



U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

A COMPENDIUM OF INTERVENTION
AND DESCRIPTIVE STUDIES
DESIGNED TO PROMOTE THE
HEALTH OF CAREGIVERS FOR OLDER
ADULTS

August 2003

Office of the Assistant Secretary for Planning and Evaluation

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**A COMPENDIUM OF INTERVENTION AND
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INTRODUCTION

Background

Caregivers are a critical resource for older persons with disabilities and chronic illnesses. Almost all older persons with some type of activity of daily living (ADL) or instrumental activity of daily living (IADL) impairment who live in community settings (about 95 percent) receive at least some assistance from relatives, friends, and neighbors.⁽¹⁾ Two of every three older persons with some type of ADL or IADL impairment who live in noninstitutionalized settings (67 percent) rely solely on informal help, primarily from wives or adult daughters.⁽¹⁾ Families have been, and continue to be, both the “major coordinators and the providers of everyday long term care.”^(1, p.1)

A number of factors are shifting the cost and responsibility for post-acute and long-term care (LTC) for older persons to the informal care system. They include (1) changes in the health care delivery financing system that have led to shorter hospital stays,^(1, 2) (2) the high cost of nursing home care, (3) a preference for home care over institutional care, and (4) the increasing shortage of paraprofessional workers in all LTC settings.^(1, 3) All of these factors contribute to the increasing likelihood that frail, disabled, and ill older relatives will be cared for at home.

During the next few decades, as the number of older persons needing assistance to remain independent increases dramatically, the burden and cost of providing care to an ill or disabled relative will affect almost every U.S. household.^(4, 5)

There is general agreement that caring for an older individual with a disability or chronic illness is burdensome and stressful to many family members and contributes to psychiatric and physical morbidity.⁽⁶⁻⁸⁾ Researchers have suggested that the combination of loss, prolonged distress, the physical demands of caregiving, and biological vulnerabilities of older caregivers may compromise their physiological functioning and increase their risk for physical health problems, leading to increased mortality.⁽⁸⁾

The potentially negative physical and emotional effects of caregiving were recently highlighted in the Caregiver Health Effects Study, which found that family caregiving accompanied by emotional strain was an independent risk factor for mortality among older adults.⁽⁸⁾ Data from this study and others have shown that caregivers are less likely than peers of the same age to engage in health-promoting behaviors that are important for chronic disease prevention and control.⁽⁹⁻¹³⁾

These findings suggest a pressing need for effective methods to encourage caregivers to engage in activities that will benefit their own health and well-being. Such activities include improved nutritional intake, increased physical activity and exercise, maintenance of a healthy weight, and the reduction of behaviors that increase risk of illness such as use of tobacco or abuse of alcohol.

Although many projects and initiatives focused on these activities have been implemented over the years, no single source provides an inventory of them or guidance for government agencies or private sector entities about which programs seem the most promising and may merit promotion or expansion.

The Office of the Assistant Secretary for Planning and Evaluation (ASPE) has recently initiated the Health Promotion and Aging Project. An important component of this project is the development of such an inventory of health promotion, disease prevention, and health education activities targeted at informal caregivers for the Department of Health and Human Services (hereafter, the Department). ASPE has engaged RTI International to provide an initial inventory of such projects. The specific focus of this report is to highlight some state and local initiatives that have developed promising programs to support, educate, and motivate caregivers of persons age 60 and older to maintain and improve their health and functioning.

Sources of Information

The remainder of this report provides a series of case studies of state or local initiatives designed to help caregivers eat better, increase physical activity and exercise, maintain a healthy weight, stop smoking, reduce alcohol use, improve sleep, reduce stress, identify available health resources, and increase their use of recommended clinical preventive services. By definition, a series of case studies does not yield a comprehensive list of such programs over time. Rather, we have focused largely on projects supported by the federal government or by the private sector (e.g., foundations) that illustrate, collectively, promising approaches and methods for achieving these goals.

We utilized several approaches to identify the initiatives. We first conducted an electronic literature search (<http://www.ncbi.nlm.gov>). We identified articles in the National Library of Medicine's Pub Med database by using combinations of the following terms: health promotion, disease prevention, caregiver, caregiver health, and caregiving. Next, we screened out all references to caregivers of small children or young adults. We also eliminated projects that had been completed before 1996 and/or were conducted in countries other than the United States. We then obtained and reviewed all relevant abstracts and articles (n=25).

Next, we held discussions with members of our technical expert panel to get specific leads on projects or literature (published or unpublished) and descriptions of any programs with which they themselves were involved. From these discussions, we were able to follow a "snowball" strategy of contacting yet other experts through several iterations. In all, we spoke with 25 individuals who could provide leads or information about promising caregiver health promotion activities. Finally, we conducted Internet searches to identify additional programs that may be too new to have generated any publications or received much attention to date.

It is important to note that the projects/initiatives described in the pages that follow are illustrative, not comprehensive, of the range of activities that are either currently underway or have recently been completed. There may be a number of efforts that have focused on the health and well-being of caregivers that went undetected by our multistage search strategy.

