

**EASING THE FAMILY CAREGIVER BURDEN:  
PROGRAMS AROUND THE NATION**

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**FORUM**  
BEFORE THE  
**SPECIAL COMMITTEE ON AGING**  
**UNITED STATES SENATE**  
ONE HUNDRED FIFTH CONGRESS  
SECOND SESSION  
—  
WASHINGTON, DC  
—  
SEPTEMBER 10, 1998  
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# FORUM ON EASING THE FAMILY CAREGIVER BURDEN: PROGRAMS AROUND THE NATION

THURSDAY, SEPTEMBER 10, 1998

U.S. SENATE,  
SPECIAL COMMITTEE ON AGING,  
Washington, DC.

The committee met, pursuant to notice, at 2:17 p.m., in room SD-608, Dirksen Senate Office Building, Jeanette C. Takamura, Assistant Secretary for Aging, Department of Health and Human Services, Moderator.

Present: Senator Breaux.

## OPENING STATEMENT OF JEANETTE C. TAKAMURA

Ms. TAKAMURA. If I could just have your attention, I understand that Senator Breaux is on his way. He is in a hearing. Thus, we thought that we would begin this afternoon's forum by introducing our speakers, giving the Senator time to get here.

Perhaps before I introduce our panelists, we should acknowledge some very special people in the audience. We are very honored to have former First Lady Rosalynn Carter here this afternoon. She did an excellent job of testifying at this morning's hearing.

Rosalynn Carter is a woman who is deeply committed to the issues that pertain to caregiving. She is an expert in her own right. She is an acclaimed author and advocate, a role model for all generations. Please join me in acknowledging Rosalynn Carter. I know that Mrs. Carter has to catch a plane later this afternoon. Hence, we certainly are grateful to her for joining us for a few minutes. [Applause.]

We have a number of people present from across the country. We have with us representatives from Florida, if you would raise your hand—well, I think maybe they are on their way, too—from Pennsylvania, Rich Browdie; California, Dixon Arnett, I know you are here; Georgia, Oregon, New Jersey, Arkansas, Connecticut, and I am sure I have missed another State. Excuse me? New York. New York is also here.

We have a number of representatives who have come here as observers, who hopefully will participate in the dialog that will follow.

Welcome. This is an important forum, dedicated to presenting a very compelling issue—family caregiving. Let me introduce our panelists who have come to share their expertise.

On your left, and my right, is Susan Friedman, the executive director of the Grotta Foundation, from South Orange, NJ. The Grotta Foundation is a philanthropic organization which funds national and statewide initiatives to assist family caregivers. Execu-

tive Director Susan Friedman will discuss the national involvement of the grant-making community in the family caregiving field and the need to increase that involvement. Though philanthropic foundations do fund projects which have a very positive effect on families and their loved ones, very few focus specifically on family caregivers. She will discuss the evolution of corporate concern over family caregiving issues.

We have a number of people today who will be presenting the States' perspectives, and one of them is Kathleen Kelly, the executive director of the Family Caregiver Alliance, which is located in San Francisco, CA. The Family Caregiver Alliance is a non-profit organization which contracts with the State of California, Dixon Arnett and his staff, to provide services, information, and education to the family caregivers of adults with brain-impairing disorders. One unique effort by the alliance has been to develop a comprehensive range of services in response to identified caregiver needs regardless of the patient's diagnosis. Thus, they offer information and services that are both standardized and tailored to each caregiver.

Susan Reinhard, who is Deputy Commissioner of the New Jersey Department of Health and Senior Services, from Trenton, NJ, is the Deputy Commissioner of the New Jersey department, and there she oversees the Wellness and Family Support Program, which serves some 2,000 families who care for elderly or disabled relatives in their homes. Services include day-care, homemaker respite services, nursing home placement for short-term needs, and private-duty nursing services. The program, interestingly, is funded by casino revenues.

Senator Breaux just entered the room. I know that he is an extremely busy Senator. We are pleased to be able to welcome him to the podium because he provides tremendous leadership not just on aging issues but for a multitude of issues that impact so many areas of our life. I have had the opportunity to visit the Senator's home State I came away tremendously impressed with his leadership as a policymaker, as well as rapport with his constituents. I have been so impressed with how he works with his staff and the quality of their work.

So it is actually my pleasure to introduce Senator Breaux this afternoon.

#### OPENING STATEMENT OF SENATOR JOHN BREAUX

Senator BREAUX. Well, thank you, Jeanette. [Applause.]

I apologize for not being here on time. We had a vote on the Senate floor. But I want to say to Jeanette Takamura how honored and pleased we are to have her involvement in this program. As our Secretary and leader in the administration on aging, she has been a real leader in trying to focus in on the necessity of people being involved in solving these problems. It obviously cannot all be done out of Washington. In fact, very little can be. But she is really trying to incorporate the real feelings of people throughout the country, and their advice and suggestions and input is incredibly important.

I am also very pleased that Ron Blereau, who is the Deputy Assistant Secretary for our Louisiana Administration on Aging, is also with us. Of course, my wife, Lois, just came back from a lunch-

eon with Mrs. Carter and got two of your books, and you were kind enough to autograph one for her, and we thank you, Rosalynn, very much for your leadership and your work, because what you say and what you do by example can be so inspiring to so many people. It is very, very important.

My wife and I just had our mother-in-law move in with us, and all of my friends have been repeating all the mother-in-law jokes to me. But it works very well, and I think more and more people realize that each generation has to be the caretaker in a very important way with the next generation, our children, but also the previous generation, our parents, and grandparents. All of the things we are talking about here are incredibly important, and I want to lend my support to your actions and activities.

Jeanette, thank you very, very much, Madam Secretary, for your leadership in this area as well. And I thank all of our participants.

Ms. TAKAMURA. Again, I would like to thank the Senator for being here this afternoon. I know how busy he is. We appreciate his leadership and his supportive concern. I have been most impressed with the level of Senator's commitment and the quality of his leadership. It is just really a pleasure and a privilege to work with Senator Breaux.

Senator BREAUX. Thank you.

Ms. TAKAMURA. Let me then complete the introduction of the panel members.

The next person is the Honorable E. Bentley Lipscomb, the Secretary of the Department of Elder Affairs from Tallahassee, FL. I think many of you know that Florida has one of the largest aging populations in the country, and so it is no surprise that the Florida Department of Elder Affairs offers several programs which assist family caregivers. Many of them were developed as offshoots of an AOA respite program created a few years ago. Among them is an extensive respite program created to ease the burden of those who might otherwise fall between the cracks.

Respite for elders living in everyday families or relief include services to caregivers who are not blood relatives or who do not fall in any financial need category. Volunteer respite providers are equipped with knowledge on aging, dementia, first aid, communication, the stresses of caregiving, and other relevant topics. Respite services are available during the evenings and on the weekends, offering more flexibility than similar programs.

I am going to emphasize that these services are provided by volunteers.

Next to Bentley is the Honorable Richard Browdie, Secretary of Aging for the Department of Aging, in Harrisburg, PA. The Family Caregiver Support Program in Pennsylvania is a reimbursement program for family caregivers serving approximately 6,000 families each year.

Two requirements must be met in order to qualify for the program: first, the caregiver must be a blood relative of a frail senior; and, second, the caregiver and care recipient must live together. Reimbursements, which can total about \$200 a month, or about \$2,000 per person, generally cover respite care services, casework services, home modifications, and special equipment. Families also

receive counseling and training, and the aim of the program is to supplement existing care relationships.

Leah Eskenazi is the manager of senior and community programs with Legacy Health Systems in Portland, OR. She will provide us with the local perspective. Legacy Health Systems serves the Portland community with in-home respite services, adult day-care services for Alzheimer's patients, and I think we heard Barbara Boyd speak so eloquently at lunch about the needs of families with persons with Alzheimer's: caregiver education courses, caregiver support groups, a resource library, and rotation for area medical students, and more. Programs are both detailed oriented—that is, they carefully match respite volunteers, again, volunteers, with elderly patients—and they are also creative, for example, participating in Kaleidoscope, an art program which celebrates the creativity of Alzheimer's patients.

Finally, and certainly last, but not least, Connie Ford, who is Vice President of Product Development and Services for AdultCare, located in Deerfield Beach, FL. For those of you who may not be familiar with AdultCare, Incorporated, it is a Fortis-owned company that specializes in providing services to caregivers who are either covered by Fortis long-term care insurance or who care for an individual who is policy holder.

AdultCare functions as an information resource maintaining a national data base of credentialed providers and assisting caregivers in locating community-based services and arranging for things such as home modifications. This particular agency focuses on productive aging and on four things that they think families ought to be thinking about: planning, prevention, positive support, and positive decisionmaking.

These, then, are our witnesses. I expect that we will all learn much from them.

Very briefly, in the back of the room are three overheads with information that you might have heard at the hearing. In the interest of time, I will not be reviewing the charts, but I think we all know and we certainly all appreciate the extent to which caregivers are called upon to give their older and younger family members quality of care.

There are nearly 7 million informal caregivers, mostly spouses, mostly wives, adult children, most daughters, other relatives and friends, who help disabled older persons to remain at home. We know that caregivers assist about 95 percent of all older Americans who need help, and we know that family caregivers are often the sole source of assistance for almost two-thirds of these older persons.

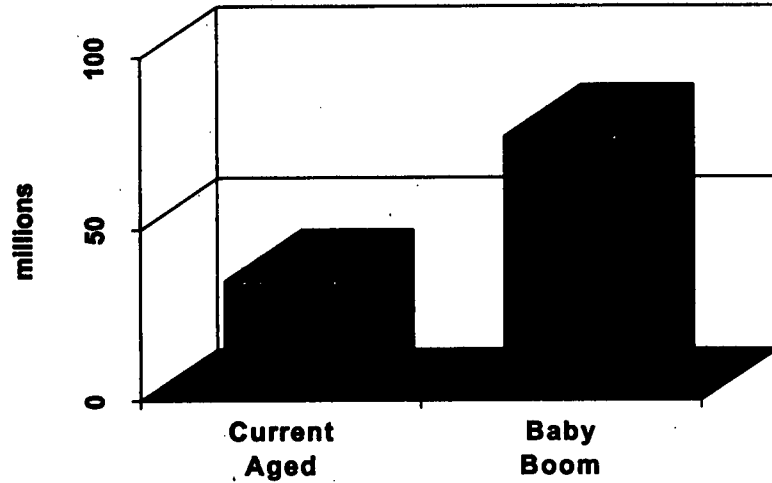
[The chart follow:]

