Weldon, which now has elderly and handicapped housing in fully equipped apartments. Many of the residents of Weldon House were eager to be trained in an overview of Alzheimer's and to work with the persons who would take advantage of Admiration Night. Eight women were trained as caregivers but only two families made use of the program. Once again, the answers received from families were, "I don't want to put anyone out...no one really knows how to take care of John...Mary doesn't know there is anything wrong with her..." and so forth.

We are fortunate to have an Adult Day Health Program in a self-contained free standing building. Initially sponsored by the Franklin County Mental Health Association, a community mental health resource, the Elder Day Center is now under the auspices of the Franklin Medical Center which is itself a part of the Baystate Medical Systems of Springfield, MA. Because of the availability of subsidized transportation in privately owned wheelchair accessible minivans, many clients are picked up in



their homes and returned at days end. The EDC also has the capability of doing personal care, showers, and other activities of daily living. The EDC operates from 9:00 a.m. to 3:00 p.m. five days a week.

Alzheimer Support Groups have been in existence in this area for up to ten years. The group in the eastern part of the FCHCC area meets monthly at the Athol Memorial Hospital. The Greenfield area group meets bi-monthly at the Elder Day Center. This group hopes to have "sitters" available on site to allow families to come to group bringing their family member to be watched during meetings.

In addition, the Franklin County Mental Health Association just celebrated five years of service with their Peer Counselling Program. These volunteers are for the most part retired persons, or near retirement age, who have been trained in listening skills as well as problem solving. They work one on one with elders who are their peer age group to offer support, guidance, and sometimes referral to the more extensive psychotherapy offered through psychiatrists, psychologists and social workers at the Mental Health Center. These individuals have received specialized training of about ten hours in dementia and related disorders. Many of those already involved in the program have expressed an interest in working with family caregivers as well as early stage dementia clients.

Although designated as a "rural area",

I find that many of our programs in place and services available far surpass those still in embryonic stage in other metropolitan areas. Perhaps having communities celebrating their Tricentennial has given us a head start!

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**CASE STUDY 4**  
**CEDAR ACRES ADULT DAY CARE**  
**JANESVILLE, WISCONSIN**

Written By: Lois Oliver, R.N., B.S.N.  
Director, Cedar Acres Adult Day Center

Located about 15 miles north of the Wisconsin-Illinois border, in the central part of the state, Janesville, Wisconsin finds itself bordered by the rolling hills and rich corn fields of America's dairy land. Janesville is a rural community of 51,000 people and is the largest city in Rock County which has a population of about 139,400. Rock County is primarily a farming county and covers approximately 650 square miles. In Janesville the economic base is supported by a General Motors plant and several other smaller manufacturing companies. Beloit, Wisconsin, the second largest city in Rock County has a population of 35,000 and is located just north of the state line and south of Janesville.

Recent estimates on the number of adults 65 years or older living in Rock County indicate that 18,002 people fall into that category. It is further estimated that of this population about 2,700 persons are diagnosed with some form of dementia. Because of the high level of dementia victims, Cedar Crest, Inc. developed its community outreach program, Cedar Acres Adult Day Center.

Cedar Crest, Inc., a non-profit retirement community, now in its 27th year of service to Janesville and the surrounding areas, has in its mission

statement the goal "to provide elderly persons with housing facilities and services especially designed to meet their physical, social and psychological needs, and to contribute to their health, security, happiness and usefulness in longer life." To meet that goal the Retirement Home was completed in 1963 with additions in 1977 and 1986; the 95-bed health center, in 1970; the Chapel and activity area, in 1975; and Cedar Acres Adult Day Center, in 1987.

Cedar Acres opened January 6, 1987 offering adult daycare services primarily to older adults and their families/ caregivers who are victims of Alzheimer's Disease and related disorders. Housed in a lovely farm home situated on three acres of park-like property, Cedar Acres' mission is to provide a program which will strengthen and/or maintain a member's ability to continue living in the community in his or her home setting. Offered is a protective, home-like environment, the members can enjoy a variety of life-enriching activities. Upon entering the house, the aromas of a home-cooked noon meal fill the senses. Other services offered include social work case management and counseling, nursing services and health care management/ education, assistance with activities of daily living, structured recreational activities, family support groups and

educational sessions. Inherent in the program is the respite offered to caregivers while their loved ones attend Cedar Acres. Hours of operation are Monday through Friday, 7:30 a.m. to 5:30 p.m.; Saturday, 9:00 a.m. to 4:00 p.m.; Tuesday and Friday evenings, 5:30 p.m. to 9:00 p.m.