PROMISING PROJECTS/STUDIES: CASE STUDIES

The remainder of this report provides our compilation of promising initiatives and programs that address the range of caregiver health issues noted above. We have grouped these “case studies” based on whether they were intervention or descriptive studies and have listed them alphabetically within each group. Included in this information is the sponsor, a description of the program and its results to date, any lessons learned or next steps for the project in question, and a contact person.

INTERVENTION STUDIES

Family Caregiving Grant Initiative: Making Room for Family Caregivers

Sponsor. United Hospital Fund.

Purpose. The purpose of the Family Caregiving Grant Initiative was to support seven hospital-based projects designed to respond more effectively to the needs of family caregivers during and after the hospitalization of the persons for whom they were providing care.

Description. The Grant initiative funded seven projects between 1998 and 2002. Although the specifics of each initiative varied, each project aimed to develop practical approaches to supporting family caregivers' needs, through outreach, education, or a reshaping of the health care culture itself. The projects included interventions that provided frontline support for caregivers, built and sustained institutional support, and involved caregivers as advisors in the care of the treatment of care recipients. Two of the seven projects focused on helping caregivers to take better care of themselves.

The Brooklyn Hospital Center/Wartburg Lutheran Home for the Aging project provided information and training for caregivers of neurologically impaired African-American patients and sensitized caregivers to their own needs.⁽¹⁴⁾ The intervention included (1) an assessment of caregivers' stress levels and their need for home care assistance so that appropriate services could be established and (2) upon discharge of their relatives, follow-up assistance and one or two in-home visits for help in making the hospital to home transition. In addition, caregivers were given individualized notebooks with information about resources and supports for their particular caregiver situation.

The Maimonides Medical Center/First to Care Home Care program was designed to offer caregivers a broad range of services and resources—including welcoming sessions, community referrals to health care providers for their own health care needs, and a hotline both during and after their relatives' hospitalizations.⁽¹⁴⁾ Two groups of individuals participated in the program, one considered high risk.

To be considered for the high risk group, a caregiver had to be identified by project staff as meeting at least one of the following criteria: advanced age, poor health, or having many other responsibilities such as child care or care for another ill person. The high risk group received information on benefits and entitlements to Medicare, Meals on Wheels, food stamps, and other community resources while their relatives were still in the hospital. In addition, they met with a social worker both while their relatives were in the hospital and within 24 hours of their relative's discharge to learn about how to take care of their own health during the transition home.

The second group included caregivers who identified themselves as candidates for the program and did not meet any of the criteria of the high risk group. These individuals received the same information materials as the high-risk group but did not visit with a social worker during or following hospitalization.

Results. All of the hospital-based projects were completed in 2002. No uniform approach was developed to track results across projects; rather, each project was encouraged to develop its own evaluation process. Caregivers involved with the Brooklyn/Wartburg project (relative to caregivers not involved with the project) reported having less caregiver strain and a greater understanding of the health promotion benefits available to them under the Medicare and Medicaid programs. Similarly, the Maimonides program, which began on two inpatient units in 2000, expanded to 15 units by 2002 because of its positive reception at the hospital. As of August 2002, more than 4,000 caregivers had attended 382 welcoming sessions, about 400 caregivers had attended monthly support groups and entitlement/benefits talks, and its partner, First to Care Home Care, reported more than 1,000 social work referrals.

Next Steps. Even though not all of the projects have been able to maintain their same level of service as under the United Hospital Fund Family Caregiver Initiative, the projects are expected to be continued and to obtain new funding in the future either within the hospital or from outside sources.⁽¹⁴⁾

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Health First Study: Caregivers Take Time to Stay Active

Sponsors. National Institute on Aging.

Purpose. This research project is designed to develop, implement, and evaluate a telephone-based counseling intervention to promote physical activity among female caregivers whose spouses have been diagnosed with Alzheimer's disease or a related disorder (ADRD).

Description. The specific aims of the research are to (1) develop a curriculum for a telephone-based counseling intervention to promote physical activity; (2) conduct a field test of the intervention with 200 randomly selected intervention and control group participants recruited primarily from spouse caregivers of patients seen at the Michigan Alzheimer's Disease Research Center; (3) evaluate the process of implementing the intervention, including the extent to which the delivered activities fit the original design and factors external to the program that competed with program effects; and (4) evaluate the impact of a telephone-based intervention on caregiver physical health, physical activity, self-efficacy for physical activity, depression, and caregiver burden at 12-month follow-up.⁽¹⁵⁾

The intervention has been implemented as follows. First, caregivers speak with a behavior-change counselor to set an individualized exercise goal to achieve by the end of the project period. During subsequent telephone calls, participants set short-term goals and used problem-solving skills to address barriers to success. Options for home-based exercise are provided, but participants are also free to join group exercise programs to meet their personal goals.⁽¹⁵⁾

Results-to-Date. The first three specific aims of the project have been completed. Data analysis, including assessment of the impact of the intervention at 12-month follow-up, is in the final stage of completion.

Next Steps. Four manuscripts will be submitted for publication within the next few months. In addition, the principal investigator will submit a grant application to replicate the *Health First* project with other groups of dementia caregivers (e.g., adult children and older men). The proposed replication will offer a variety of caregiver interventions in addition to physical activity, such as weight and stress management programs.