**U.S. ADMINISTRATION ON AGING**

**Readying America  
for Longevity**

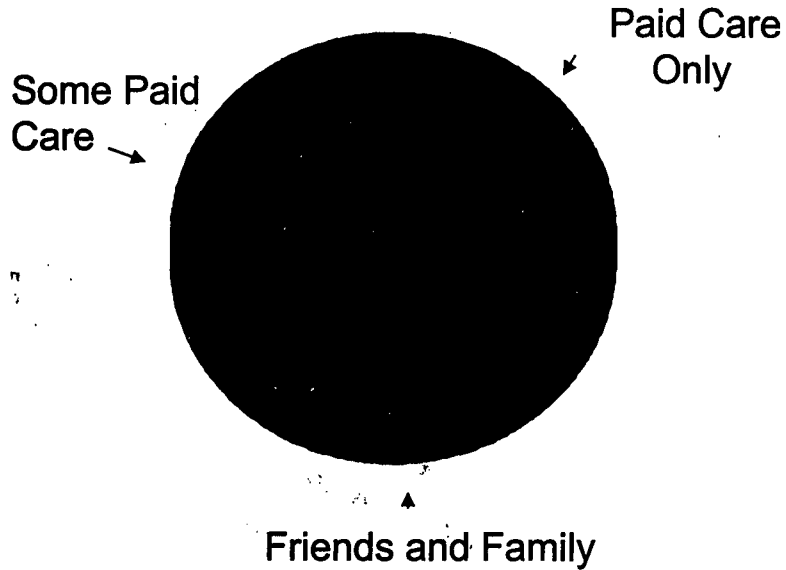


# Baby Boom on the Cusp of Aging



Administration on Aging

# Families Care



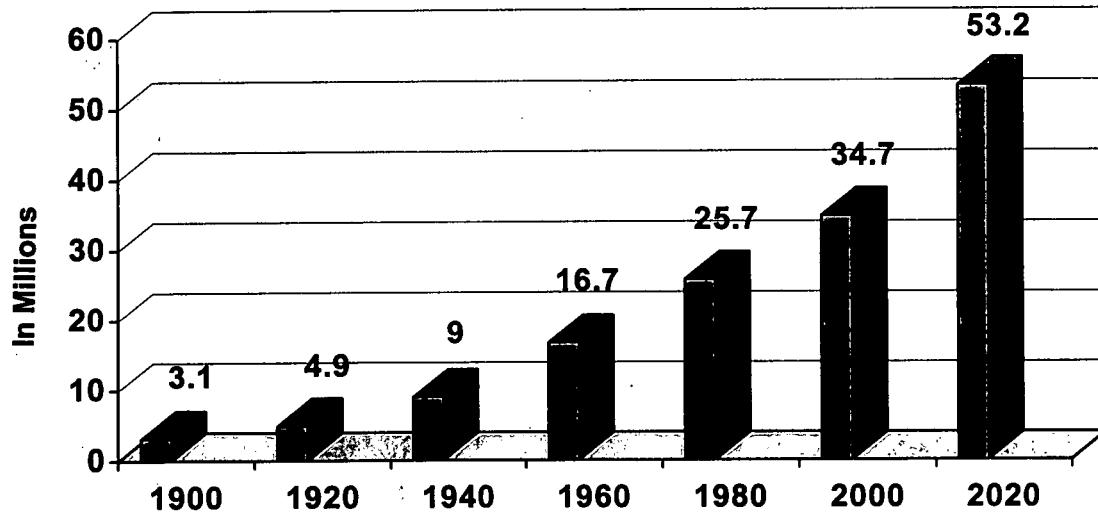
*Increased Stress  
for Families*

*Women: Elderly  
Spouses and  
Baby Boomer  
Daughters*

*Sandwich  
Generation*

Administration on Aging

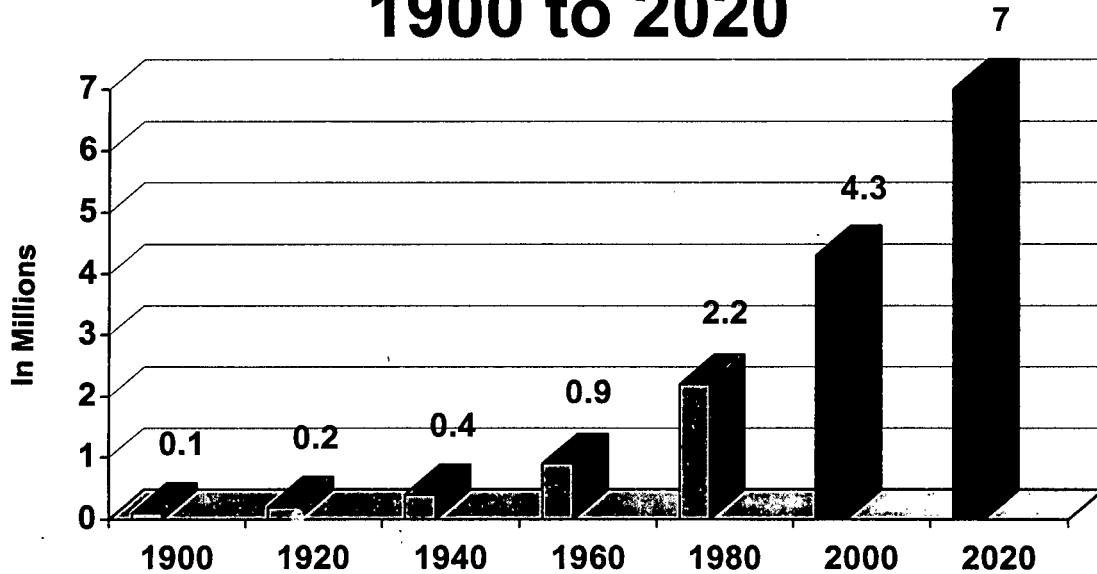
# Number of Persons 65+ : 1900 to 2020



Source: U.S. Bureau of the Census. (1993). *Population Projections of the United States by Age, Sex, Race, and Hispanic Origin: 1993 to 2050*, Current Population Reports, P25-1104.

Administration on Aging

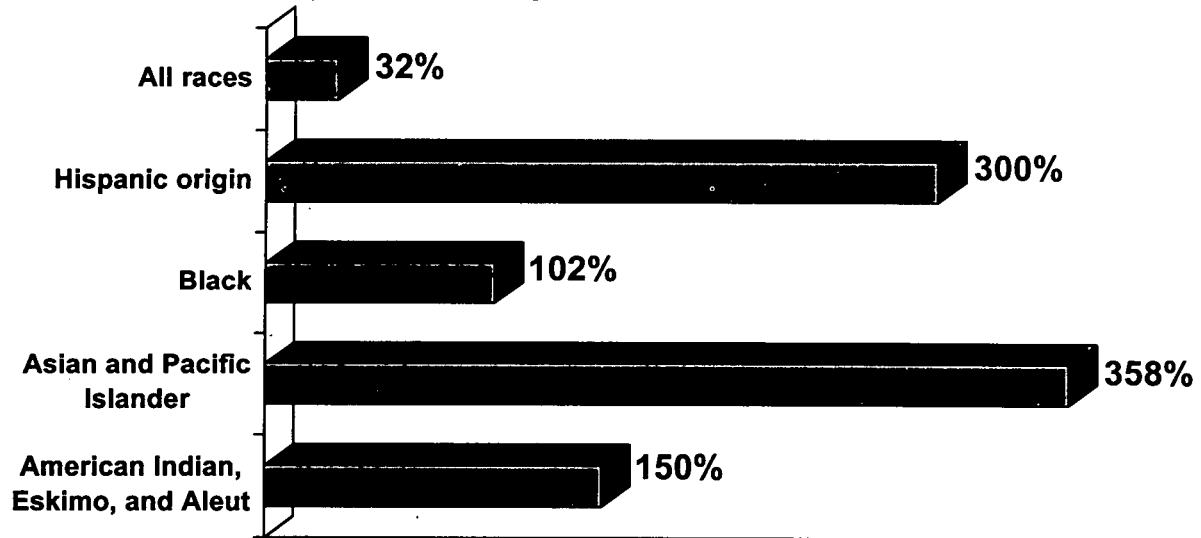
# Number of Persons 85+ : 1900 to 2020



Source: U.S. Bureau of the Census. (1993). *Population Projections of the United States by Age, Sex, Race, and Hispanic Origin: 1993 to 2050*, Current Population Reports, P25-1104.

Administration on Aging

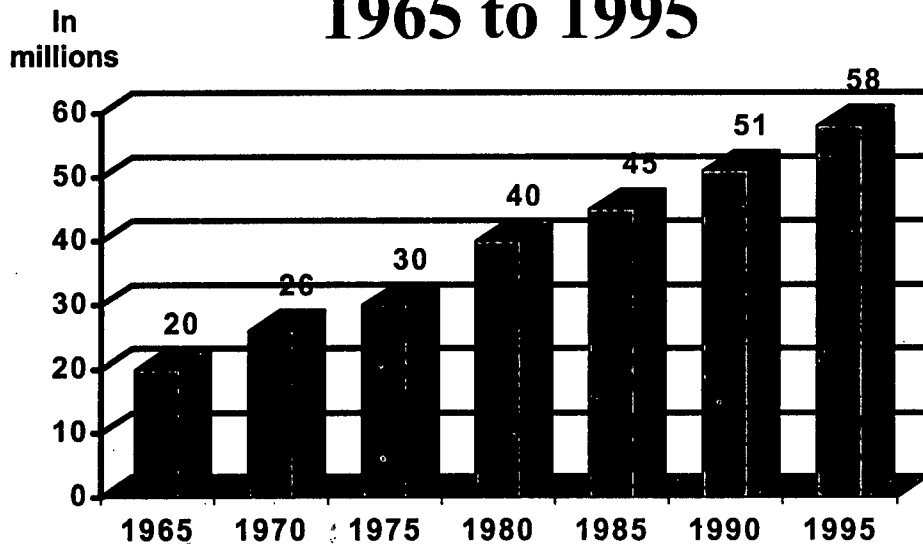
# Population Increase among Ethnic Minority Elderly 65+ : 1990 to 2020



Source: National Institutes of Health. (1996). *Chartbook of Morbidity and Mortality*. U.S. Bureau of the Census. (1993). *U.S. Population Estimates, by Age, Sex, Race, and Hispanic Origin*.

Administration on Aging

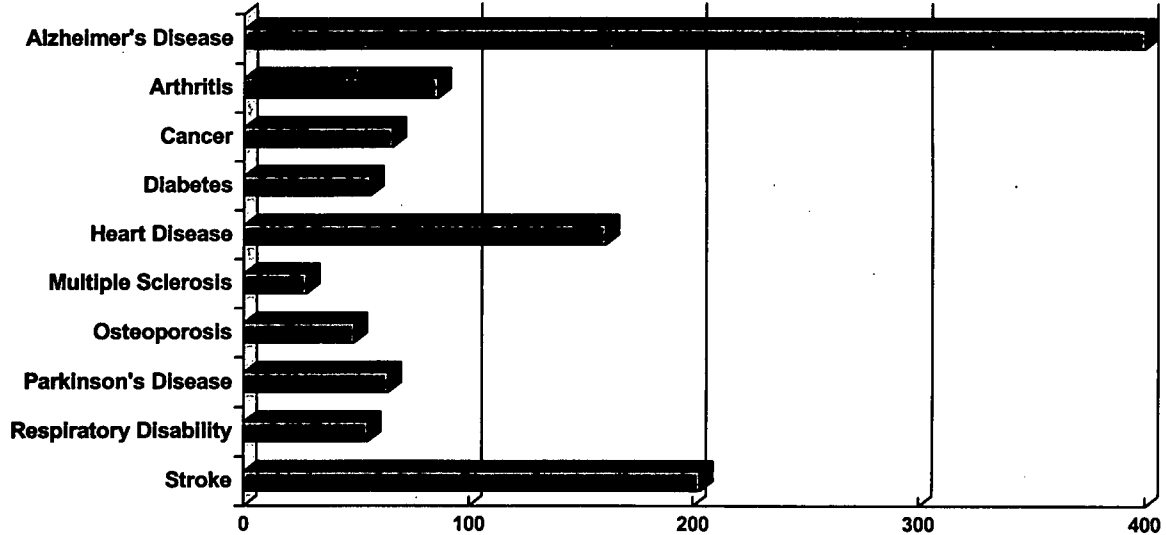
# Number of Jobs Held by Women: 1965 to 1995



Source: Women's Bureau. (1997). *Women's Jobs 1964-1996: More Than 30 Years of Progress*.

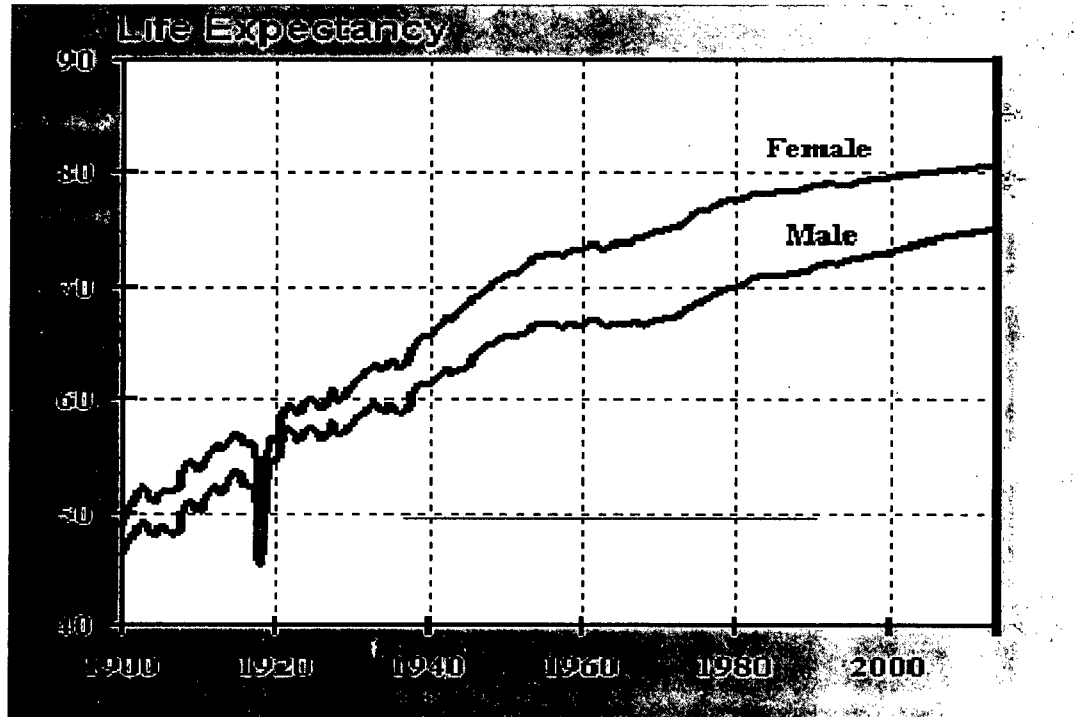
Administration on Aging

# Primary Chronic Conditions of N.J. Respite Enrollees



Source: Division on Aging. (1997). *The 1996 New Jersey Statewide Respite Program*.

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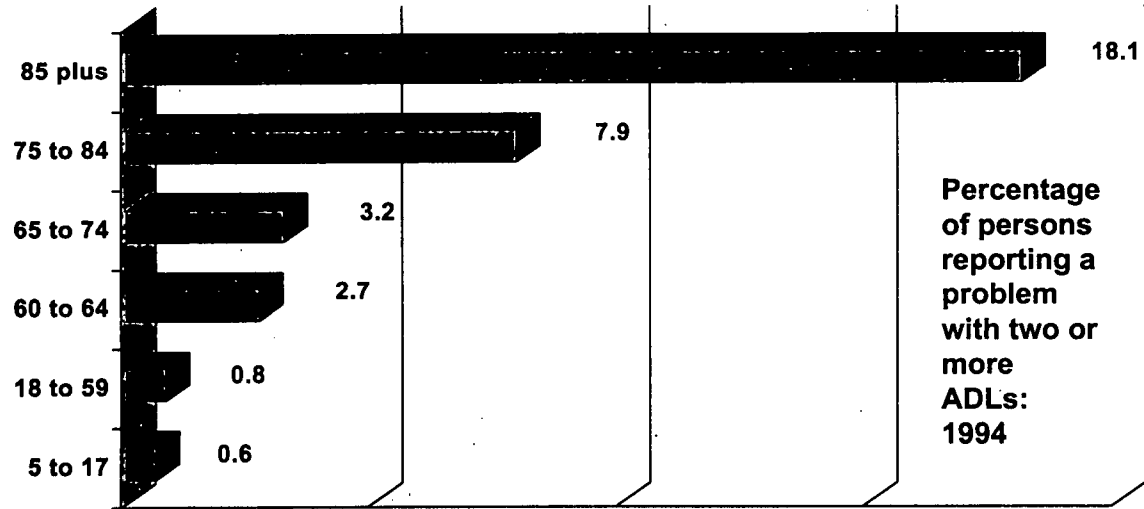


Source: Social Security Administration/Office of the Chief Actuary. (1998). *Social Security Area Population Projections: 1997*.