Rock County has, on the whole, a comprehensive social services system, both public and private. Though the respite and support services are available for families who may need these services, in my experience, I see families reluctant to use the services. In some cases the issue of non-use involves lack of financial means to pay for the services, though in most cases, non-use results from caregiver guilt or denial that a need exists. It seems to be very difficult for persons to reach out for help.

The agencies in Rock County which are most involved in offering respite services include the following:

- home nursing services
- Senior Services of Rock County
- adult daycare
- hospices
- nursing homes offering daytime care
- Rock County Department of Social Services.

Rock County offers an excellent array of respite services programs. It seems to be unique in that most of the service providers have formed a network of cooperation. Agencies refer families readily to one another so that the families' needs can be best

met. This inter-agency communication enhances the quality of services offered and, in my opinion, is essential for successful respite programs in rural areas. It is also interesting to note that neighboring counties refer families for services in Rock County. Cedar Acres currently is offering daycare services to three families from Walworth County.

Other general principles which govern the successfulness of respite programs include the availability of well-trained respite workers, the consistency with which workers are assigned to the same family, and the cost of the service. In the case of adult daycare services in rural areas, the single most important factor leading toward success is the availability of transportation. Cedar Acres owns and operates two vehicles to provide transportation for the members traveling about 250 miles per day.

Since Cedar Acres began, offering support groups and educational sessions for families in the community has been paramount. Two family support groups are provided each month, one for families using Cedar Acres, and one for those caregivers not using daycare. Educational series on Alzheimer's disease and other dementias, behavior management, legal/financial issues, and community resources are offered at least three times per year. Each series is four weeks in length with the meeting times in the evening. Cedar Acres offers respite care during these sessions as well as during the support groups. In-home respite workers are utilized by families attending these meetings, also. If formal respite services are not utilized

for the educational series, usually the primary caregiver relies on other family members to provide care. Cedar Acres will be offering daytime educational series in the future. The availability of respite services via the daycare program may enhance the attendance at the series.

Families requiring overnight respite for weekends or vacations can use group homes (in Wisconsin called community based residential facilities, CBRF) or nursing homes. Cedar Acres formed a "vacation package" with a local CBRF which combined daycare with overnight care while the families were away. Unfortunately, when the families needed the service, the CBRF had no beds available, so the feasibility of this program has not been tested. Nursing homes offer limited respite services, though a two-week minimum stay is usually required.

In summary, the respite services available in Rock County are plentiful. It is the concern of many providers that the services are under utilized, however. It appears that one of the most common reasons for non-use is caregiver denial and guilt. Rural practitioners will not only have to overcome those issues, but will also have to address transportation issues and marketing issues. Creating a strong network among providers seems to lead to a successful system. Cooperation and referrals between agencies result in a quality system.

To contact the author:

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Director  
Cedar Acres Adult Day Center  
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Janesville, Wisconsin 53546-9983  
(608) 756-8144



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## CAREGIVER TRAINING PROGRAMS AND SETTING UP RESPITE PROGRAMS

The programs listed in this section are of two types: 1) those designed to assist practitioners in setting up and carrying out training sessions for family caregivers; and 2) those designed to assist practitioners in setting up respite programs for family members who are providing regular caregiving for a homebound person. The programs are listed by title and author, and addresses and phone numbers in the event more information is wanted about each program. In so far as possible, the Center on Rural Elderly has assembled information on nearly all programs nationwide that are currently available. In an effort to assist practitioners in deciding whether a program is appropriate to their setting, the Center has developed a publication, *DIRECTORY OF CAREGIVER EDUCATIONAL PROGRAMS*. Information about this publication can be obtained by phoning the Center, 816-235-2180.