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PREP: Family Based Care for Frail Older Persons

Sponsors. National Institute on Aging, National Institute for Nursing Research, and Northwest Region of Kaiser Permanente.

Purpose. The Family Based Care Study is designed to increase Preparedness, Enrichment, and Predictability (PREP) of family care for frail elders and their caregivers.

Description. The PREP Family Based Care Study for Frail Older Persons is a two-group randomized controlled trial designed to provide frail older persons and their family members with a range of services chosen by the family unit during a 12-month intervention period. Frail older persons who are members of the Northwest Region of Kaiser Permanente and who meet Medicare criteria for skilled home care are recruited into the study based on a physician's referral to home health care. A screening form is completed for each potential caregiving unit (both caregiver and recipient) to determine whether the client and family caregiver are eligible to be in the study. Caregivers must help with at least one activity of daily living or two instrumental activities of daily living. Eligible study participants (i.e., care recipients and caregivers) are randomly assigned to either the PREP intervention or the standard home health benefit provided at Kaiser Permanente's Northwest Regional medical offices. Approximately 240 family units, including at least 40 African-American families and at least 40 low-income white families, are being followed.

Each family unit assigned to the intervention self-administers a systematic assessment, which includes measures of family and caregiver health and well-being. A nurse reviews the results with the caregiver and identifies areas where either the care recipient or caregiver (or both) scored above or below average. The family then prioritizes its needs and decides what types of services and social supports it would like to receive. If the family decides to select caregiver health supports as part of its service package, then an in-depth health assessment is conducted to determine the types of caregiving services needed. PREP services must be agreed to by the family before any services are initiated.

PREP nurses deliver the services with input and guidance from an interdisciplinary team of experts from Kaiser Permanente's health care system. Both in-person and telephone support services are provided for a 12-month period, with the frequency determined by each family unit. Comparison group subjects receive the standard home care benefit through the Medicare HMO benefit at Kaiser Permanente's Northwest Regional medical offices.

The investigators are using three research measures: the Family Care Inventory, the Quality of Family Care Scale, and the Family Health Diary, and three data sources: the Kaiser Permanente Northwest Region's Home Health automated clinical information system, the Kaiser Permanente Northwest Region's automated data systems, and the Family Expense Calendar.

Data are being collected at 5 points in time (baseline, 5 months, 10 months, 15 months, and 20 months after the receipt of the intervention). Analyses (including regression, survival analysis, and repeated measures ANOVA) are planned to determine:

1. whether, compared to standard home health benefits, PREP have a significant effect on family care variables (e.g., caregiver skill, caregiver role strain, health status of caregiver and care recipient, etc);
2. whether the effectiveness of PREP varies by race and income; and
3. whether any effects of PREP on family care variables and health continue after the intervention is withdrawn (after 12 months).

The study will also address two secondary aims related to measuring the use and cost of formal and informal health care services for care recipients in PREP compared to standard home health care.

Results to Date. Data collection is not finished. The study, currently in its fourth year, will continue for one more year, ending in August 2004. Results will be available within the next 12 to 16 months.

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REACH II: Resources for Enhancing Alzheimer's Caregiver Health

Sponsors. National Institute on Aging and National Institute of Nursing Research.

Purpose. The REACH II intervention seeks to increase caregiver knowledge, skills, and well-being while enhancing support to the caregiver. Specifically, the study is designed to (a) test a multi-component intervention for caregivers, (b) assess the intervention's impact on ethnically diverse populations, (c) provide new measurements for assessing the quality of care provided by caregivers and tools for identifying caregivers at risk for adverse outcomes, and (d) evaluate the cost effectiveness and public health significance of the intervention.⁽¹⁶⁾

Description. The REACH II intervention comprises 10 home visits by trained staff plus five contacts with trained staff through an innovative computer/telephone technology system over a 6-month period. The technology provides access to formal services for both family and other caregivers. The intervention begins with the administration of a health risk appraisal following a battery of baseline assessments. Project staff prioritize risk areas for each caregiver, and then develop a stepped intervention approach that addresses risk in multiple health areas (including caregiver health and self-care, caregiver burden/depression, social support, problem behaviors of recipient, and safety of both the patient and caregiver).⁽¹⁷⁾

The care plans developed and services recommended vary based on the results of the health risk appraisal; they range from home-based exercise programs to computer-based monitoring systems and individual consultations with medical providers.⁽¹⁷⁾

The study design is a multisite, two-group randomized clinical trial, comparing outcomes in the active intervention group to those in an information-only control group; the intervention and control groups are of equal size. Unlike REACH I, which implemented a variety of active interventions at six different sites, this study will implement the same two interventions at each of five participating sites: Birmingham, Memphis, Miami, Palo Alto, and Philadelphia. Across the five sites, 600 caregiver-care recipient dyads (120 per site) will be enrolled; the goal is for 510 dyads to complete the intervention.⁽¹⁶⁾

The study will be conducted in two Phases. Phase 1 is for refining the intervention and training staff to conduct the intervention protocol; in Phase 2, the randomized clinical trial is conducted. A uniform battery of baseline and outcome measures is being collected at baseline and 6 months. Cost-effectiveness and clinical significance of the intervention will also be evaluated. Final follow-up will occur 12 months after initial enrollment in the program.⁽¹⁶⁾

Results to Date. The study is ongoing. Data are being collected on caregivers in both the intervention and control groups. Approximately 50 percent of all caregivers have completed the protocol.⁽¹⁷⁾

Next Steps. The final results of the REACH II initiative will be disseminated widely on the Internet and in peer-reviewed journals, and will be presented at national conferences.