## Administration on Aging



# The Need for Personal Assistance with Everyday Activities Increases with Age



Source: 1994 National Health Interview Survey on Disability Original tabulations from public use data file.

Administration on Aging

Ms. TAKAMURA. Now, let me call upon Susan Friedman to share with you information that I know all of us will find invaluable. And as she comes to the podium to my left and your right, let me point out that we will be using a timing system that I am well acquainted with. When the green light is on, the speaker can continue. When the yellow light comes on, the speaker has one more minute to go. When the red light comes on, the speaker's time is up.

Thank you.

**STATEMENT OF SUSAN R. FRIEDMAN, EXECUTIVE DIRECTOR,  
THE GROTTA FOUNDATION, SOUTH ORANGE, NJ**

Ms. FRIEDMAN. Thank you, Secretary Takamura, and thank you to the Special Committee on Aging for this opportunity to participate in this very timely dialog on how we can support the irreplaceable role of family caregivers, and a special thanks to Mrs. Carter for her moving remarks this morning and for lending her presence and her name to such an important cause. I really appreciate that. I think we all do.

The Grotta Foundation, was created in 1993 from the sale of a nursing home and in 1997 made the decision through a strategic planning process to focus exclusively on caregiving as our major priority. This was in part because of the compelling demographics that you have all heard about, but also because it was a subject that resonated deeply for the Foundation's board. All of us are, will be, have been caregivers at one point or another.

In creating its agenda, the foundation hoped to draw from models from around the country, both philanthropic and corporate. What we discovered however was, for the most part, caregiving has yet to take its rightful place on the Nation's philanthropic agendas. There are certainly notable exceptions. I am just going to briefly mention them. There are foundations which have made caregiving a major commitment, like Archstone Foundation of California, the Brookdale Foundation in New York City, the United Hospital Fund, certainly, the Jewish Health Care Foundation of Pittsburgh, and the Robert Wood Johnson Foundation.

Now, I am sure, this does not touch on every one, out there and there are corporate names I am going to mention in a moment. But when you consider that there are thousands of foundations in this country, even if I am missing a few, this is a very telling remark.

The corporate response to caregiving predates philanthropy, and initially—and still is, I think, to a certain degree—a human resource/employee productivity issue. Major corporations, like Travelers and Stride Rite and American Express rose to the challenge of the "sandwich generation" by all kinds of employee benefits and support of education over the last decade in order to help employees stay on their jobs. More recently, a few corporations and their foundations have supported caregiving initiatives out of the public interest and to support their communities. They are, most notably, Equitable through its Linkages campaign and its very highly respected Caregiver Guide, and Pfizer as a partner with NCOA, the National Council on Aging, in their Innovations in Independent Living this year, which focuses on caregiving. Because there were so few models to draw from the Grotta Foundation elected to take

a broad-brush approach to its initial funding. As a result, we are now supporting 18 caregiving-related projects at the local, State, and national levels.

Even in our first year—this is just our first year—we have learned quite a bit.

First, what we have learned is that, as you probably all know, most caregivers are not corporate employees who do not have access to the benefit of major corporations, and many of them are not even adult children, who have been the main focus of the media and industry. In fact, many caregivers are spouses and have problems of their own physically, and emotionally. What is the impact on a marriage when one member of a couple has to assume the role of caregiver for the other?

One of our grantees, Main Street Counseling, has developed a special outreach to spousal caregivers. It provides marriage counseling and peer support to help these older couples deal with the changing roles and responsibilities inherent in the caregiver relationship.

Caregivers, as you have heard earlier, can also be grandparents, some of them raising their grandchildren because of pandemics of AIDS and drugs. What happens to these grandparents when they are also caring for a spouse who is in need or an elderly parent? Another of our grants to the Salvation Army focuses on multigenerational caregiving and offers a variety of tailored services to those families.

Another emerging demographic—and I was excited to hear that there is going to be a hearing on this, I think in about a week or two—is the aging-in of the developmentally disabled population. These individuals now survive into their 50's, 60's, and beyond, and, therefore, their caregivers, usually their parents, are in their 70's, 80's, 90's. The question of who is going to take care of my child when I die takes on great poignancy and urgency with these people. The aging service and developmental disabilities communities need to unite around advocacy positions—I know they have begun to do this—to look at this new dimension of caregiving. Two of our grants are now looking at different approaches, one educational, one around care coordination, to try to help families maintain their critical roles.

What do caregivers need—to maintain their roles?

Well, we have been looking at that. They certainly need respite, and I am not going to touch on everything, but respite is certainly an interest of ours, in all of its permutations, and with adult day-care, at its cornerstone.

We support the expansion of social model day-care through our partnership with the Brookdale Foundation's National Group Respite Program for Alzheimer's Families, which is in 30 States and now in New Jersey with our support. We also support a number of special initiatives. One is The Club sponsored by Senior Care and Activities Center of Montclair. It is an adult day-based, early intervention program for Alzheimer's victims and their caregivers. The Club helps family members acclimate to the knowledge that their loved one has an Alzheimer's Disease which is a tremendous shock to any family. It also has become a central access point and

focal point for education, assessment, information, support, forestalling crises, hopefully, before they happen.

As we all know, caregiving is a 24-hour day or, as Marian Roach has written, a 36-hour day, and planning for respite services must take that into account. One of our recent grants extends day-care into evening care a few hours a month, so that working caregivers can attend support groups without worrying about who is going to be watching their spouse or parent. There is a very unique program in the Hebrew Home for the Aged in Riverdale which takes this concept to the next level, called Elderserve at Night Program. There, Alzheimer's victims who no longer sleep at night—which is a middle-stage Alzheimer's disease problem—are cared for while their caregivers get a good night's sleep and, therefore, can help care for them during the day.

This Nation needs to rethink its commitment to adult day services, and at the same time, we must explore long-term funding mechanisms that make day-care affordable for the average American.

In 1996, the Grotta Foundation, along with five corporate funders, supported the National Council on Aging's association of day-care providers in a blue ribbon task force, which developed universal standards and guidelines for adult day services.

With the publication of those guidelines in 1997, we feel the Government now has to turn to managed care and corporations to fill in the gap.

I am going to skip a few parts I had hoped to make because of the time and just say a few other things. Homecare, of course, is something that we are very interested in, affordable quality, homecare that is sensitized to the need of caregivers. A Grotta funded program of the Jewish Vocational Service (JVS) of Metro-west trains homecare providers in how to work with caregivers.

Another one of our grants brings homecare education and caregiver education into the home so that therapeutic programming that happens in day-care setting, like music therapy, art therapy, can be taught to caregivers so they can carry out these activities at home.

We would like to see the caregivers as an integral part of the treatment team. You heard about the NYU project from Dr. Mittelman this morning. Grotta is funding NYU to develop a caregiver guide on how families of dementia patients can help their family member through the hospital experience. The hope is that such family intervention will also reduce the number of days that the Alzheimers victim is in the hospital, which is so dramatically longer than the non-dementia patient.

Last, we are looking to develop new resources. We have a particular interest in faith-based communities and feel their potential has been overlooked. We are funding pilot programs in congregations. As a surrogate family, a source of mutual support and pastoral outreach, congregations, regardless of denomination, can make great impact here.

On October 27 the Grotta Foundation is sponsoring a conference "Putting Elders Back on the Congregational Agenda", and at that conference, the Winter Park Health Foundation, will be presenting a model caregiver education curriculum, specifically targeted to

faith-based organizations which we hope to bring to New Jersey. Through this initiative and other such efforts we hope to harness the resources of faith based communities on behalf of our communities caregivers.

So, in conclusion, I would like to say that the Grotta Foundation believes that caregivers of the elderly, are a national treasure, and their collective selflessness in providing continuing care for the Nation's old and frail has spared our society a staggering financial burden. Without the extraordinary contributions of ordinary people, the security of life and the quality of life that we have in this country would be greatly diminished.

I am just going to end by quoting Elizabeth Cady Stanton who noted that the prosperity of a society can be judged by the way it treats the elderly. I would suggest that the way we support those who care for the elderly will also define us in our future.

[The prepared statement of Ms. Friedman follows:]

**GROTTA**

**Foundation for Senior Care**

**"EASING THE FAMILY CAREGIVER BURDEN:  
A PHILANTHROPY'S PERSPECTIVE**

**Presented by  
Susan R. Friedman  
Executive Director  
The Grotta Foundation for Senior Care**

**To  
The Senate Special Committee on Aging**

**September 10, 1998**

Thank you Secretary Takamura, And thank you to the Senate Special Committee for providing a forum for these very timely deliberations, on how we might strengthen and support family caregivers in the critical and irreplaceable roles they play in our society.

The Grotta Foundation was created in 1993 from the sale of the Grotta Center for Senior Care, a non profit nursing home and rehabilitation facility with a 75 year tradition of compassionate care for the elderly. In 1997, through a process of community based needs assessment, and strategic planning the Foundation identified a board definition of caregiving for the elderly as the priority focus of its grantmaking. Caregiving was selected by the Foundation's Board not only because it is an area of need, compellingly supported by this nations emerging demographics, but also because it is a subject that resonated deeply for them on a personal level. For in truth most of us have been, are, or will be caregivers at some point in our own lives.

In creating its own agenda, the Foundation hoped to draw from role models in the philanthropic and corporate worlds. What is discovered however was that for the most part, caregiving for the elderly has yet to take its rightful place on this nation's philanthropic agendas. Some notable exception of course include the Archstone Foundation of California which has most recently issued a three year national funding initiative to "identify new solutions and forge new partnerships that meet the unmet needs of caregivers" the New York City based Brookdale Foundation, which for the past 10 years has funded a National Group Respite Program for Alzheimer's Families, now in 30 States (most recently through a partnership with Grotta in New Jersey) The Jewish Health Care Foundation of Pittsburgh, which looks at caregiving from the perspectives of a women's health, and elder abuse prevention, the United Hospital Fund, with its Families and Health Care Project described earlier today, and the Robert Wood Johnson Foundation's with its faith based volunteer caregiver initiative "Faith in Action." Although this list is I am sure not all inclusive, it is very telling nonetheless when you consider the thousands of foundations that exist in this country.

The corporate response to caregiving predates philanthropy's interest and was initially considered a human resource /employee productivity issue. Major corporation, Travelers, Stride Rite, America Express to name some early leaders, rose to the challenge of the "sandwich generation" by creating a range of employee benefits, EAP caregivers stay on the job. More recently a number of corporations have begun to address the overall human cost of caregiving, and have supported initiatives as a public service to education through the publication and broad dissemination of a practical guide for caregivers. "Aging Parents and Common Sense", and through its Linkages campaign that reaches out to allied health professionals who come into regular contact with caregivers, and who can help connect them to services, "Pfizer Inc. has also taken a proactive role, in partnering with the National Council on Aging in a nations Request for Proposals.

"Innovations in Independent Living" to foster original solutions to the challenges faced by care givers.

Given the existing State of the Art, the Grotta Foundation elected to take a broad brush approach towards care giving in its initial funding. As a result it currently is supporting 18 care giving related projects at the local, state and national levels.

Even in its first year the Foundation has already learned much to guide it in the future.

First, it has found that most care givers in this country are not corporate employees, and significant

numbers are not the adult children, who have been industry's focus. In fact, many care givers are spouses, who have impairments of their own. What is the impact upon a marriage when one member of a couple must assume the role of caregiver for his or her spouse? Through a Grotta grant, the Main Street Counseling Center of West Orange, New Jersey is looking at this question. It has developed a special outreach to spousal caregivers in senior housing. Through marital counseling and peer support the project helps these older couples work out issues in their marriage that arise because of changing roles and responsibilities inherent in the care giving relationship.

Caregivers can also be grandparents. Today particularly in urban settings, too many of these grandparents find themselves called upon to raise grandchildren, orphaned by the AIDS and drug pandemics. Both the Brookdale Foundation and Hunter College's Brookdale Center on Aging have been leaders in bringing the needs of these at risk families to nation attention. What happens however, when these grandparents are also the care givers of a elderly spouse or parent/ A Gotta grant to the Salvation Army's Grandfamilies Program focuses upon these multigenerational care giving situations offering a panoply of supports to these beleaguered families.