### IN SUPPORT OF CAREGIVERS

Carole Stuckey  
Publications Unit  
The Vocational Studies Center  
University of Wisconsin-Madison  
964 Educational Sciences Building  
1025 W. Johnson St.  
Madison, WI 53706  
(608) 263-3696

### HELPING FAMILIES HELP

Rhonda J.V. Montgomery, Ph.D.  
Wayne State University  
Institute of Gerontology  
71-C East Ferry Knapp Bldg.  
Detroit, MI 48202

### HAND IN HAND: LEARNING FROM AND CARING FOR OLDER ADULTS

Dawn S. Bressler, M.G.S.  
Program Specialist  
AARP Program Department  
1909 K Street, N.W.  
Washington, DC 20049

### AS FAMILIES GROW OLDER

Dolores M. Halls  
Acting Director  
TIGRE  
Inst. for Gerontological Res. & Ed.  
3000/Dept. 3TG  
Las Cruces, NM 88003-0001  
(505) 646-3426

### CARING FOR OLDER FAMILY MEMBERS

Ann M. Rhinesmith  
Extension Home Economist  
Wayne Bucmont Jr. Admin. Building  
Route 51  
Belvidere, NJ 07823  
(201) 475-5361

### HELP FOR FAMILIES OF THE AGING

Jane Dewey Heald, M.S.  
President  
Support Source  
420 Rutgers Ave., Ste. #2  
Swarthmore, PA 19801  
(215) 544-3605

GROWING OLDER: SENSORY CHANGES

Vicki L. Schmall  
Extension Gerontology Specialist  
Oregon State University  
161 Milan Hall  
Corvallis, OR 97331  
(503) 754-3211

FAMILY CAREGIVER PROGRAM

Judith L. Warren  
Family Life Ed. Aging Specialist  
Texas Agricultural Extension Service  
Texas A&M University  
College Station, TX 77843-2251  
(409) 845-1146

WHEN DEPENDENCY INCREASES: "BEST WISHES EDITH AND HENRY"

Vicki Schmall  
Extension Gerontology Specialist  
Oregon State University  
161 Milan Hall  
Corvallis, OR 97331  
(503) 754-3211

HELPING YOU CARE: SKILLS BUILDING FOR CARE OF THE CHRONICALLY ILL OR FRAIL ADULT

Marilyn Cleland  
Caregiver Education Coordinator  
Good Samaritan Hospital & Med. Center  
1015 N.W. 22nd  
Portland, OR 97210  
(503) 229-7348

MANAGEMENT OF AGGRESSIVE BEHAVIOR IN THE ELDERLY

Marilyn Cleland  
Caregiver Education Coordinator  
Good Samaritan Hospital & Med. Center  
1015 N.W. 22nd  
Portland, OR 97210  
(503) 229-7348

HOME IS WHERE THE CARE IS

Angela Heath  
Women's Initiative  
AARP  
1909 K Street, N.W.  
Washington, DC 20049

CAREGIVER EDUCATION AND TRAINING PROJECT

Nancy Bryant, Dr. P.H.  
Manager, Senior Programs  
Grossmont District Hospital  
P.O. Box 158  
La Mesa, CA 92041  
(619) 465-0711

WELLSPRINGS: A TRAINING PROGRAM FOR FAMILY CAREGIVERS

Amanda S. Barusch, D.S.W.  
Principal Investigator  
Univ. of Utah Social Research Inst.  
Graduate School of Social Work  
Salt Lake City, UT 84112  
(801) 581-4857

FAMILY EDUCATION SERIES ALZHEIMER'S DISEASE TRAINING MANUAL

Kathleen A. Kelley  
Training Specialist  
Family Survival Project  
425 Bush St., Suite 500  
San Francisco, CA 94108  
(415) 434-3388

CAREGIVER INFORMATION PROJECT - AGING AND OUR FAMILIES

Louis Goldblatt  
Connecticut Department on Aging  
175 Main St.  
Hartford, CT 06106

VOLUNTEER INFORMATION PROVIDER PROGRAM

Burton Halpert  
Center on Aging Studies  
5245 Rockhill Road  
Kansas City, MO 64110  
(816) 276-1740

PRACTICAL HELP FOR THOSE CARING FOR AN ELDERLY PERSON IN THE COMMUNITY

Wendy R. Wilson  
Director of Development  
Suffolk Co. Dept. of Health Services  
225 Rabro Rd.  
Mauppage, NY 11788  
(516) 348-2917

FAMILIES CARING FOR ELDERS

Sara Burczy  
Cooperative Extension Service  
University of Vermont  
Burlington, VT 05405

A SERIES OF TRAINING MODULES FOR INFORMAL CAREGIVERS

Kristine Bursac  
Arizona Long-Term Care Ger. Center  
1807 East Elm  
Tucson, AZ 85719