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Supporting Older African-American Caregivers: Assessing Needs, Building Skills, and Maintaining Health

Sponsor. Administration on Aging.

Purpose. This demonstration program, based in Philadelphia, Pennsylvania, is designed to assess the efficacy of a short-term nursing intervention in meeting the diverse needs of female African American and Caucasian caregivers. The goal is to enhance the services that caregivers receive through the Family Caregiver Support Program.⁽¹⁸⁾

Description. This program is designed to enhance the service strategy of the Philadelphia Corporation on Aging's (PCA's) existing Family Caregiver Support Program. It offers an intensive nursing intervention designed to maintain caregiver health, strengthen caregiver skills, and reduce caregiver stress. The intervention targets female African-American caregivers 65 years of age or older who provide care to a spouse or parent. Caregivers who meet the target criteria (identified through the PCA's automated client data system) are randomly assigned to the intervention or the control group condition. The goal is to enroll 200 caregivers (100 African American and 100 Caucasian) to complete the intervention by the end of Year 3.

The intervention consists of four in-home visits by a master's prepared nurse over a 3-month period, followed in some cases by more extensive intervention (i.e., in cases where the complexity of the caregiving situation or special needs of the caregiver require additional visits). During the first visit, the caregiver receives a thorough physical examination, completes the Caregiver Health Interview tool, develops a plan for health care (including both preventive health care and medical care services), and receives health education materials. During the second through fourth visits, individualized health care plans are reviewed, referrals are made to other health care providers, and additional caregiver training is provided. In addition, during the final (fourth) in-home visit, the nurse reevaluates the caregiver's health (repeating the assessment conducted at the time of the initial visit) and asks additional questions about the caregiver's perception of the intervention. Changes in health status and well-being are tracked from baseline through 3-month follow-up.⁽¹⁹⁾

A second intervention, known as the telemedicine component, has been offered as an add-on to those caregivers who are considered at risk of deterioration in their own health (due to advanced age; the presence of two or more chronic conditions or unstable management of chronic disease; limited informal resources and social isolation, depression and/or anxiety; and medically complex or physically demanding caregiving tasks). Those who agree to participate in this intervention, have on-going contact with the nurse (via telemedicine) over an additional 3-month period, both to reinforce their original care plan and to monitor the health status of the caregiver over time.

The control group for the second intervention receives two in-home visits by a nurse over the same 3-month period. The same evaluation tool is used for both the intervention and control group at both points in time.

Results to Date. Individuals are still being recruited into the program. Interim results should be available by fall 2003.

Next Steps. Baseline and follow-up data on caregivers in both the intervention and control group will be collected and analyzed. Changes in the following outcomes will be examined at 3- and 6-month follow-up: caregiver health, performance of caregiver tasks, caregiver stress, and caregiver quality of life.

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Teaching Healthy Lifestyles for Caregivers Study

Source. National Institute on Aging.

Purpose. The objective of this study was to determine the health and quality-of-life effects of moderate-intensity exercise among older women family caregivers.

Description. This study provided the first systematic investigation of the effectiveness of a physical activity intervention tailored to the challenges and needs of older women who are family caregivers. This 12-month randomized control trial involved a volunteer sample of 100 women ages 49 to 82 who were sedentary, free of cardiovascular disease, caring for a relative with dementia, providing at least 10 hours of unpaid care per week, and not participating in a regular program of physical activity. Study participants were randomized to an intervention comprising 12 months of home-based, telephone-supervised, moderate-intensity exercise training or to a control program that provided nutrition education.

The exercise training comprised 30- to 40-minute endurance exercise sessions prescribed four times a week. Participants were also encouraged to increase other forms of routine activity throughout the day, such as leisurely walking and gardening. Participants choosing outdoor activities generally chose to walk briskly in the neighborhood; indoor programs included the use of stationary cycling or project-provided exercise videotapes. Participants were instructed on how to take their heart rates, monitor their perceived exertion, and record their exercise frequency, intensity, and duration. They initially received a 30- to 40-minute face-to-face introductory counseling session. Once the study had begun, project staff contacted all study participants by telephone on a bi-weekly basis during the first 2 months and then once per month through month 12. Telephone contacts were used to monitor progress, answer questions, and provide individualized feedback.

Main study outcomes included stress-induced cardiovascular effects, self-rated sleep quality, adherence to protocol, caloric intake (percentage of calories derived from total fats and saturated fats, intake of high-fat snacks and sweets, and fruit and vegetable intake), and reported psychological stress.⁽²⁰⁾ Study participants kept their own records (which they mailed to study staff on a monthly basis); they were also examined by study staff at the university at baseline (before the study began) and at 12-month follow-up (after completion of the exercise program).