Another emerging demographic is the "aging in" of the developmentally disabled population. These individuals now often survive into their 50's 60's and beyond - their care givers generally are parents whose ages span the 70's to 90's. The question "who will take care of my child when I die" is one of great poignancy and urgency. It poses both a challenge and an opportunity for the aging service and developmental disabilities communities to combine resources, and unite around advocacy positions important to this new dimension of caregiving. Grotta grants to JESpY House of South Orange and the ARC of Union County respectively look at an educational and service coordination approach to helping these elderly caregivers and their adult children plan for their futures.

What do caregivers need from our society to help them maintain their critical roles?

They certainly need respite in all of its permutations, with adult day care at its cornerstone Grotta supports the expansion of social model day care through its partnership with The Brookdale Foundation, and funds a variety of special initiatives within existing programs in New Jersey. A Gotta grant to the Senior Care and Activities Center of Monclair has established "The Club" an adult day care based, early intervention program for early stage

Alzheimer's victims and their caregivers. The Club helps members acclimate to their new and demanding caregiving roles. It has also become a central access point for assessment, education, information, support, and respite.

As we all know caregiving is a 24-hour a day commitment. Planning for respite services must take this into account. A grant to Muhlenberg Adult Day Care Center extends day care to several hours of evening care. This allows for working caregivers to attend support group meetings without worrying about the welfare of their family member. A very innovative program at the Riverdale New York based Hebrew Home for the Aged takes the concept to its next logical level with its Elderserve at Night Program. Here Alzheimer's victims who no longer sleep at night - a frequent symptom of the disease in its middle stage - receive over night care, while their caregivers get a good night sleep.

This nation needs to rethink its commitment to Adult Day Services. At the same time it must explore long term funding mechanisms that makes adult day care an affordable option for the



average American. In 1996 the Grotta Foundation along with five corporate funders supported the National Adult Day Services Association in convening a Blue Ribbon Task Force - its goal to develop universal standards and guidelines for adult day services. With the standardization of quality care and the publication of the guidelines in 1997, it is now time to look not only to government but also to the managed care industry and corporate America for a financial commitment that allows adult day services to take its rightful place in the continuum of care.

For many caregivers however care begins and remains at home. The availability of affordable, quality home care is without a doubt the lynchpin of any home based caregiving plan. What is needed is a home care workforce that is sensitized to the issues facing caregivers and the stresses of the caregiving situation. A Grotta funded project of the Jewish Vocational Service of Metro West recruits mature adults, many of whom have personal experience of caregiving and trains them as certified home health aides. The curriculum specifically addresses the role of the home health aide in relation to the caregiver and reinforces the concept of a care partnership between the caregiver and aide.

In addition several Grotta grants have experimented with creative ways to bring a variety of the therapeutic services offered in the day care setting into the home through caregiver education and training.

The Alzheimer's Association of Northern New Jersey has created "At Home with the ARTS", a 12 week art and music therapy program designed to stimulate mental functioning in Alzheimer's victims. The staff trains family caregivers to carrying out the therapeutic regimen so that they can continue it themselves. Telephone consultation and institutional materials support the caregiver's efforts. Using the same caregiver education principle, Family Services of Morris County, brings occupational and recreational services to mentally intact frail elderly and maintains project community through training and support of the recipient's family or professional caregiver.

Including the caregiver as an integral part of the treatment team has become a repetitive theme of Grotta's funding. This partnership extends from the physician in the hospital to the paid home care provider in the home.

Earlier to day, Dr. Mary Mittleman of NYU's Alzheimer's Disease Center presented findings of the Center's longitudinal caregiver study. One of the lessons learned over the course of the study has been the hospitalization of a dementia patient poses unique difficulties for caregivers, patients and hospital staff. With a grant from Grotta, the Center has begun work on a handbook that will educate caregivers to the ins and outs of hospital care for the dementia patient and guide them in how to become an effective advocate within the hospital system. An educational program for hospital staff on how to involve the caregiver in the treatment plan is also in the works with the support of the Untied Hospital Fund. Ultimately the goal is to establish special hospital based case management teams that will work with families and hospital staff together to improve the hospital experience for these high risk elderly.

Grotta has also directed its funding to developing new resources for caregivers to reduce their isolation and burden.

One area of opportunity often overlooked by planners and policy makers alike is, the wealth of volunteer resources and other supports which faith based communities can offer to ease the plight

of caregivers. Through a special Grotta initiative Synagogue HOPE (Help, Opportunities and Programs for Elders) the Foundation is funding pilot programs in local congregations to identify the special role that they can play in enhancing and improving the lives of older adults and their caregivers. As a surrogate extended family, and the locus for mutual support, pastoral outreach, and life cycle celebration, congregations of all denominations have a unique potential to reach and positively effect the lives of caregivers and the elders in their care. On October 27, 1998, The Grotta Foundation will sponsor a conference "Putting Elders Back on the Congregational Agenda" which will explore these issues and areas of opportunity.

Presenting at the conference will be the Winter Park Health Care Foundation on a pilot caregiver education curriculum created specifically for use by faith based organizations. This model is designed to be volunteer driven and delivered through congregational consortium that would pool their resources and share their experiences.

Older people themselves are an unplumbed resource who are often uniquely qualified to offer caregivers solace and support. A very successful grant to the Alzheimer's Association has provided caregivers with specially trained and supervised senior volunteer companions, who reinforce the project's care coordination services and provide the caregiver with a supportive presence in the home.

Clearly we have only just begun to fully comprehend the many dimensions of caregiving and the implications that these have for our future. This hearing and forum represent a very commendable step in that important direction. However much more work must be done to bring the various sectors of our society together around a commitment that ensures a dignified old age for all Americans. That is why the Grotta Foundation is pleased to join other funders in support of the National Health Council's first Consensus Development Conference on caregiving. This landmark event scheduled for this December will engage government leaders, practitioners and individual caregivers in developing concrete recommendations to integrate family caregiver services within the formal health care system.

Caregivers of the elderly should be viewed as national treasures. Their collective selflessness in providing continuing care for this nation's old and frail has spared our society a staggering financial burden. Without the extraordinary contribution of ordinary everyday people, the quality and security of life that we hold so dear in this country would be dramatically diminished. Elizabeth Cady Stanton once noted that the prosperity of a society can be judged by the way in which it treats its elderly. I suggest that the way we care for those who give care also will define us for future generations.

Thank you.

Ms. TAKAMURA. Susan, thank you very much. I just want you all to know that Chairman Grassley, Senator Breau, and the members of the committee have indicated that we will be able to receive our panelists prepared text as the committee will be issuing a report. They would like to invite any of you who might be interested to submit comments to the committee for inclusion in the report. I believe they must receive these comments no later than 2 weeks from today.

Let me invite Kathleen Kelly to the podium.

**STATEMENT OF KATHLEEN A. KELLY, MPA, EXECUTIVE DIRECTOR, FAMILY CAREGIVER ALLIANCE, SAN FRANCISCO, CA**

Ms. KELLY. Good afternoon. It is really an honor to be here to address the Senate forum today. I am very pleased to participate in a national discussion, which is examining just not the needs of family caregivers, but models that are already in place at the State level to assist families who care for loved ones with chronic illnesses and disabilities.

My role is to tell you a little bit about the Family Caregiver Alliance and its affiliates of the Caregiver Resource Centers operating throughout the State of California.

We began as a grassroots effort. There are many stories about how one individual effort really makes a difference, and it was very true in our genesis as well. Ours was a story of one woman who could not find a nursing home placement for her husband who had Alzheimer's disease, although in the mid-seventies it was not called that. This story came to the attention of a task force of the Mental Health Association in San Francisco, and they started holding public meetings about the issues of caregiving. Unfortunately, I will use the term "woodworking effect" because people came out in droves. These meeting received a lot of public attention because caregiving was taking place in the middle 1970's, as well, and this was really the first time that attention was starting to be paid to this issue.

It caught the attention of the Department of Mental Health that funded a study in 1978. The study made recommendations for caregiver support at that time which spanned from diagnosis to nursing home placement. The study caught the attention of Assemblyman Art Agnos from San Francisco. Family caregiver alliance asked him to introduce legislation, AB 1043 chapter 1058, 1979 statutes in 1979, to pilot test a model of support services dedicated to families caring for a loved one with an adult-onset impairment, such as Alzheimer's disease, stroke, Parkinson's, traumatic head injury, occurring after the age of 18.

The pilot project was awarded to Family Caregiver Alliance. We developed a core package of services, which I will speak to in a moment, and delivered and refined these services for 3 years starting first in San Francisco and then radiating out into the other Bay Area counties. But we were getting calls from all over the State, as you can well imagine.

In 1984, we asked Assemblyman Agnus to introduce AB 2913 chapter 1658, 1984 statutes as amended which would accomplish two major goals. First, to establish regional services, through the

location of resource centers similar to the pilot project we were operating in San Francisco, in each major geographic region throughout the State in order to provide a single-entry information network. Second, the legislation provided for statewide coordination through the establishment of a statewide resources consulting role to the Department to oversee aspects of the new law that were statewide in nature. The legislation was entitled the Comprehensive Act for Families of Caregivers of Brain-Impaired Adults and it established the Caregiver Resource Center system of 11 centers covering all 58 counties of the State.

The range of services that are offered under a Caregiver Resource Center are this: A specialized information advice and referral to services, offered directly by the CRC or in combination with other community services that knit together the kinds of care and care plans that families are looking for.

We also provide a uniform assessment administered in the family caregiver's home. It identifies and records specific caregiver problems, the care recipient's functional problems, the caregiver's perceived burden, the extent to which caregivers' personal, social, and emotional well-being are affected by caregiving, determine the impact of caregiving on the caregiver's physical and mental health, and collect demographic data to develop a statewide data base on caregiving.

The assessment helps in putting together a care plan which is done through a family consultation process. Staff goes into the home to assess the situation and begin a long-term relationship with a family. We rarely will lose clients, we just hear from them when the situation changes. It is not unusual to have clients that we have been working with for 10 years or more.

We offer short-term counseling because we found many of our caregivers show signs of clinical depression. We offer one-time legal consultations with a panel of attorneys under contract with us who are specialists on elder care law; estate planning and public benefits eligibility. We provide education and training targeted to ethnic populations and rural populations that are especially hard to serve. We offer support groups and highly structured psycho-educational programs that teach skills to caregivers to manage anger or frustration to better care for their individual. We also offer and broker respite services, which is a large component of our budget.

The respite program offers financial assistance for a flexible array of service options. Using a capped voucher model, families are free to choose the type of service that is best for them, whether it is in-home, day care or short-term overnight stays.

Briefly, I would like to touch on some trends in the data that we have seen over the past 5 years that are interesting to consider. Please note that the demographics of our population is not much different than the caregiving statistics you have heard today.

Our caregiving population is changing. We now see more adult children than before. Adult children are stepping into the roles of primary caregivers. That means that adult children are most likely to be working outside of the home particularly in urban areas such as the San Francisco Bay Area and Los Angeles County.

We are seeing an increasingly ethnically diverse caregiving population in California and need to tailor our services accordingly.

Caregivers are also reporting that they are less likely to receive help from their own friends and family. Finally, the care recipients are more likely to be enrolled in managed care programs.

There are many other issues covered in the written testimony. In closing, I would like to be the bearer of good news to Washington this afternoon and let you know that during the last State budget process, which ended in August, the Caregiver Resource Center system received a \$4 million increase, effectively doubling the size of the program in the state to over \$9 million. I thank you for your attention today.

[The prepared statement of Ms. Kelly follows:]

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## **Easing the Family Caregiver Burden: Programs Around the Nation**

**September 10, 1998**

**United States Senate, Special Committee on Aging  
Washington, DC**

**By:**

**Kathleen A. Kelly, MPA  
Executive Director  
Family Caregiver Alliance  
San Francisco, CA**

**PROGRAMS**

- BAY AREA CAREGIVER RESOURCE CENTER
- STATEWIDE RESOURCES CONSULTANT
- ETHNIC OUTREACH PROGRAM
- RESEARCH AND POLICY DEVELOPMENT
- COMMUNITY EDUCATION

Good Afternoon, my name is Kathleen Kelly and I am the Executive Director at the Family Caregiver Alliance in San Francisco. It is an honor to be here to address this Senate Forum today. I am especially pleased to participate in a national discussion which is examining not just the needs of family caregivers, but models already in place at the state level to assist families who care for loved ones with chronic illnesses and disabilities. In particular, my role here is to describe Family Caregiver Alliance (FCA) and its affiliate system of Caregiver Resource Centers (CRCs) in California.

*How Did Family Caregiver Alliance Begin?*

Family Caregiver Alliance (FCA) began as a grassroots effort by a small group of San Francisco families and concerned professionals during the mid 1970's. The plight of one local woman, Anne Bashkiroff, helped launch California's statewide service system. In a time before Alzheimer's disease was a household word, Mrs. Bashkiroff struggled in her own private hell trying to understand and meet the enormous care demands of her husband who, following surgery and high fever had become confused, disoriented and unable to work. Mr. Bashkiroff received a diagnosis of "pre-senile dementia" from a neurologist—and Mrs. Bashkiroff received the news that the disease was progressive, untreatable, and beyond the scope of the neurologist's practice. She returned home with her husband and suffered through the full spectrum of emotional, physical, and financial despair now familiar to millions of Americans who have viewed documentaries and other public awareness efforts on Alzheimer's disease.