A TIME OF NURTURING

Theodore H. Koff, Ed.D.  
Principal Investigator  
Arizona Long-Term Care Ger. Center  
1807 E. Elm  
Tucson, AZ 85719  
(602) 626-4854

INSTRUCTIONAL MANUAL FOR PARENT CARING

Sheila Vedder  
Arrowhead Regional Coordinator  
College of St. Scholastica  
1200 Kenwood Ave.  
Duluth, MN 55811  
(218) 723-6000

INTERFAITH CAREGIVERS "TRAIN-THE-TRAINERS" PROJECT

Francine M. Flood  
Program Development Coordinator  
College of Education and Human Ecology  
University of the District of Columbia  
1100 Harvard Street, N.W. - Room 114  
Washington, DC 20009

HOUSING AND LONG-TERM CARE FOR THE ELDERLY

Kenneth E. Barber, Ph.D.  
Extension Sociologist  
A Family Living Program  
Washington State University Cooperative  
Extension Service  
104 E. White Hall  
Pullman, WA 99164-2010  
(509) 335-2918

YOU AND YOUR AGING PARENT

Jean Toon  
Assistant Director  
Midland Area Agency on Aging  
305 N. Hastings - P.O. Box 905  
Hastings, NE 68902  
(402) 463-4565

AS PARENTS GROW OLDER

Helen Sorenson  
3420 University, Suite B  
Waterloo, IA 50701



WHEN DEPENDENCY INCREASES: "THE DOLLMAKER"

Vicki Schmall  
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161 Milan Hall  
Corvallis, OR 97331-5106  
(503) 737-3211

DEVELOPING A CAREGIVER TRAINING PROGRAM

Marilyn Cleland, R.N.  
Family Support Center  
Good Samaritan Hospital & Med. Center  
1015 N.W. 22nd Avenue  
Portland, OR 97210-5198

HANDBOOK FOR INTERFAITH VOLUNTEER CAREGIVING

Health Services Research Center  
The Benedictine Hospital  
Kingston, NY 12401

DEVELOPING A CAREGIVER EDUCATION PROGRAM

Marilyn Cleland, R.N.  
Family Support Center  
Good Samaritan Hospital & Med. Center  
1015 N.W. 22nd Avenue  
Portland, OR 97210-5198

FOR THOSE WHO CARE

Cynthia Highea, M.A.  
Manager, Older Adult Services  
Lee Memorial Hospital  
P.O. Drawer 2218  
Fort Meyers, FL 33902  
(813) 332-1111

INNOVATIVE APPROACHES TO THE DISSEMINATION OF CAREGIVER INFORMATION

Joseph Geordano, M.S.W.  
Project Director  
American Jewish Committee  
New York, NY 10022

AS PARENTS GROW OLDER

Mary Egnor  
Interim Director  
Child and Family of Michigan, Inc.  
2157 University Park Drive  
PO Box 348  
Okemos, MI 48805  
(517) 349-6226

SENIOR EMPOWERMENT PROJECT, ASIAN HUMAN CARE CENTERS

Lynn Fuchita  
Asian Human Care Centers  
Synod of Southern California & Hawaii  
1501 Wilshire Blvd.  
Los Angeles, CA 90017-2293  
(213) 483-3840

TRAINING THE ELDERLY AND THEIR CAREGIVERS IN THE HOME (T.E.A.C.H.)

Abigail Walters  
Medical Health Care Program Analyst  
State of Florida Department of  
Health and Rehabilitative Services  
1321 Winewood Blvd  
Tallahassee, FL 32301  
(904) 488-2881/278-2881

INTERGENERATIONAL SERVICE LEARNING PROJECT

Robert G. Bringle, Ph.D.  
Associate Professor, Psychology Dept.  
Indiana University-Purdue University  
1125 E. 38th St., P.O. Box 647  
Indianapolis, IN 46205  
(317) 274-6753

ALZHEIMER'S 101: THE BASICS FOR CAREGIVING

Marilyn Koerber  
Executive Director  
South Carolina Commission on Aging  
400 Arbor Lake Drive, Suite B-500  
Columbia, SC 29223  
(803) 735-0210

IN-HOME RESPITE CARE: GUIDELINES FOR PROGRAMS SERVING FAMILY CAREGIVERS FOR MEMORY-IMPAIRED ADULTS

Lisa P. Gwyther  
Program Director  
Duke Family Support Program  
Box 3003 - Duke Medical Center  
Durham, NC 27710