Results. Compared to the control group, exercise participants showed significant improvements in the following outcomes: total energy expenditure, stress-induced blood pressure, and self-rated sleep quality. The nutrition control group showed reductions in the percentage of total calories from fats and saturated fats relative to the exercise participants. Both groups reported reductions in psychological distress. These results showed that properly tailored health promotion programs can promote sustained improvements in health behaviors that are important to the ongoing health and functioning of older women family caregivers. More specifically, older

women family caregivers can benefit from initiating a regular, moderate-intensity exercise program in terms of reductions in stress-induced cardiovascular activity and improvements in self-reported sleep quality.⁽²⁰⁾

Next Steps. Although this particular study has been completed, it will be replicated with additional caregivers, including homebound dementia caregivers who are unable to obtain assessments in a university setting, minority caregivers, and less educated caregivers.

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DESCRIPTIVE STUDIES

Caregiver Health Effects Study (CHES)

Sponsors. National Institute of Mental Health, National Institute on Aging, National Heart, Lung and Blood Institute, Oregon State University.

Purpose. This study was designed to examine the relationship between caregiving demands among older spousal caregivers and 4-year all-cause mortality, controlling for demographic factors, prevalent clinical disease, and subclinical disease at baseline.

Description. The sample for this study was drawn from the Cardiovascular Health Study (CHS), a large population-based study of older persons designed to determine the risk factors and consequences of cardiovascular disease in older adults. For this ancillary study, the CHES, the focus was on examining the relationship between caregiving and mortality. Caregivers were defined as “individuals whose spouse had difficulty with at least one activity of daily living or instrumental activity of daily living due to physical or health problems or problems with confusion.”^(8, p. 2216) The noncaregiving group included individuals whose spouses did not have any difficulty with ADL or IADL. A total of 819 persons (392 caregivers and 427 noncaregivers) were selected among the four recruitment sites enrolled into the study.

Caregiver status was subdivided into four mutually exclusive categories based on responses to a combination of questions about caregiver status and the emotional or mental strain involved with taking care of a disabled spouse. The four categories were defined as (1) spouse not disabled (control subjects), (2) spouse disabled but not helping him/her, (3) spouse disabled and helping but no reports of caregiving strain, and (4) spouse disabled and helping and reports of caregiving strain.

Study participants were followed for an average of 4.5 years. Death was confirmed through reviews of obituaries, medical records, death certificates, and the Health Care Financing Administration’s health care utilization data base for hospitalizations.

Results. After more than 4 years of follow up, 103 deaths had occurred among the total sample. After adjusting for sociodemographic factors and physical health status, participants who were providing care and experiencing caregiver strain had a relative mortality risk 63 percent higher than the relative risk for those whose spouses were not disabled.

The other two groups (spouse disabled but not helping him/her, and spouse disabled and helping but no reports of caregiving strain) did not have significantly higher adjusted mortality risks. Therefore, the caregiver-mortality link found in this study

applied only to the subset of the caregiving population that experienced higher levels of strain and burden when caring for a disabled spouse.

These findings were consistent with other outcomes reported for this cohort showing that strained caregivers compared with age- and sex-matched noncaregiving controls had significantly higher levels of depressive symptoms, higher levels of anxiety, and lower levels of perceived health. They were also much less likely to get enough rest in general, have time to rest when they were sick, or have time to exercise relative to age- and sex-matched noncaregivers.⁽¹³⁾

The authors recommended that primary care physicians who care for community-residing older adults need to identify caregivers at risk. They stated that older married couples should be evaluated as a unit, in terms of both their health status and the caregiving demands that exist in the home environment. Finally, they reported that it is essential for medical care providers to develop treatment approaches for older marital dyads that focus on the needs of both individuals simultaneously.⁽⁸⁾

Next Steps. The study has been completed.

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Maine Primary Partners in Caregiving (MPPC) Program

Sponsor. Administration on Aging.

Purpose. This program, initiated in April 2001, is designed to demonstrate that primary health care can be an effective and efficient point of entry for a caregiver intervention in rural Maine.

Description. The MPPC Program identifies caregivers who are stressed by their caregiving responsibilities and encourages them to obtain support and assistance. The program first identified primary care physicians in four counties who were willing to participate in the program. Those who participated were provided with screening forms, and their office staff were trained to follow routine screening procedures. Since April 2002, all individuals 18 and older who visited these physician's offices for routine, non-emergency visits have been asked to complete a brief screening tool designed to identify patients who were burdened with caregiving responsibilities. The screening form uses five questions:

1. Do you help someone aged 60 years or older who is not in good health or is not managing as well as he/she used to? If yes,
2. Do you ever find helping this person difficult in any way?
3. Do you ever find yourself worrying about the condition of this person?
4. Do you ever feel at all stressed when giving this person help?
5. Have you had a significant weight change within the past year?