In 1976, a community volunteer learned of Mrs. Bashkiroff's unsuccessful efforts to locate a nursing facility for her husband and offered to bring Mrs. Bashkiroff's story to a local mental health organization. Upon hearing Mrs. Bashkiroff present her case, a task force, calling itself Family Survival Project, was convened to examine the problem of middle income families coping with chronic care for adults with irreversible brain impairments. Families like the Bashkiroff's were confronting similar situations elsewhere, and many were seeking help from over-stressed health, mental health, and social service providers. But the approach chosen by the task force to respond to problems in San Francisco was unique in the United States.

The task force consisted of family members with relatives who suffered from a variety of brain disorders (e.g., degenerative dementing illnesses, aneurysm, Parkinson's disease, and traumatic brain injury). Other task force members included an attorney, a psychotherapist, and a psychiatrist. In 1977, the task force sponsored a community meeting receiving considerable press attention both locally and nationally. Additional meetings were held with agency administrators and public officials. The public attention drew hundreds of inquires from throughout the U.S. and Canada. As a result, public officials informed the task force that the problems they were attempting to address would extend far beyond the abilities and jurisdictions of local service agencies.

Drawing on broad grassroots support generated by their public awareness activities, the task force members began calling on officials in the State Capitol and in Washington, DC. The result was a special grant in 1978 through the California Department of Mental Health to determine the number of individuals with adult-onset brain damage and available services; to establish a support network of families and conduct a public awareness campaign; and to publish a handbook on legal and financial information. Among the most significant task force findings was the dearth of services available for families caring for brain impaired adults.

The task force got support from a local state legislator (former Assemblyman Art Agnos) to sponsor legislation (AB 1043) to pilot test a model of support services dedicated to families caring for a loved one with an adult-onset brain impairment (e.g., Alzheimer's disease, stroke, Parkinson's disease, traumatic brain injury). FCA applied for the pilot project funds after the legislation was enacted and was awarded the contract in 1980. Under the administration of the California Department of Mental Health, the pilot project, which developed a core package of family caregiver support services, was tested for three years. At the end of 1983, the pilot project was deemed to be a success and had documented an extensive need for a coordinated, comprehensive, and affordable service package for family caregivers.

FCA then asked Mr. Agnos to introduce legislation (AB 2913) that would accomplish two major goals: 1) *Regional Services*. The location of resource centers similar to FCA's pilot program in each major geographic region throughout the state in order to provide a single-entry information network; and 2) *Statewide Coordination*. The establishment of a Statewide



Resources Consultant role for Family Caregiver Alliance, under contract to the state, to oversee aspects of the new law that were statewide in nature. The resulting landmark legislation was called *The Comprehensive Act for Families and Caregivers of Brain Impaired Adults* (Chapter 1658, 1984 California Statutes, as amended).

The new law was passed in 1984 to establish a statewide system of Caregiver Resource Centers (CRCs) which replicated FCA's pilot project. Over a period of four years, 10 additional Caregiver Resource Center (CRC) sites were phased-in so that in 1989 a full complement of 11 CRCs were designated in all regions of the state. All CRCs are non-profit organizations under contract to the Department of Mental Health and all are modeled after the San Francisco pilot project. Moreover, Family Caregiver Alliance (formerly Family Survival Project) as the original Caregiver Resource Center was given an additional role under the new law to serve as the Statewide Resources Consultant (SRC). In this capacity, the SRC assists the Department of Mental Health in statewide program development, data analysis and reporting functions, and technical assistance to the 11 CRC sites. The SRC also operates an information clearinghouse on adult-onset brain impairments and caregiving issues, conducts education and training, and carries out applied research.

#### *The Range of CRC Services*

Today, the CRC system provides an array of caregiver support services including:

**Specialized Information advice and referrals** to help families understand the nature of a brain disease, prognosis and how to cope with functional and behavioral problems associated with brain disorders. Basic information is also provided on legal and financial issues, long-term care planning, and community resources.

All family caregivers who require assistance beyond basic information receive a uniform assessment administered at the family caregiver's home. Assessment methodically and uniformly identifies and records specific caregiver problems and assists both the CRC staff and the caregivers in determining the most appropriate type and mix of services. Assessment seeks to: determine the care recipient's functional problems; determine perceived burden, that is the extent to which caregivers' personal, social and emotional well-being is affected by caregiving; determine the impact of caregiving on the caregiver's physical and mental health; and collect demographic data to develop a statewide database on caregivers and brain impaired

adults. Once the assessment is completed, the CRC staff work with the caregiver to develop a care plan for the most appropriate type and mix of CRC family support services, based on the caregiver's identified service needs. Caregivers are reassessed at six-month intervals as long as the need for assistance continues.

**Family Consultation** is used to help caregivers develop and implement a personalized care plan. CRC staff, called "Family Consultants," assist families in making difficult decisions, problem-solving, and coping with stress. Through family consultation, caregivers learn how to manage difficult behaviors in the persons they care for, how to make their homes safe for their impaired relative, and practical skills (e.g., for lifting or bathing a non-ambulatory person). In addition, caregivers learn strategies to cope with their frustration, anger, or isolation.

For those caregivers shown to have high levels of depressive symptoms, CRCs provide short-term counseling. Under the leadership of FCA, the CRC system has developed a six-session structured counseling protocol which helps caregivers address psychosocial issues related to the caregiving role (e.g., feelings of hopelessness, guilt, or anxiety). Depending on the needs of the family caregiver, trained licensed clinicians help caregivers to "work through" difficult issues such as role reversal, sexuality and intimacy with a demented spouse, or fears/guilt associated with the move—or possible move—of a loved one into a nursing home.

One-time legal consultations are used to help families sort through complex legal and financial issues including surrogate decision-making and advance directives, conservatorship, estate planning, and public benefits eligibility. CRCs subcontract with attorneys specializing in eldercare and estate planning to help families prepare durable powers of attorney for health care (DPAHC). When possible, advance planning can save families time, money and heartache by avoiding a costly and time-consuming court-ordered conservatorship process.

**Education and training** events are useful vehicles for promoting public awareness and reaching caregivers in their own communities to provide caregiver-specific training. Training events are conducted regionally throughout the state as a means of educating families about the course of a disease, care techniques, current biomedical research breakthroughs, legal planning issues, long-term care options, and self-care/stress reduction strategies. Annual rural trainings on Alzheimer's disease bring current research and other information to underserved rural

communities and individually-tailored trainings are conducted for professionals, volunteers and allied health providers, such as nursing home staff and home health aides.

CRCs sponsor support groups for families, caregivers and brain-impaired adults, such as concurrent groups for individuals with early-stage dementia and their caregivers, a peer group for brain injury survivors, and an on-line caregiver support group through the FCA website. In addition, a number of the CRC sites conduct psychoeducational groups which are structured eight or ten-session classes used to teach caregivers skills to manage anger or frustration.

Respite care for families offers financial assistance for a flexible array of respite service options. Monthly respite vouchers are provided through subcontracts with local home care agencies, adult day programs, or facilities offering overnight respite. Or, families may choose a *direct pay* option, where they receive a cash subsidy (capped at \$425 per month) to hire an independent provider to provide in-home respite care. The CRC respite program maximizes consumer choice by letting families select the option(s) which best fit their needs. In addition, CRCs across the state sponsor periodic weekend respite "camps" and retreats, often targeting families on their respite waiting lists.

***How Was The Service Need Identified?***

As mentioned earlier, a San Francisco Task Force was formed in 1977 to more closely examine the problem of adult-onset brain disorders. Among the charges of this pioneering group was to determine the incidence and prevalence of individuals afflicted with brain-impairing conditions and to develop a support network of families. A task force report highlighted the difficulties of obtaining any reliable estimates on the number of people affected. Differing nomenclatures used to describe dementing illnesses, inconsistency in medical data reporting, and the lack of any registries to record diseases like Alzheimer's made incidence and prevalence figures elusive. The report also identified significant service gaps for brain impaired adults and their families. While service systems were in place for children and adults with developmental disabilities, as well as for persons with mental health and psychiatric problems, no services existed for those with adult-onset organic brain disorders. Moreover, in the late 1970's no services existed to address the needs of the family caregiver and the support required to assist with what has since been termed the "36-hour day."

*The Function Of Family Caregiver Alliance As It Pertains To State Services*

FCA's mission is to support and assist families and caregivers through education, services, research and advocacy. Our goals are to: 1) serve as a leader in health and long-term care services, education, research and advocacy. 2) Develop, implement and evaluate leading-edge programs which respond to the ever-changing needs and characteristics of caregivers in the community. 3) Advocate for inclusion of family caregivers and adults with brain impairments in health and long-term care policies. 4) Uphold quality and effectiveness of direct services, education and information. 5) Generate a strong resource base that enables more caregivers to be served.

Governed by a 14-member Board of Directors, a staff of 24, and technical consultants for specific projects, FCA undertakes a wide variety of activities in support of caregiving families in six counties of the greater San Francisco Bay Area and statewide. Current activities include those under the two contracts held with the Department of Mental Health for regional and statewide services: The Bay Area CRC (direct services for caregivers, education and program development), and the SRC (technical assistance, education and training, research, information management, clearinghouse). Other FCA activities funded by private foundations and corporations include weekend respite camps, specialized educational events (e.g., a 1997 conference on genetics and ethics); and applied research on decision-making and consumer-directed care (funded by The Robert Wood Johnson Foundation).

At the state level, in addition to serving as the model program to create the CRC system, FCA staff have participated on the California Workgroup on Alzheimer's Disease Management Guidelines (1997-98); In-Home Supportive Services Agenda Coalition (1997-98); Medicaid Blue Ribbon Committee, California State Senate (1996); Elder Care Advisory Committee, State of California Little Hoover Commission (1996); Technical Advisory Committee, California Public Interest Center on Long-Term Care (1994-97); Health Access Coalition Steering Committee (1991-95); California Interdepartmental Committee on Aging (1986-97); and California's first Alzheimer's Disease Task Force (1985-87). In cooperation with DMH and the CRCs, FCA sponsored four public forums across the state for the 1995 White house Conference on Aging; sponsored the first working conference on respite policy in California (1992); testified many times before legislative committees on the needs of family

caregivers; prepared commissioned policy research reports; and serves as a credible, timely source of information on caregiver issues for state policy makers.

***Patterns In Participation, Family Needs, And Program Growth***

Key findings from the CRC statewide assessment database are as follows<sup>1</sup>:

- ◆ The typical caregiver is 60 years old, female (76%), and most likely a wife (33%) or an adult daughter (31%).
- ◆ The typical care recipient is a 75 year old male who has suffered from Alzheimer's disease for an average of nearly 5 years.
- ◆ Both the caregiver and the care recipient are low middle-income with a median household income range of \$20,000 to \$25,999 (1996 dollars).
- ◆ About one-third (34%) of CRC family caregivers of all ages are employed. Of those under the age of 65, the employed caregiver population is over half (53%).
- ◆ Caregivers provide an average of 73 hours of care per week—an average of 10.5 hours of care per day for a brain-impaired relative.
- ◆ Prior to contacting the CRC, most caregivers (58%) had not received any help from other service agencies.
- ◆ Depression continues to be a pervasive problem for nearly six in ten (58%) of the family caregivers.

Most recently, the following key trends have emerged from our uniform, statewide assessment database comparing data on family caregivers in 1992 and 1997:

- ◆ *Caregivers are more likely to be caring for aging parents.* Although spouses are still the largest kin group, adult child caregivers increased from 36% in 1992 to 40% in 1997, while spouse caregivers fell from 51% to 47% during the same time period.
- ◆ *The proportion of caregivers who also work outside the home increased.* Caregivers under age 65 (those most likely to be in the workforce) increased from 47% to 53% in 1997. Even more dramatic, those who reduced their work hours because of caregiving responsibilities at home soared from 18% in 1992 to 43% in 1997.
- ◆ *Caregivers served by California's CRC are increasingly ethnically diverse,* rising from 14% non-white in 1992 to 18% non-white in 1997.

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<sup>1</sup> Data are from a six-month representative sample of 1,159 caregivers assessed by one of California's Caregiver Resource Centers during January-June, 1997.

- ◆ *Caregivers are less likely to receive adequate support from their own friends and family.* In 1997, 44% of caregivers said the help they received from their own family network was "far less than they need" compared to 28% who said the same thing in 1992.
- ◆ *Brain-impaired care recipients are more likely to be enrolled in managed care plans.* The proportion of brain-impaired adults enrolled in an HMO nearly doubled from 21% in 1992 to 40% in 1997.

Service usage continues to grow at CRCs as California families seek a variety of supportive services. Often, however, demand for services outstrips the limited resources at the CRCs. The following are highlights from the most recent service utilization database:

- ◆ More than 10,000 individuals were served by California's CRCs during FY 1996-97.
- ◆ The top four services at CRCs (beyond intake and assessment) were: 1) family consultation; 2) follow-up information & referral; 3) support groups; and 4) in-home respite assistance.
- ◆ The most common service package was family consultation with either follow-up information and referral *or* CRC respite assistance.
- ◆ Over 5,400 family caregivers completed the intake process, contacting a CRC for the first time. Nearly two-thirds (65%) completing intake went on to receive additional CRC services.
- ◆ On average, most family caregivers served at CRCs during FY 1996-97 received about three (3.2) hours of caregiver support services,<sup>2</sup> beyond basic information and initial assessment (excludes respite assistance).
- ◆ The average service use per family client across all CRC core services (i.e., includes those receiving respite and/or other services) was 21 hours during the fiscal year.
- ◆ A total of 774 family caregivers received CRC respite assistance in FY 1996-97. CRC respite clients received an average of seven hours of respite care per week at an average cost of \$234 per month (including an \$18 client copayment).