IN-HOME RESPITE CARE: GUIDELINES FOR TRAINING RESPITE WORKERS SERVING MEMORY-IMPAIRED ADULTS

Lisa P. Gwyther  
Program Director  
Duke Family Support Program  
Box 3003 - Duke Medical Center  
Durham, NC 27710

RESPITE CARE FOR ALZHEIMER'S VICTIMS

Louis Goldblatt  
Dir. of Services to the Frail Elderly  
State of Connecticut Dept. on Aging  
175 Main St.  
Hartford, CT 06106  
(203) 566-8661

ELDER CARE SHARE

Mary R. Sawicki  
Executive Director  
Southcentral Michigan Com. on Aging  
Suite 1-C, 8135 Cox's Drive  
Portage, MI 49002  
(616) 327-4321

CARING THAT MAKES A DIFFERENCE

Marilyn Cleland  
Caregiver Education Coordinator  
Good Samaritan Hospital & Med. Center  
1015 N.W. 22nd Ave.  
Portland, OR 97210  
(503) 229-7348

HOW TO START A RESPITE SERVICE FOR PEOPLE WITH ALZHEIMER'S AND THEIR FAMILIES

Anna H. Zimmer, M.S.W.  
Director, Institute on Mutual Aid/Self-Help and Aging  
Brookdale Center on Aging  
Hunter College  
425 E. 25th St.  
New York, NY 10011

ADULT SITTER CLINIC WORKBOOK

Diane G. Smathers, Ed.D.  
State Program Leader  
Human Environment  
Georgia Cooperative Extension Service  
University of Georgia  
Athens, GA 30602

GERIATRIC RESPITE CARE: EXPANDING AND IMPROVING PRACTICE

Carol R. Hegeman  
Director of Research  
The Foundation for Long-Term Care  
194 Washington Avenue  
Albany, NY 12210

RESPITE CARE

Eric Pfeiffer, M.D.  
Suncoast Gerontology Center  
Univ. of South Florida Med. Center  
12901 North 30th St. - MDC Box 50  
Tampa, FL 33612

RESPITE COMPANION PROGRAM MODEL

Lorraine Lidoff  
National Council on the Aging, Inc.  
600 Maryland Ave., S.W.-West Wing 100  
Washington, DC 20024

RESPITE: HELPING CAREGIVERS KEEP  
ELDERLY RELATIVES AT HOME

Sally Harrs  
Program Director  
Nat'l. Council of Catholic Women  
1312 Massachusetts Ave., N.W  
Washington, DC 20005  
(202) 638-6050

HOW-TO MANUAL ON PROVIDING  
RESPITE CARE FOR FAMILY CAREGIVERS

Project SHARE  
P.O. Box 2309  
Rockville, MD 20852

ADULT SITTER CLINIC PROGRAM  
MANUAL

Judith L. Warren  
Gerontology Specialist  
Texas Agricultural Extension Service  
Texas A&M University  
College Station, TX 77843  
(409) 845-1146

TRAINING RESPITE CAREGIVERS FOR  
ALZHEIMER'S FAMILY SUPPORT

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Texas Agricultural Extension Service  
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TRAINING RESPITE CARE WORKERS FOR  
ALZHEIMER'S DISEASE PATIENTS

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DEVELOPING IN-HOME RESPITE SERVICES

Marilyn Cleland, R.N.  
Family Support Center - Good Samaritan  
Hospital & Medical Center  
1015 NW 22nd Ave.  
Portland, OR 97210-5198

DEVELOPING A CAREGIVER'S LISTING  
SERVICE

Marilyn Cleland, R.N.  
Family Support Center  
Good Samaritan Hospital & Med. Center  
1015 N.W. 22nd Avenue  
Portland, OR 97210-5198

FAMILY FRIENDS

Miriam Charnow  
National Council on the Aging, Inc.  
600 Maryland Ave., S.W.  
Washington, DC 20024  
(202) 479-1200

**ADDITIONAL RESOURCES:  
SELF HELP MATERIALS FOR CAREGIVERS**

The resources listed below are pamphlets and books that are expressly designed for the caregivers themselves. These materials provide practical information in three areas: 1) Community and In-Home Services; 2) Alzheimer's Disease and Related Disorders; and 3) General Caregiving. Information is provided to assist caregivers in obtaining copies of these materials.