Completed screening forms are faxed to the caregiver specialists associated with the project, who identify those at risk of being burdened by their caregiving responsibilities. The specialists contact those at risk and offer them customized services, including education, training resources, and access to a statewide telephone hotline. Those who agree to participate in the program receive follow-up calls in the 3rd and 6th month of the program.⁽²¹⁾

Results to Date. During the first year of operations (April 2002-March 2003), 21 medical offices participated in the program, more than 7,000 patients were screened, and approximately 500 (7 percent) were identified as being caregivers who have experienced some stress.⁽²²⁾ The majority of these caregivers have been willing to receive assistance from caregiver specialists. Most individuals have requested information about potential caregiver service options for the future, but they did not yet want to obtain respite services. Most apparently have not been a caregiver for a long period of time, have not yet self-identified as caregivers, have not yet sought out caregiver services, and primarily have wanted to learn more about health and respite services that may be useful to them in the future.

Next Steps. The program will continue for one more year.

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Making the Link Program

Sponsor. Administration on Aging.

Purpose. This nationally developed, locally implemented program is designed to raise awareness among physicians about three issues: (1) caregiving can take a toll on the health of caregivers, (2) caregivers are an important part of the health care team, and (3) services to support caregivers and ease their burden are available in the local community through local Area Agencies on Aging (AAAs) and Title VI-Native American aging programs.

Description. The National Association of Area Agencies on Aging's (N4A) *Making the Link Program* has brought together two distinct but complementary systems --the aging network and health care providers--to benefit family caregivers across the United States. The goals of this program are to strengthen the ability of individual AAAs and Title VI grantees to serve family caregivers through a local, state, and national campaign. The campaign has two aims: (1) to involve physicians more actively in identifying caregivers and referring them to National Family Caregiver Support Program (NFSCP) services, and (2) to promote within the local medical community the concept that caregiving is a public health issue and increase awareness of the important health care role of family caregivers.⁽²³⁾

Approximately 100 AAAs and Title VI grantees are providing information about caregivers and caregiver services to their local physicians. This information has been developed by N4A based on input from an advisory board comprising major medical association representatives, individuals from agencies with an interest in public health, and caregiver advocates. The tools provided to medical care providers include information on caregiver health, available community services, and a caregiver self-assessment questionnaire developed by the American Medical Association.⁽²⁴⁾ N4A also is conducting a national awareness campaign for physicians, designed to focus on caregiving as a health care issue.

The following organizations have agreed to participate in the program: American Medical Association, American College of Physicians-American Society of Internal Medicine, American Geriatrics Society, American Association of Medical Society Executives, National Medical Association, American Project Access Network, Indian Health Service, National Alliance for Caregiving, the Families and Health Care Project at the United Hospital Fund, Health Resources and Services Administration, and representatives of AAA and Title VI programs. The American Academy of Family Physicians and the National Health Care Council will also join in the national awareness campaign.

Results to Date. The AoA grant began in October 2002. Caregiver health and educational materials have been developed, physician partners have been identified, and materials have been disseminated through the AAAs to partnering medical offices. The goal for the first grant year is for each AAA to have seven medical offices actively

participating in the program.⁽²³⁾ A national media campaign has been developed and various national advisory board members are currently commenting on draft materials. The project will continue through September 2004.

Next Steps. Project staff will continue to develop and maintain relationships with medical office staff, following up with providers and visiting them on a regular basis. Information used by medical offices will be tracked and replenished throughout the program. Referrals from medical offices to AAA offices will also be tabulated and reported. Individual sites and advisory group members will continue to work with N4A to refine media materials to promote the program at the state and local levels.

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Massachusetts Health and Aging Project

Sponsors. Massachusetts Department of Public Health (Office of Elder Health), Massachusetts Executive Office of Elder Affairs (EOEA) Family Caregiver Support Program, and MassPRO, the Healthcare Quality Improvement Organization in Massachusetts. The project was funded through a grant program funded by the National Association of State Units on Aging and the Association of State and Territorial Chronic Disease Program Directors. Ten states received grants.

Purpose. The purpose of the grant was to encourage collaboration between state health departments and state units on aging. The 10-month project in Massachusetts was designed to accomplish two goals: (1) encourage caregivers age 65 and older to increase their use of most or all prevention screening benefits provided through the Medicare program, and (2) recruit caregivers as liaisons in bringing prevention messages to the Medicare beneficiaries (older adults and younger persons with disabilities) for whom they care.

Description. Two strategies were developed to improve caregivers' use of prevention benefits under Medicare Part B. First, train-the-trainer workshops were developed. The curriculum for these sessions was written in collaboration with an MPH student at the Tufts University School of Public Health and project partners. Six train-the-trainer workshops were conducted to educate caregiver specialists and elder care advisors (through the EOEA Family Caregiver Support Program) in six regions across the state. The trainers were then expected to reach out to caregivers and provide them with information on prevention benefits under Medicare Part B. Second, working in collaboration with three students from Boston University's Hot House Productions, the project team developed a health communications video to reach older consumers with information about their prevention benefits under Medicare Part B.

Results. All train-the-trainer workshops have been completed. Thirty-five family caregiver support staff members were trained at these sessions. Each training program served as an opportunity to revise and refine the presentation. Evaluations completed at the training sessions indicated that 75 percent of those trained had little to some knowledge of the prevention benefits under Medicare Part B before the session; 25 percent of those trained had a fair amount of prior knowledge of the topic. More than 95 percent of the trainees judged the information to be useful and indicated that they would use the information in their work.⁽²⁵⁾

The project also developed and circulated a health communications video, "Take Charge: Medicare Part B Benefits and You," for use on cable TV programs and for individual and group viewing. The video is close-captioned for the hearing impaired. As part of the development process, project partners, social marketing staff, and Centers for Medicare & Medicaid Services (CMS) staff previewed the video to verify content and messages. Staff from the Family Caregiver Support program and some older consumers also previewed the video to provide additional feedback on its format and length.