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<sup>2</sup> Includes one or more of the following: family consultation, counseling, legal assistance, support group, caregiver retreat, education/training, and psychoeducational group.

- ◆ The need for basic information continued to be the Number One need expressed by caregivers at intake followed by, emotional support and respite care. However, for caregivers who went on to receive the more in depth CRC assessment, emotional help (87%) and respite care (76%) were the top two needs.

#### *Program Strengths*

- **Not Disease-Specific Nor “Aging” Specific:** The CRC system has a broad focus on all adult-onset brain-impairing conditions. Twenty years of experience has shown that families caring for adults across diagnostic categories of brain impairments share similar concerns, common family problems, and corresponding service needs. Typical among the experiences of family caregivers, regardless of age or their relative’s diagnosis, are: profound grief over the gradual loss of a loved one through a degenerative disease or sudden change as a result of a traumatic brain injury; physical and emotional fatigue due to nearly constant needs for care and supervision; financial strain, and often impoverishment; and stress from the multiple responsibilities of work, caregiving, and the needs of other family members.
- **The Caregiver is the Client:** FCA was the first program in the U.S. to recognize the family caregiver (rather than the impaired individual) as the client. FCA and its affiliate CRC system recognize that the care recipient’s family caregiver needs assistance and support and a comprehensive range of services responsive to the caregiver’s need. In essence, the statewide program recognizes the family caregiver as a legitimate consumer of long-term care services. While public awareness has greatly increased since the inception of our service system, it is imperative that we continue to support families who are the backbone of long-term care assistance in this country. It is estimated that families (not agencies or institutions) provide 80% of all long-term care to functionally-impaired loved ones. Our data indicate that California families using CRC services provide an average of 73 hours of care assistance per week—more than a full-time job.
- **The Focus is Consumer-Directed:** As mentioned earlier, CRC services are consumer-directed. CRC staff understand that their role is to inform and support, but that care decisions remain the purview of the family caregiver. Families participate fully in planning and service delivery issues. Families retain maximum control over care

decisions. This concept has been heavily supported by the disability community for years. Recently, however, one of our research studies examined consumer choice among in-home respite users at nine CRC sites (Friss Feinberg & Whitlatch, 1996). Among the most significant findings was that caregivers preferred *direct pay* respite (where the family caregiver receives a cash subsidy to hire an independent provider) more than two to one over agency-based respite care. Among the advantages of this option is the fact that families can afford more care, since the hourly cost of hiring an independent provider is lower than receiving assistance from a home care agency.

- **Package of Support Services, Not Respite Only:** Research has shown that a package of supportive services including ongoing, targeted education and mental health interventions *in addition to respite care* for family caregivers helped delay institutionalization of persons with dementia by nearly a year (Mittelman et al., 1996). CRCs offer a full range of caregiver support services, not just information and referral, not just support groups, and not respite alone. The service options allow families to address the multiple needs for emotional, practical, and financial support.
- **Statewide Resources Consultant (SRC) Function:** The cohesiveness of the CRC system network is fostered by the SRC role. A primary function of the SRC is to provide technical assistance to the CRCs. This assistance builds a strong statewide CRC network and is a uniform yet flexible approach to meeting the changing needs of family caregivers. Family Caregiver Alliance, as the SRC, works with the CRC sites to promote program development; expand and refine service delivery; analyze data, including client-based and service utilization trends; and provide ongoing technical assistance to CRCs on clinical skills building; current-policy and research updates; uniform information development; assistance with data collection and reporting; and systemwide strategic planning. Collectively, our technical assistance has addressed program design (FCA wrote the original *CRC Operations Manual* of policies and procedures for the CRC system and, under the direction of the Department of Mental Health, has continuously updated it to meet the changing needs of the sites); start-up (e.g., understanding the client population, developing job descriptions, setting up office procedures, establishing service subcontracts, providing initial outreach, establishing an advisory committee, establishing program and



fiscal reporting requirements, etc.); program information (e.g., preparing a statewide brochure, fact sheets, educational displays); on-going program and service implementation (e.g., marketing and fundraising techniques, software development for client tracking; implementation of a uniform assessment tool and process, establishing procedures for when to "open" and "close" client cases; refinement of procedural information for community coordination, services and administrative areas); and strategic planning to help shape the continuous development of the CRC system, and provide staff support to implement system-wide goals. Additionally, the following functions are also designated to the SRC:

- ◆ Serve as the Statewide Information and Technical Assistance Clearinghouse on adult-onset brain impairments and caregiving issues.
- ◆ Work closely and coordinate with other statewide organizations which serve brain-impaired adults, their families, and caregivers.
- ◆ Develop and conduct training appropriate for families, caregivers, service professionals, advocacy organizations, educational institutions.
- ◆ Conduct conferences to assist families, caregivers, service professionals, advocacy organizations, educational institutions, business associations, community groups, and the general public in order to enhance the quality and availability of high-quality, low-cost care and treatment for brain impaired adults.
- ◆ Assist the Department of Mental Health in identifying and securing increased federal financial participation and third party reimbursements.
- ◆ Conduct Social policy research.
- ◆ Make recommendations to the California Department of Mental Health and the Secretary of Health and Welfare for a comprehensive statewide policy to support and strengthen family caregivers.
- **On-Line Information Technology:** Application of information technology is starting to transform the way that older adults, families, caregivers, and practitioners find information, make decisions, connect with experts, gain mutual support, and transact business (Kelly, 1997). FCA operates an award-winning (1998 Mature Media Award) website < [www.caregiver.org](http://www.caregiver.org) > with an estimated 7,500 visits per day. The site incorporates a number of innovative features for users including over 30 on-line fact

sheets, information on California's CRC system, research highlights, policy issues and advocacy alerts, book reviews, community events, and links to other notable sites. An on-line information request form is used to assist inquirers by asking them to provide some basic information about their caregiver situation. An on-line support group allows caregivers in disparate locations to share information and mutual support. As well, FCA is working to develop an Internet-based information and support system via a secure Internet site integrated with several CRC sites.

#### ***Barriers In Serving Family Caregivers***

- **Outreach/Getting the Word Out:** We understand that long-term care and dementing illnesses are not foremost on everyone's mind. Yet when a family faces a devastating diagnosis, or the sudden stroke of a loved one, it become a very personal and immediate need; they desperately want information and help. Thus, outreach is an ongoing challenge for the CRCs. Publicity is constantly sought in the print media, radio and television. And, access via the World Wide Web has brought CRC services and information resources to countless families. CRCs report routinely that high profile media campaigns bring in new clients. Gaining access to underserved communities and all those in need remains a primary objective at all CRCs.
- **Reluctance to Use Services:** Research has shown that family caregivers are reluctant to use support services, particularly respite care. CRCs address this issue by working with families to overcome any concerns about leaving their loved one in another's care. Support services such as caregiver retreats, psychoeducational classes, or support groups enable caregivers to meet their peers and decrease their isolation. Learning what has worked for others can encourage them to take advantage of additional CRC support services. Moreover, weekend respite camps are an excellent opportunity to allow caregivers to "try out" a brief period of respite. Finally, ongoing contact with and encouragement from CRC Family Consultants over time can persuade caregivers to value their own well-being enough to accept help.
- **Diversity/Language Barriers:** California is home to millions of immigrants and is becoming increasingly ethnically diverse. Large populations of Latinos, African Americans, Filipinos, Chinese, Vietnamese, and other Asian populations (among many

others) present real challenges in reaching out to these communities in a culturally appropriate manner. CRCs continue to emphasize targeted ethnic outreach programs, and to work with other community-based groups to reach underserved minority communities. A number of the CRC fact sheets have been translated into Spanish and some materials have been translated into Chinese. On a regional level, virtually all CRCs have bilingual and bicultural staff and have worked to gain access to communities including Native Americans, Vietnamese, Hmong, Chinese, Mexican and Central Americans, inner-city African Americans, and many others.

- **Rural Areas:** CRC service regions cover the entire state of California including vast rural areas. Large service regions for each CRC site provides numerous challenges for reaching and serving isolated communities. To assist rural caregivers, CRCs play active roles in coordinating with other local task forces and committees and many take on leadership positions in promoting community program development for such services as adult day care centers, residential facilities, day programs for brain injury survivors, and other services needed at the community level. CRCs facilitate a variety of support groups in rural areas—often the only support service available for miles, and promote education of both families and service professionals through annual rural trainings on Alzheimer's disease, which are cosponsored with other state agencies and community-based organizations.
- **Funding:** Inadequate funding is a problem that plagues most state programs and human services agencies. CRCs have worked to develop a service package which is cost effective, with strategies for reaching out to and serving caregivers, even as they wait for CRC subsidized respite care (e.g., with weekend respite camps). Nonetheless, currently, more than 3,000 family caregivers are on respite waiting lists at CRCs in California.

Just recently, however, we have had the best news that any state-funded program can have. Last month, Governor Wilson signed a \$4 million budget augmentation for the 11 CRCs and the SRC. After a nine-year period of no growth in the state general fund, the state appropriation for the CRC system will nearly double from \$5.047 million in FY 1997-98 to \$9.047 million in FY 1998-99. This funding will be used to provide respite to

many of the families currently on waiting lists and to expand other support services to serve more family caregivers.

On behalf of Family Caregiver Alliance and California's Caregiver Resource Centers, thank you for the honor and privilege of testifying before you today.

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Ms. TAKAMURA. Thank you, Kathleen.

Susan Reinhard, who is Deputy Commissioner of the New Jersey Department of Health and Senior Services, will present next.

**STATEMENT OF SUSAN REINHARD, RN, Ph.D., DEPUTY COMMISSIONER, NEW JERSEY DEPARTMENT OF HEALTH AND SENIOR SERVICES, TRENTON, NJ**

Ms. REINHARD. Good afternoon. Congratulations to all of you who spent all day focusing on this very important issue.

I am responsible for all senior programs in New Jersey, including all of the financing and regulation of senior service programs, and I am going to focus on three of the programs that we have dedicated to caregivers; the Statewide Respite Care Program, and the Dementia Care Program, and something we call New Jersey Ease.

But I am also a community health nurse who started her career in home care, and a lot of what was discussed this morning really resonated with me—the idea of working with caregivers, actually paying attention, not only to the person you are providing the nursing care to, but saying to the caregiver, “Come with me in this room and talk to me. How are you doing?” Someone said this morning that caregivers are really very modest in what they are looking for. They need simple, “You are doing a good job. This is what you are doing right.” They deserve respect, respect for what they do.

I have also spent a number of years in the research of family caregiving and caregiver burden across populations—the family caregivers of the elderly, the developmentally disabled, and the seriously mentally ill. I agree with Mrs. Carter that one of the biggest areas to work with is with professionals. The curriculum has to be changed. Professionals need to give that kind of respect and understand that these are not just adjuncts in the care plan. They are the care plan. So I am more motivated than ever. I have received as much as I hope I can give anyone here today in this area.

I only have a few minutes. I have cheated quite a bit because I put everything in a handout that Rick Greene, if you can raise your hand, a very dedicated colleague in the Department of Health and Senior Services, who has been working in this area since the early eighties, has put together. If you did not get it, I would be happy to give it to you.

Just a little context. New Jersey is the most densely populated State in the country. I know that my friend, Bentley, is going to tell you that Florida is everything, but we are the most culturally diverse State in the country. We have 8 million people, we have 1.4 million seniors, and we have a legislature that meets year-round, even though they are part-time, and our legislative director Scott Allocco is here to tell you about that. The legislature has been very supportive, not just to this Governor, but to previous Governors in addressing these issues.

It was about 15 years ago that the legislature created the New Jersey Alzheimer’s Study Commission which held public hearings with real caregivers. They found out that what real caregivers needed was respite and day-care, and so that is what we did. The legislation was enacted in 1987, although we did not wait until then we started a demonstration program around 1983. We found it was very successful, the statewide respite program, and it has

become one of the most important programs for seniors in our state.

Governor Whitman and the legislature did just approve an additional \$1 million, so we now have about \$5 million going into this program. We had an independent evaluation by Rutgers University, which demonstrated success in providing support for caregivers. The handout, as I noted, gives all of the details, how much money, all of the different services, everything you could possibly want to know how we manage them, how the counties figure into this. So I do not want to go through that, but what I would like to do is highlight a few points.

We do not view respite care as a service, but a strategy. It is one part of what you can do to help caregivers, and it is not just home care. It could be anything that person needs. It is a whole range of services. It could be a private-duty nurse. It could be having your family member go into a nursing home for 2 weeks. However you want to spend that money to help the caregiver is fine with us.

We have been serving about 2,000 families a year. But with the extra funding, we believe we can reach another 500 a year. In the last 10 years we have served 20,000 families. I wish we could do more.

Half of the caregivers are adult children. Forty percent of them are daughters and many are caring for both parents. The thing that I found most interesting is that the average caregiver has already been providing care for 7 years before they call us. That is a lot. Eight out of ten are providing 12 to 24 hours of care. So these are people in great need of help.

On Monday, we are holding a conference to celebrate these caregivers, and we are providing respite care, so they can come.

The day-care program—let me just turn a little attention to that—is for people with Alzheimer's disease and their family caregiver. We have found that you need to reach out to both. You need to provide a very structured program for the person with Alzheimer's. They do benefit from programs like music therapy, art, forms of reminiscence, reality orientation, meals, those kinds of things help not just while they are there, but when they get home they are better. They are a little bit more oriented. At the same time, you need to work with a family caregiver with the kinds of counseling, referrals, emotional support, and connections that they need.