**Community and In-Home Services**

- **Care Management (Arranging for Long Term Care)**  
AARP - Health Advocacy Service-Program Department

To obtain: AARP - Fulfillment Section  
1909 K Street, NW  
Washington, DC 20049

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- **A Checklist of Concerns/Resources for Caregivers**  
AARP

To obtain: AARP - Fulfillment Section  
1909 K Street, NW  
Washington, DC 20049

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- **A Handbook About Care in the Home - Information on Home Health Services**  
AARP - Health Advocacy Service-Program Department

To obtain: AARP - Fulfillment Section  
1909 K Street, NW  
Washington, DC 20049

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- **Home Is Where the Care Is**  
AARP - Health Advocacy Service-Program Department

To obtain: AARP - Fulfillment Section  
1909 K Street, NW  
Washington, DC 20049

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- **The Right Place at The Right Time - A Guide to Long-Term Care Choices**  
AARP - Health Advocacy Service-Program Department

To obtain: AARP - Fulfillment Section  
1909 K Street, NW  
Washington, DC 20049

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- **Miles Away and Still Caring - A Guide for Long Distance Caregivers**  
AARP - Social Outreach and Support Section, Program Department

To obtain: AARP - Fulfillment Section  
1909 K Street, NW  
Washington, DC 20049

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- **Home Health Care Handbook, A Guide for the Family of the Homebound Patient**  
Upham's Corner Health Committee, Inc.  
(1987) Owings Mills, MD: Rynd Communications.

To Obtain: Available at local bookstore

### Alzheimer's Disease and Related Disorders

- **Alzheimer's Disease Fact Sheet**  
Alzheimer's Disease and Related Disorders Association, Inc., Chicago, IL

To obtain: Alzheimer's Disease and Related Disorders Association, Inc.  
70 East Lake Street, Suite 600  
Chicago, IL 60601  
800-621-0379

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- **Alzheimer's Disease and Related Disorders Fact Sheet (An Overview of the Dementias)**  
Alzheimer's Disease and Related Disorders Association, Inc., Chicago, IL

To obtain: Alzheimer's Disease and Related Disorders Association, Inc.  
70 East Lake Street, Suite 600  
Chicago, IL 60601  
800-621-0379

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- **If You Have Alzheimer's Disease: What You Should Know, What You Can Do**  
Alzheimer's Disease and Related Disorders Association, Inc., Chicago, IL

To obtain: Alzheimer's Disease and Related Disorders Association, Inc.  
70 East Lake Street, Suite 600  
Chicago, IL 60601  
800-621-0379

- **If You Think Someone You Know Has Alzheimer's Disease**  
Alzheimer's Disease and Related Disorders Association, Inc., Chicago, IL

To obtain: Alzheimer's Disease and Related Disorders Association, Inc.  
70 East Lake Street, Suite 600  
Chicago, IL 60601  
800-621-0379

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- **Standing By You: Family Support Groups**  
Alzheimer's Disease and Related Disorders Association, Inc., Chicago, IL

To obtain: Alzheimer's Disease and Related Disorders Association, Inc.  
70 East Lake Street, Suite 600  
Chicago, IL 60601  
800-621-0379

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- **Financial Services You May Need**  
Alzheimer's Disease and Related Disorders Association, Inc., Chicago, IL

To obtain: Alzheimer's Disease and Related Disorders Association, Inc.  
70 East Lake Street, Suite 600  
Chicago, IL 60601  
800-621-0379

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- **Alzheimer's Disease and Related Disorders - A Description of the Dementias**  
Alzheimer's Disease and Related Disorders Association, Inc., Chicago, IL

To obtain: Alzheimer's Disease and Related Disorders Association, Inc.  
70 East Lake Street, Suite 600  
Chicago, IL 60601  
800-621-0379

- **Alzheimer's Disease: Services You May Need**  
Alzheimer's Disease and Related Disorders Association, Inc., Chicago, IL

To obtain: Alzheimer's Disease and Related Disorders Association, Inc.  
70 East Lake Street, Suite 600  
Chicago, IL 60601  
800-621-0379

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- **Memory and Aging**  
Alzheimer's Disease and Related Disorders Association, Inc., Chicago, IL

To obtain: Alzheimer's Disease and Related Disorders Association, Inc.  
70 East Lake Street, Suite 600  
Chicago, IL 60601  
800-621-0379