Next Steps. The grant ended in June 2003.

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Powerful Tools for Caregiving Program

Sponsors. Legacy Health System, Mather LifeWays Foundation, Robert Wood Johnson Foundation/Local Initiative Funding Partners Program, Northwest Health Foundation, Good Samaritan Foundation, Administration on Aging, Oregon Community Foundation, and other community agencies and extension programs.

Purpose. The Powerful Tools for Caregiving Program has been developed by the Legacy Health System in Portland, Oregon, to provide self-care training to caregivers to help them to take better physical and emotional care of themselves. The program was initiated in 1995 in Oregon to provide caregiver training to caregivers. It has since been expanded to several other states (including California, North Carolina, Washington, and Wisconsin).

Description. The program is modeled after the successful *Chronic Disease Self-Management Program*, developed by Dr. Kate Lorig and colleagues at Stanford University's Patient Education Research Center. Concepts from Dr. Lorig's work have been adapted to address the needs and concerns of family caregivers. Caregivers attend six 2.5 hour classes over a 6-week period. The educational course is designed to help caregivers develop self-care tools to reduce personal stress, take better physical and emotional care of themselves, communicate their needs to family members, and make difficult caregiving decisions when a family member can no longer live alone, drive safely, and/or manage his/her finances. Caregivers also receive a 300-page book, entitled *The Caregiver Helpbook*, developed specifically for the class.⁽²⁶⁾ The *Helpbook* provides a list of basic wellness practices for caregivers, including proper diet, adequate sleep, and regular exercise. Materials have been developed in English, Spanish, and Korean.⁽²⁷⁾

The project includes a train-the-trainer program, which recruits and trains current and former caregivers to co-lead the classes. Class leaders also receive a comprehensive step-by-step guide, known as *The Class Leader's Guide*, as part of their training. A Master Trainer Program has also been developed so that trainers can teach other professionals to offer training at their agency locations.⁽²⁷⁾

Results-to-Date. The program has reached more than 700 family caregivers in Oregon and many more in other states in the United States, as well as Canada. Initial evaluation results have shown that the program reduces caregiver guilt and anger, increases caregiver self-care behavior (including increased use of physical exercise and decreased health-related self-neglect), increases positive feelings about caregiving, reduces depression, and increases knowledge and use of services available in the community.⁽²⁸⁾

Although program effects were particularly dramatic immediately following program participation, significant effects for several caregiver outcomes have been observed 6 months after the program was completed: reduced anger, guilt, depression, and health-related self-care neglect, as well as increased use of community services.⁽²⁹⁾

Next Steps. The Legacy Health System recently sold the Powerful Tools for Caregivers program to the Mather Institute on Aging in Evanston, Illinois. The Mather Institute is currently planning training sessions across the United States, using a grant provided by the Administration on Aging, to refine the training program further and to evaluate the course at four points in time (pre-course, post-course, 6 months post-course, and 12 months post-course). The Mather Institute on Aging is also planning to disseminate materials widely throughout the United States (<http://www.matherlifeways.com>).

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Rosalynn Carter Institute (RCI) and Johnson & Johnson Caregivers Program and the CARE-NET Project

Sponsors. Rosalynn Carter Institute (RCI) for Human Development, Georgia Southwestern State University in Americus, Johnson and Johnson, the Administration on Aging, and private donors.

Purpose. The RCI was formed in 1987 to promote the mental health and well-being of individuals, families, and professional caregivers; encourage effective caregiving practices; build public awareness of caregiving needs; and advance public and social policies that enhance caring communities. The RCI currently has several caregiver initiatives under way.

Description. RCI currently has two major initiatives for caregivers. The Johnson & Johnson Caregivers Program was developed in 2000, when Johnson & Johnson joined with RCI to create a signature program in caregiving. Through its *Practice in Action* component, the program awards grants of \$25,000 to five programs per year that advance science and contribute to knowledge in caregiving.

Through its *Science to Practice Initiative*, the program convenes expert panels to consider caregiving issues related to their specialty areas. In 2002, four expert panels were convened to meet and develop monographs based on their areas of expertise, answering the questions “what is known?” and “what is needed?” in the field of caregiving. Finally, through *Caring for You, Caring for Me*, the program seeks to help caregivers to take better care of themselves while caring for an older relative.⁽³⁰⁾

The second major RCI initiative is the *CARE-NET* project, funded by a grant from the AoA National Family Caregiver Support Program. The first goal of *CARE-NET* is to establish a network of caregiving communities, or CARE-NETs, within and among six of the Georgia Area Agencies on Aging, based on the model of two existing community coalitions, known as CARE-NET I and CARE-NET II. The second goal of the project is to develop a new Community Caregiving Capacity Index (CCCI) instrument to help communities assess their caregiving strengths and needs and, based on the assessment, develop an action plan for a coordinated, community-wide response to improve caregiving services.⁽³⁰⁾

Results-to-Date. Under the *Practice in Action* Initiative, five grants were awarded in 2002. Winning proposals were (1) a school-based mental health program that engages parents of African-American and Latino-American children traumatized by violence, (2) a rural church-based program aimed at African-American caregivers of seniors with chronic conditions and/or physical disabilities, (3) a psycho educational support program for both family and professional caregivers of individuals with mental illness, (4) a program to engage and support Hispanic families/caregivers of individuals with mental illness, and (5) a peer-support and community health promotion program for breast cancer prevention and early detection.