In the past 10 years, we have served about 2,200 clients and their families. We know this is an effective program. We have linked up with Dr. Stephen Zarich at the University of Pennsylvania and his colleagues at Kent State with a 5-year grant from the National Institute of Aging. We have evaluated caregiver burden and have found, after 3 months in this program, caregiver burden, depression and anger decreases significantly from a control group that did not receive these services in Ohio. We are going to try and extend that funding from the National Institute on Mental Health. We also just got more funding. The Governor approved another three-quarters-of-a-million dollars for that.

The last thing, for just a moment, is the New Jersey Ease Program. These services do not do any good if people do not know how to find them. We have put into place into every county one-stop

shopping. There will be a statewide number. The number will bounce to wherever you call from. You can have access to a professional care manager, as Mrs. Carter suggested we should have, to help you organize the kinds of services you might need and that menu that you might need. For anyone who would like to know more about that, I would be happy to talk to you.

Thank you.

[The prepared statement of Ms. Reinhard follows:]

**New Jersey's Approach to  
Helping Family Caregivers**

**Testimony for the  
U.S. Senate Special Committee on Aging  
September 10, 1998**

**Presented By:**

**Susan C. Reinhard, R.N., Ph.D.  
Deputy Commissioner  
New Jersey Department of Health and Senior Services**



**TESTIMONY TO THE SENATE SPECIAL COMMITTEE ON AGING**

Good afternoon. I am Susan Reinhard, Deputy Commissioner for the New Jersey Department of Health and Senior Services. I am responsible for all senior programs, financing and regulation, including administration of three programs designed to assist caregivers of the elderly and disabled: the Statewide Respite Care Program, the Dementia Day Care Program, and NJ EASE. As a community health nurse, I began my career in home care asking caregivers how they were managing their responsibilities. I am also on the faculty of Rutgers University where I conduct research on family caregivers of the elderly, severely mentally ill and developmentally disabled. My focus has been caregiver burden and how professionals can support caregivers to reduce burden and depression.

I appreciate the opportunity to share our experiences providing services to family caregivers. I hope that our experience with more than ten years of administering the respite and day care programs will be useful to members of the Committee and other states.

I only have a few minutes to provide some highlights, so let me start with a little context and history, and make substantial use of the handout on programs (attached).

New Jersey is the most densely populated state in the country. We have 8 million people, including 1.4 million seniors. We have a legislature that meets year round, so we have many opportunities to interact with

policymakers who listen to their constituents.

About 15 years ago, the Legislature created the New Jersey Alzheimer's Disease Study Commission, which convened a series of public hearings for family caregivers with a relative experiencing dementia. Many of the caregivers testified that there was a need for subsidized day care for their relatives and respite care for themselves. The Commission's final report recommended that legislation be introduced to initiate these programs. Both programs were officially enacted through legislation in 1987, but we did not wait for the bills to pass to get started.

We actually started right after the public hearings to develop a respite program through a demonstration program in 1983. It was very successful and we applied for federal support to help us expand the program five years later when the law was enacted. This is one of our most important programs for older adults and their family caregivers. Governor Whitman and the Legislature just approved an additional \$1 million dollar appropriation for a total of \$5 million annually. An independent evaluation by Rutgers University has documented excellent outcomes in providing support for caregivers.

The handout provides all the details on the Statewide Respite Care Program such as, eligibility criteria, delivery structure, specific services, program management, and client profiles. Let me just emphasize a few points:

- We do not view respite as a single service, but rather a strategy to

enable the family to continue their caregiving role for extended periods of time. This involves offering a menu of services, from which families select, based on their specific needs, as well as those of their impaired family member. Using an assessment of the stress and burden level demonstrated by the caregiver, our services are designed to provide intermittent, short term relief and support. For some of our families, that might mean two to three hours a week of in-home service from a home health aide over a period of months. For others, it might mean placing their loved one in a nursing home for a two week period, so that the family can have a vacation. For someone who provides care and supervision 24 hours a day, three hundred and sixty-five days a year, this can mean the difference between maintaining a spouse or parent at home, or feeling compelled to place them permanently in a long-term care facility.

- We had been serving about 2,000 families a year, but the extra funding should help us support 2,500 families each year. We have served over 20,000 families in the past 10 years.
- Half of the caregivers are adult children - 40% are daughters - and many are caring for both parents.
- The average caregiver has provided care for 7 years before they seek our help, and 8 out of 10 provide 12-24 hours of care daily.

On Monday, we are holding our 10th Anniversary Celebration/Conference on Respite Care and Caregivers. We are providing respite care to make it possible for caregivers to come. We've had five caregiver conferences in recent years - always well attended.

Let me turn some attention to another very important program we have for family caregivers - the Adult Day Care Program for people with Alzheimer's disease and other forms of dementia.

Again, the details are in the handout, so I will just make a few points now.

- Adult day care has been found to be beneficial to both the victim of Alzheimer's disease and related disorders and their caregivers. Research indicates that even persons in advanced stages of Alzheimer's disease can benefit from a structured, secure, stable environment in which there is concern for the client's needs. Experience has shown that two to three days of attendance at day care each week not only lightens the emotional and physical burdens experienced by family members, but also may promote a better quality of life for the clients by maintaining an optimal level of functioning for a longer period of time. The clients function better when they get home from day care. Family or other caregivers who provide care to these relatives are frequently under substantial stress: physical, emotional, and financial. Day care programs can provide relief from the steadily

increasing responsibilities of care for the dementia client at home. Family members can be helped to accept and learn how to handle the various changing aspects of the illness as a result of education and support given by the day care center.

- This program includes a care plan for each person with dementia and his or her caregiver. The client is involved in exercise, music, art, forms of reminiscence, reality orientation and meals. The caregiver receives counseling, referrals, educational programs, and support groups.
- We know the program is very effective because we have teamed up with Dr. Steven Zarit at Penn State University and his colleagues at Kent State to evaluate the program. The National Institute on Aging funded a 5 year study comparing a New Jersey treatment group of caregivers to an Ohio control group who did not participate in a day care program. The results showed that use of adult day services for three months significantly lowered caregivers' appraisals of primary stressors, including feelings of overload and strain. Caregivers in the treatment group also had significantly lower symptoms of depression and anger, while people in the control group had increases in depression and anger. After one year, the treatment group had significantly lower feelings of overload and depression than the controls.
- We have recently submitted a grant application to the National

Institute on Mental Health to conduct a follow-up study examining the effect of adult day services on clients' behaviors and the relationships between use of health and long-term care services.

- Governor Whitman and the Legislature just approved an additional three-quarters of a million dollars to expand this program - for a total of \$1.7 million annually.

The last effort I want to touch on is our one-stop shopping for seniors and their families at the county level. We call it NJ EASE (Easy Access, Single Entry) and by the end of the year we will have one toll-free number to call statewide to help seniors and family caregivers find the services they need - including the respite and day care programs, meals on wheels, senior companions, more intensive services, and care managers. The call will bounce to the county where local care managers can help.

Our greatest challenge is to reach caregivers before they are in crisis - to provide relief, education and the tools they need. The more we reduce the fragmentation of services at the local and state level, the more likely caregivers will know where to go for help. That's why we consolidated all senior programs and financing into one department of state government, the New Jersey Department of Health and Senior Services. And, that's why we are working with every county to create a single point of entry for senior services. We cannot help caregivers if we cannot find them and they cannot find us.

Thank you for your interest in what we do in New Jersey to help families care for their members. Please feel free to contact me if you have any questions.

## NEW JERSEY DEPARTMENT OF HEALTH & SENIOR SERVICES

### SERVICES FOR FAMILY CAREGIVERS

#### STATEWIDE RESPITE CARE PROGRAM

**Program:** The NJ Statewide Respite Care Program (PL 1987, Chapter 119) has been operational since April of 1988. This program provides respite care services for elderly and functionally impaired persons to relieve their unpaid caregivers of the stress arising from the responsibility of providing daily care. A secondary goal of the program is to provide the support necessary to help families avoid making nursing home placement of their loved ones. Services are available for emergency and crisis situations, as well as for routine respite for caregivers.

Services provided under the Statewide Respite Care Program include:

- Companions (adult "sitter" type services)
- Homemaker/home health aides (hourly or overnight care)
- Medical or social adult day care services
- Temporary care in licensed long term care facilities
- Camperships (day or overnight placement in accredited camp facilities)
- Private duty nursing service (hourly LPN or RN)
- Alternate family care (short term placement in the home of a trained, approved individual)

The program is administered on a county level by "sponsor" agencies who are responsible for outreach, intake, eligibility determination, care planning, service provision and monitoring. County sponsor agencies are varied and include county offices on aging, home care agencies, hospitals, and county-level human service agencies. The actual services are delivered directly by the sponsor agency or purchased by the sponsors from a wide variety of community agencies.

The program serves families with adult members who have physical and mental impairments resulting from accidents, illness or the aging process, as well as families with members age 18 and above who are physically or developmentally disabled.

**Eligibility Criteria & Service Limitations:** There is a cap of \$3,000 per year on services for each case. Out-of-home placements (nursing home, overnight camp, etc.) are limited to 21 days per year. Care recipients of the program must have an income below \$1,482.00 per month and liquid resources of less than \$40,000. Cost-share, ranging from 0 to 25%, is assessed for individuals whose income exceeds the federal poverty level. Both the service cap and the cost-share requirements may be waived, with central office approval, on a case-by-case basis. Although the caregiver can receive services up to \$3,000, the average amount of service purchased is approximately \$1,700 per year.



**Purpose:** The Statewide Respite Care Program has been designed to provide relief and support to the unpaid caregivers of elderly and disabled adults. The goals of the program are to delay, reduce, or prevent the need for institutionalization and to encourage families to continue to provide care, in the community, for their elderly or disabled relatives.

**Cost:** The program is funded at a level of \$5,000,000 (Casino Revenue Funds) for State Fiscal Year 1999 (7/1/98 - 6/30/99). A total of \$4,800,000 is provided to the 21 county sponsor agencies for program operations and purchase of services. The remainder of the funding is allocated for central office administrative expenses.

**Program Management:** Contracts with the county sponsor agencies are managed by the Office of Finance, with program oversight from the Wellness and Family Support Program within the Division of Senior Affairs, Department of Health and Senior Services. On-site monitoring and monthly case and quarterly financial report reviews are also handled by Division staff.

An independent evaluation of the program was conducted by the Rutgers University Center for Health, Health Care Policy and Aging Research from June 1989 through June 1992.

**Clients Served:** Between 1988 and 1992, the program served over 11,000 clients (unduplicated count). An estimated 2,000 families received respite services under this program for each calendar year thereafter. We expect to serve approximately 2,500 families during this state fiscal year as a result of the increased appropriation.

During Calendar Year 1996, the Statewide Respite Program served 1895 families. Of this total, 837 families were new. Our caregivers are predominately female (78%), and have provided care for an average of 7 years prior to using our service. The average age of caregivers in New Jersey is 64 years. The following is the caregiver profile for persons using the program in Calendar Year 1996:

- 39% of caregivers were daughters caring for one or both elderly/disabled parents.
- 17% were wives caring for their husbands.
- 14% were husbands caring for their wives.
- 10% were sons caring for one or both elderly/disabled parents.
- 3% were mothers caring for a functionally impaired adult child.
- 17% were other family members or friends.

Eighty percent of the caregivers provide between twelve and twenty-four hours of care per day for their relative. Caregivers request service primarily due to their need for personal time (89%); 5% request it for a vacation; the balance of service requests are due to the caregiver becoming ill or incapacitated.

The average age of the care recipients is 78, and 70% are females. Twenty six percent of the care recipients have Alzheimer's disease; 13% have had a stroke; 9% have some form of heart disease. Other disabilities include: Parkinson's; cancer; arthritis; mental illness; multiple sclerosis; respiratory diseases; frailty, etc.

Sixty four percent of the services purchased are homemaker/home health aide; adult day care is requested by 18% of the families; 15% of the families use a form of in-patient respite care, usually in a long term care facility.

In 1996, 943 clients were terminated from the program. Twenty seven percent were due to institutional placement; 25% death; 17% due to the family qualifying for another program; and 16% since the service was no longer needed by the family.

### **Adult Day Care Program for Victims of Alzheimer's Disease and Related Disorders**

**Program:** Adult day care has been found to be beneficial to both the victim of Alzheimer's disease and related disorders and their caregivers. Research indicates that even persons in advanced stages of Alzheimer's disease can benefit from a structured, secure, stable environment in which there is concern for the client's needs. Experience has shown that two to three days of attendance at day care each week not only lightens the emotional and physical burdens experienced by family members, but also may promote a better quality of life for the clients by maintaining an optimal level of functioning for a longer period of time.

Family or other caregivers who provide care to these relatives are frequently under substantial stress: physical, emotional, and financial. Day care programs can provide relief from the steadily increasing responsibilities of caring for the dementia client at home. Family members can be helped to accept and learn how to handle the various changing aspects of the illness as a result of education and support given by the day care center.

Legislation was enacted in 1987, (Public Law 1988, Chapter 114), appropriating \$1.1 million to the Department of Health to subsidize adult day care for victims of Alzheimer's disease. Working closely with the Alzheimer's Association and the NJ Adult Day Services Association, the program was designed and all medical and social day care programs were invited to participate. Initially, 28 elected to do so.