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- **Communicating with the Alzheimer's Disease Patient**  
Alzheimer's Disease and Related Disorders Association, Inc., Chicago, IL

To obtain: Alzheimer's Disease and Related Disorders Association, Inc.  
70 East Lake Street, Suite 600  
Chicago, IL 60601  
800-621-0379

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- **Especially for the Alzheimer's Caregiver**  
Alzheimer's Disease and Related Disorders Association, Inc., Chicago, IL

To obtain: Alzheimer's Disease and Related Disorders Association, Inc.  
70 East Lake Street, Suite 600  
Chicago, IL 60601  
800-621-0379

- **Legal Considerations for Alzheimer's Disease**  
Alzheimer's Disease and Related Disorders Association, Inc., Chicago, IL

To obtain: Alzheimer's Disease and Related Disorders Association, Inc.  
70 East Lake Street, Suite 600  
Chicago, IL 60601  
800-621-0379

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- **The Caregiver Learning Guide - 5 Videotapes**  
1) **Meeting Daily Challenges**, 2) **Communicating**, 3) **Safety First**, 4) **Managing Difficult Behaviors**, 5) **Caring for the Caregiver**  
Alzheimer's Disease and Related Disorders Association, Inc., Chicago, IL

To obtain: Alzheimer's Disease and Related Disorders Association, Inc.  
70 East Lake Street, Suite 600  
Chicago, IL 60601  
800-621-0379

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- **Alzheimer's Disease Orientation Kit - Videotape and Learner's Guide**  
Alzheimer's Disease and Related Disorders Association, Inc., Chicago, IL

To obtain: Alzheimer's Disease and Related Disorders Association, Inc.  
70 East Lake Street, Suite 600  
Chicago, IL 60601  
800-621-0379

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- **The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer's Disease, Related Dementing Illnesses, and Memory Loss in Later Life**

Mace, N. L., and Robins, P. V. (1981).  
Baltimore: Johns Hopkins University Press.

To obtain: Available at local bookstore

- **Loss of Self**  
Cohen, D., and Eisdorfer, C. (1986). A Plume Book. New York: New American Library.

To obtain: Available at local bookstore

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- **Communication: Basic Issues and Techniques, What to do? A Guide for Families Caring for Persons with Dementia-Related Diseases**

- **Communication: Hearing Problems, What to do? A Guide for Families Caring for Persons with Dementia-Related Diseases**

- **Communication: Vision Problems, What to do? A Guide for Families Caring for Persons with Dementia-Related Diseases**

Veterans Administration, Washington, DC

To obtain: Veterans Administration  
Office of Geriatrics  
810 Vermont Ave., NW  
Washington, DC 20420

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- **The Role of the Caregiver, A Guide for Families Caring for Persons with Dementia-Related Diseases**

Veterans Administration, Washington, DC

To Obtain: Veterans Administration  
Office of Geriatrics  
810 Vermont Ave., NW  
Washington, DC 20420

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- **Respite Care: When You Need a Break, A Guide for Families Caring for Persons with Dementia-Related Diseases**

Veterans Administration, Washington, DC

To Obtain: Veterans Administration  
Office of Geriatrics  
810 Vermont Ave., NW  
Washington, DC 20420

- **Managing from Day to Day Part 1: Dealing with Decline in the Patient's Abilities, What To Do? A Guide for Families Caring for Persons with Dementia-Related Diseases**

- **Managing from Day to Day Part 2, Creating a Safe and Workable Environment, What To Do? A Guide for Families Caring for Persons with Dementia-Related Diseases**

Veterans Administration, Washington, DC

To Obtain: Veterans Administration  
Office of Geriatrics  
810 Vermont Ave., NW  
Washington, DC 20420

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- **Special Care Problems, Inappropriate Sexual Behavior, What To Do? A Guide for Families Caring for Persons with Dementia-Related Diseases**

- **Special Care Problems Part 1: Restlessness, Wandering and Sleep Disturbances, What To Do? A Guide for Families Caring for Persons with Dementia-Related Diseases**

- **Special Care Problems Part 2: Aggressive and Violent Behavior, What To Do? A Guide for Families Caring for Persons with Dementia-Related Diseases**

- **Special Care Problems Part 4: Urinary Incontinence, What To Do? A Guide for Families Caring for Persons with Dementia-Related Diseases**