The *CARE-NET* project has established six new CARE-NETs in Georgia and has developed the Community Caregiving Capacity Index, which currently is being used as an individualized assessment tool and integral part of the curriculum for the *Caring for You, Caring for Me* educational program for caregivers.

Next Steps. Grants will continue to be issued through the *Practice in Action* Program to help grantees appropriately address the challenges of developing, maintaining, expanding, and replicating successful caregiving interventions. Results from *CARE-NET* project--including information on the development and testing of successful approaches to support family caregivers--will be disseminated to the community at large. The *Caring for You, Caring for Me* educational program for caregivers will continue to be evaluated and refined.

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Study of Health Practices of Adults with Elder Care Responsibilities

Sponsor. Northern California Kaiser Permanente Division of Research, Kaiser Foundation Research Institute.

Purpose. This study examined health-risk behaviors and preventive health care activities among a cross-sectional, stratified random sample of caregivers for older adults.

Description. A stratified sample of caregivers and noncaregivers was randomly selected from a listing of individuals ages 50 and older who were members of the Kaiser Foundation Health Plan in Northern California. An initial screening questionnaire was mailed to approximately 10,000 individuals and 7,391 usable questionnaires were returned (74 percent response rate).

Based on responses to this questionnaire, respondents were classified as caregivers if they met all of the following criteria: (1) they provided assistance to another person(s) with at least one personal ADL or at least two IADL, (2) the assistance was provided at least monthly, (3) persons receiving the assistance were at least age 65 or older, (4) recipients did not pay respondents for providing the services, and (5) respondents had provided this care for at least the past 12 months.

Those who met the criteria received a more detailed health practices questionnaire, which included questions about health behaviors, preventive health care activities, level of caregiving assistance, respondent characteristics, and care recipient characteristics. A sample of noncaregivers matched on age, sex, and race also received the health practices questionnaire. Twelve-hundred thirty-six of 1,574 persons (80 percent) completed the questionnaire. Of these respondents, 272 individuals were determined to be caregivers and 917 were determined to be noncaregivers (i.e., they were not currently providing unpaid assistance to the older person).

Results. After controlling for age, sex, race, education, marital status, and income level, caregivers were more likely than noncaregivers to eat breakfast daily, get influenza shots, and receive pneumonia vaccines. Caregivers and noncaregivers did not differ with regard to any of 10 other health practices (including regular exercise, sleep, smoking, alcohol use, normal weight, receipt of a routine physical, receipt of a mammogram [for women], receipt of a rectal examination, receipt of a pelvic examination [for women], and receipt of a stool blood test); neither did the groups differ with respect to the total number of positive health behaviors. These findings suggest that, at least for caregivers who have access to the extensive health promotion resources of a large health maintenance organization, caregiving responsibility may not always have the deleterious impact on health and health practices that had previously been assumed.⁽³¹⁾

Next Steps. Although this study has been completed, additional research is needed to examine the processes by which caregiving can affect health and health behaviors and to identify those caregivers who are at greatest risk of deleterious health outcomes.⁽³¹⁾

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CONCLUSION

This report is a compilation of some promising programs to support, educate, and motivate caregivers of older persons to maintain and improve their health and functioning. We grouped these “case studies” based on whether they were intervention or descriptive studies and provided information on the sponsor, a description of the program and its results to date, any lessons learned or next steps for the project in question, and a contact person.

We described 13 different projects, funded by federal, state, and local governments, and/or by private organizations. Six of the initiatives were intervention studies, and seven of the initiatives involved descriptive studies. Some of the initiatives involved complex, multi-component epidemiologic studies (e.g., the REACH II Initiative and the Caregiver Health Effects Study) with multiple components (including visits to a physician, educational materials, and telephone follow up) and assessments of caregiver health outcomes. Others focused exclusively on the development and dissemination of information and educational materials (e.g., Making the Link and Powerful Tools for Caregivers Program).

Not all studies found caregiver burden to be as broadly deleterious as had been previously thought, but clearly “at risk” populations/subgroups existed to whom special attention is needed. Potential caregiver risk factors identified by study investigators included advanced age, poor caregiver health, having a number of other responsibilities (including work, child care, and other care recipients), caregiver strain, significant care physical/mental health problems of care recipients, caregiver isolation, and lack of social support.

The Health Promotion and Aging project will conclude with the planning and development of a national conference on health promotion and disease prevention for caregivers of older adults. The conference will be held in the fall/winter of 2003 and attended by a number of researchers, governmental officials, and public health professionals from around the country.

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