- **Special Care Problems Part 5: Bowel Incontinence, What To Do, A Guide for Families Caring for Persons with Dementia-Related Diseases**

Veterans Administration, Washington, DC

To Obtain: Veterans Administration  
Office of Geriatrics  
810 Vermont Ave., NW  
Washington, DC 20420

- **Working with Bureaucracies, What to do? A Guide for Families Caring for Persons with Dementia-Related Diseases**

Veterans Administration, Washington, DC

To Obtain: Veterans Administration  
Office of Geriatrics  
810 Vermont Ave., NW  
Washington, DC 20420

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- **Working with Family and Friends, A Guide for Families Caring for Persons with Dementia-Related Diseases**

Veterans Administration, Washington, DC

To Obtain: Veterans Administration  
Office of Geriatrics  
810 Vermont Ave., NW  
Washington, DC 20420

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- **Working with Financial and Legal Advisors: Where to Begin**

Veterans Administration, Washington, DC

To Obtain: Veterans Administration  
Office of Geriatrics  
810 Vermont Ave., NW  
Washington, DC 20420

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- **Working with Financial and Legal Advisors: Planning for Now and for the Future, What to do? A Guide for Families Caring for Persons with Dementia-Related Diseases**

Veterans Administration, Washington, DC

To Obtain: Veterans Administration  
Office of Geriatrics  
810 Vermont Ave., NW  
Washington, DC 20420

- **Working With Health Care Professionals, A Guide for Families Caring for Persons with Dementia-Related Diseases**

Veterans Administration, Washington, DC

To Obtain: Veterans Administration  
Office of Geriatrics  
810 Vermont Ave., NW  
Washington, DC 20420

.....

- **Working with Financial and Legal Advisors, Guardianships and Involuntary Treatment, What To Do? A Guide for Families Caring for Persons with Dementia-Related Diseases**

Veterans Administration, Washington, DC

To Obtain: Veterans Administration  
Office of Geriatrics  
810 Vermont Ave., NW  
Washington, DC 20420

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- **Alzheimer's Disease - Early Warning Signs and Diagnostic Resources**

Alzheimer's Resource Center

To Obtain: City of New York  
Alzheimer's Resource Center  
280 Broadway, Room 214  
New York, NY 10007  
212-577-7564

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### General Caregiving Resources

- **Ageing Parents: Helping When Health Fails**  
Good Samaritan Hospital and Medical Center

To obtain: Good Samaritan Hospital and  
Medical Center  
1015 N.W. 22nd Ave.  
Portland, Oregon 97210-5198  
503-229-7348



- **Family Caregiving, A Manual for Caregivers of Older Adults**  
The College of St. Scholastica

To Obtain: Department of Psychology  
The College of St. Scholastica  
1200 Kenwood Ave.  
Duluth, MN 55811  
218-723-6285

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- **Caring For Your Aging Parents: A Practical Guide to the Challenges, the Choices.** Kenny, James and Spicer, S. (1984) Cincinnati, OH: St. Anthony Messenger Press.

To Obtain: Available at local bookstore

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- **Understanding Aging Parents**  
Lester, Andrew and Judith. (1980)  
Philadelphia, PA: The Westminster Press.

To Obtain: Available at local bookstore

.....

- **How to Care For Your Parents**  
Levin, Nora Jean. (1987) Washington, DC: Storm King Press.

To Obtain: Available at local bookstore

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- **Caregiving: Helping An Aging Loved One**  
Horne, Jo. (1983) Washington, DC: AARP.

To obtain: AARP - Fulfillment Section  
1909 K Street, NW  
Washington, DC 20049

- **Dealing With Dietary and Eating Dilemmas**  
Good Samaritan Hospital and Medical Center

To obtain: Good Samaritan Hospital and  
Medical Center  
1015 N.W. 22nd Ave.  
Portland Oregon 97210-5198  
503-229-7348

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- **Understanding and Coping with Difficult Caregiving Relationships**  
Good Samaritan Hospital and Medical Center

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## CAREGIVER BIBLIOGRAPHY

This bibliography consists of books and articles, mostly published during the last decade, that offer information to the caregiver professional who is seeking to understand and work more effectively with family units. This bibliography is not intended to be exhaustive nor complete; it is designed to offer a representative listing of those works recognized as making a contribution to our understanding of the issues surrounding caregiving in the present era.

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