**Eligibility Criteria & Service Limitations:** Clients are provided two to five days of service per week, depending on their need and the availability of funds. Priority is given to those persons in the moderate to severe ranges of dementia. To be eligible, an older adult must meet the following criteria:

- Be diagnosed by a physician with Alzheimer's disease or a related dementia
- Be routinely supervised by an unpaid caregiver
- Reside in the community but not in a boarding home
- Meet income eligibility (approximately \$1300/month, based on care recipient's income)
- Reside in New Jersey

Once a client is determined eligible, center staff develop a care plan which includes immediate and long range goals for the client and his/her caregiver. Within a safe, supervised environment, staff incorporate physical, social, cognitive and functional activities to maximize remaining strengths and minimize deficits. Exercise, music, art, and forms of reminiscence, reality orientation and remotivation are included in the daily routines of most programs. All provide a noon meal and snacks, and the majority

furnish transportation. Services to caregivers include counseling, referral, educational programs, and support groups.

**Purpose:** This program is designed to support family caregivers caring for a relative with a form of dementia living in the community. This program provides relief and support to family caregivers of persons with Alzheimer's disease or a related disorder through provision of subsidized adult day care services. Direct services for persons with forms of dementia include structured, individualized programming in a safe environment designed to maximize clients' functional abilities, delay progressive deterioration, and prevent premature institutionalization. In addition to dependable respite, caregivers receive counseling, referral, and education which enhance their ability to continue their caregiving roles.

**Cost:** The program is funded with Casino Revenue Funds, and is administered at the State by the Division of Senior Affairs. In State Fiscal Year 1999, a total of \$1.7 million will be available for the purchase of service. Approximately \$150,000 is maintained to administer the program directly at the Division level.

**Program Management:** The Division of Senior Affairs negotiates a per diem rate of reimbursement with agencies which represents 75% of the agency's actual operating costs. Agencies are required to match not less than 25% of the amount granted either in cash, in-kind or the agency may charge up to 25% of its actual costs to clients. The amount that may be charged is based on a sliding fee scale determined by the Department.

Agencies are required to: provide a minimum of five (5) hours of structured programming a day; establish care plans for each client; provide or arrange transportation; provide family support groups (either directly or by coordinating access to community groups); and, provide one meal daily which meets 1/3<sup>rd</sup> the RDA. Forty-seven agencies are currently funded via Letters of Agreement under this program; approximately half are social and half, medical. Participating centers bill on a monthly basis for days on which authorized clients attend.

**Clients Served:** From November 1987, when service began, through June 1998, a total of 2168 clients received almost 273,000 days of service, at a cost of almost \$8.2 million. By statute, we reimburse agencies at 75% of their actual costs. The average cost per day per client to the state is \$36.20. In the previous fiscal year, the average number of days funded per client was 59.10 at an annual cost of \$2,148. As of May, 1998, 2,083 clients have been served. Currently a total of 529 persons throughout the state are receiving services.

**Evaluation:** As we progressed with this initiative, we frequently heard from center staff and family caregivers of the numerous benefits resulting from day care. We subsequently contacted Dr. Steven Zarit at Penn State University with whom we decided to collaborate on a research study to evaluate the benefits of adult day care on the caregiver. The grant, also in conjunction with Kent State University, was funded for a five year period by the National Institute on Aging. In contrast to previous studies of adult day services, the treatment group (New Jersey) received adequate amounts of service (at least 2 days a week for 3 months or longer) to have an affect on caregivers' strain and well-being. Participants in the control group (Ohio) did not use adult day services at any time during the study, and only minimal amounts of other types of paid help. The results showed that use of adult day services for three months significantly lowered caregivers' appraisals of primary stressors, including feelings of overload and strain. Caregivers in the treatment group also had significantly lower symptoms of

depression and anger, while people in the control group had increases in depression and anger. After one year, the treatment group had significantly lower feelings of overload and depression than the controls.

We have recently submitted a grant application to the National Institute on Mental Health to conduct a follow-up study examining the effect of adult day services on clients behaviors and the relationships between use of health and long term care services by the caregivers and clients in day care centers.

For more information, please contact :

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Ms. TAKAMURA. Thanks very much, Susan.

Bentley Lipscomb, who comes to us from Florida, is going to tell us about his Floridians.

**STATEMENT OF BENTLEY LIPSCOMB, SECRETARY,  
DEPARTMENT OF ELDER AFFAIRS, TALLAHASSEE, FL**

Mr. LIPSCOMB. Thank you. I was going to get up here and say that we had figured out a way to pay for additional services to caregivers because we could just take the budget for Rich and for New Jersey, since Pennsylvania and New Jersey no longer have any older people. They are all in South Florida. [Laughter.]

But Susan beat me to the punch there. Let me say that I am pleased to be able to join you this afternoon and bring you greetings from your future; that is to say, the State of Florida. Today, we have been hearing people talk about what it is going to be like in 20 years. We are there now. Florida is what the future is in aging issues. We lead the Nation in percentage of elders in our population, but by 2025 the rest of you will be where we are today demographically. In long-term care, Florida's challenges today are going to be the nation's challenges tomorrow.

Some of you might be saying, "Well, what does this have to do, long-term care? We are here today to talk about caregivers," and I would reply to you that family caregiving is long-term care. I do not think we can say that too often or strongly enough. The vast majority of elder care is not delivered in skilled nursing facilities or other types of institutions, but at home. The families of Florida are already meeting the challenge of aging today. This morning when I heard the figure that only 11 percent was long-distance caregiving, I can tell you that that is a national average. It certainly was not taken in my State because most of the caregiving down there is from a long distance.

If America is to meet the challenges of aging tomorrow, we are going to have to support our families, and we are not doing it today. Nothing makes this statement clearer than a recently concluded study by Dr. William Weissert of the University of Michigan. In an effort to make our services go to the people that need them most, we hired Dr. Weissert to help us overhaul our Client Assessment Forms, so that we could do the best job of targeting the scarce resources that we have got. We asked Dr. Weissert to study more than 20,000 case files of frail elders to see what really contributes to the risk of institutionalization. And up on these boards you see ADLs and IADLs. We are rapidly coming to the conclusion that, while those are interesting, those are not what predicts the likelihood of institutionalization.

Dr. Weissert's findings underscore the vital importance of caregivers in elder care. A client without a committed primary caregiver is five times more likely to be recommended for placement in a nursing home than one with a caregiver. The caregiver factor is more than twice as significant as whether or not the individual has cancer, three times as significant as whether the individual has had a stroke, four times as significant as whether the individual has dementia. These findings underscore, again, the importance of caregiving, and they help us make the case to policymakers and taxpayers for effective caregiver support programs.

But before we make the case to others, perhaps we should do some listening. On October the 19 and 20, our Department is going to sponsor the first-ever state-sponsored caregiver forum in Sarasota, FL. We are going to focus on helping caregivers of patients suffering from Alzheimer's and Parkinson's, which are the two biggest problems that we have in the State. We have more Alzheimer's victims in Florida today than there are AIDS patients in the entire United States of America. Sixty percent of the people in our nursing homes are at some stage of dementia, and that is the primary cause that they are in there.

We hope that this caregiver-centered forum that we have organized will give caregivers an opportunity to interact with other caregivers, to learn from each other, and to offer their insights to us, the professionals. Caregivers tell us continuously that they like this approach, and that is because that they generally feel talked down to by professionals, who want to help them. Caregivers also tell us that they need information, which is what to expect when their loved one's disease progresses, what the latest tips and techniques are, and where they can turn for help. These themes kept reoccurring throughout the testimony at the hearing this morning.

To meet this need, we produced a caregiver manual that walks step-by-step through the caregiving process, teaches someone how to do things as basic as use a bedpan, how to take out a hearing aid, or how to move a person into a bed that is using a walker. These are the kind of practical things that caregivers tell us, on an ongoing basis, that they need.

We have also published special supplements in our Elder Update Newspaper, a little newspaper we put out on a monthly basis. We send out about 150,000 copies a month, and we are now putting 12-page pullout sections on different diseases in there. Since we cannot get the medical schools to teach doctors long-term, disabling diseases, we have tried to put it in layperson's language and give it to the people who are experiencing those, so they can go in and embarrass the doctor by asking him questions they cannot answer.

I hope that Senator Grassley and the committee can provide some leadership in terms of getting our medical training facilities to understand that before we can institute a system to take care of the people who are experiencing some of the difficulties that we are here talking about today, the linchpin people—who are the M.D.s, whether or not anybody wants to think about that, that is true—have to be trained in terms of what these diseases are and what they produce in the people that are doing it. We are also putting up this information on the Web so that the people will get it.

Jeanette mentioned in her opening comments a while ago the Relief Program. We have a legislator who is very much like Barbara Boyd, who essentially did exactly the same thing. She went to the legislature and said, "My mother has Alzheimer's disease and, by God, you are going to fund this program." So in 1 year, which is practically unheard of in terms of legislative circles in our State, we had the Relief Program and had it funded with an initial level of funding of a million dollars. What it does is it hires families to take care of people at nights and on weekends, so that other members of the family can work. We anticipate that that is going to double in the next couple of years.

We have now opened up Americorps programs, which are providing respite services to caregivers and families, which are the only two in the country that we are aware of that are doing that. We have our own State Alzheimer's Disease Initiative Programs, which are providing respite services, and that has increased by 300 percent over the last 4 years.

All of these things taken in total do not come anywhere close to meeting the need. We figure we are meeting approximately 2 percent of the identified need in the Alzheimer's area alone, notwithstanding any of the other aging issues in the problems that we are dealing with.

I have heard people talk all day today, and I understand the importance of issues that they have brought to us. I understand that the instances that they have shared with us, and I do not want to take anything away from that. But I believe that the most significant barrier, in terms of caregiver support, lies not in a lot of what we have heard, but in long-term care reform. We have got to have a long-term care system that is coherent and organized, and we do not have one today. We have pieces of long-term care, and those pieces are doing a good job in many different places, but we have no coherent system that logically and increasingly supports elders and their families as aging increases dependency.

As the Nation heads into the longevity revolution, which we have depicted up here, I believe that creating such a system should be our highest priority and unquestionably caregiver support must be a part of that system.

Thank you.

[The prepared statement of Mr. Lipscomb follows:]

**TESTIMONY OF**  
**Bentley Lipscomb**  
**Florida Department of Elder Affairs**

**BEFORE THE**  
**Special Committee on Aging**

**September 10, 1998**



By Secretary Lipscomb:

Good afternoon. I am pleased to be here today to bring you greetings from your future -- that is to say, Florida.

Florida IS the future for aging issues.

The Sunshine State has a higher percentage of elders in its population than any other state.

Over the next 20 years, many other states will be where Florida is today, demographically.

We in Florida believe that the issues that we are grappling with today will be the challenges of long-term care for other states and the nation in the future.

But wait, you may say. Today's topic is family caregiving, not long-term care programs.

I would reply: Family caregiving IS long-term care.

I don't think we can say too often or too strongly . . .

. . . that the vast majority of elder care is not delivered in skilled nursing facilities or other institutions, but at home.

The families of America meet the real challenge of aging.

Our challenge is to help support them.

We have come to that conclusion in Florida because we see the contributions that families make to elder care every day.

But sometimes, it helps to have the numbers.

Recently, our Department revised its standard client assessment instrument as part of our effort to target resources to those clients who need help most.

The researcher who undertook this challenge at our request was Dr. William Weissert of the University of Michigan School of Public Health.

Dr. Weissert did some sophisticated statistical analysis of almost 20,000 case files of Florida elders.

His findings underscore the vital importance of caregivers in elder care:

A client without a committed primary caregiver is almost FIVE TIMES MORE LIKELY to be recommended for placement in a nursing home than one with a caregiver.

The Caregiver Factor is more than TWICE AS SIGNIFICANT AS CANCER in predicting whether an individual is institutionalized . . .

Three times as significant as stroke . . .

Four times as significant as dementia.

These are interesting findings. They underscore the importance of caregiving . . .

. . . And they can help us make the case to policymakers for effective caregiver support programs.

But before we make the case to others, we should do some listening, too.

On Oct. 19 and 20, our department will sponsor the first-ever state-sponsored Caregiver Forum in Sarasota.

We will focus on helping caregivers of patients suffering from Alzheimer's Disease and Parkinson's Disease.

We are organizing this forum to give caregivers the opportunity to interact with

other caregivers . . .

. . . to learn from each other . . .

. . . and to offer their insights to professionals.

Caregivers are telling us that they like this approach.

Many caregivers tell us that they sometimes feel "talked down to" by the professionals.

Caregivers also like another aspect of the forum.

We have provided for day care for frail patients while caregivers attend the sessions.

That means that caregivers can get a needed break from the unrelenting strain they are under.

That brings me to my next point: The importance of respite in supporting caregivers.

In Florida, we believe that respite can play a crucial role in supporting caregivers through respite programs.

But we also have found that different caregivers have different needs.

So we have developed a number of strategies to help different caregiver populations.

One of the first successes we had was FAVOR -- Florida Alzheimers Volunteers Offering Respite.

This program provides respite for low-income or minority families who are caring for Alzheimer's families.

We have almost 200 FAVOR volunteers in this program, and they have provided service to more than 400 families per year.

We want to express our thanks to the Administration on Aging and to the Congress for its support of this model program.

We also want to express our thanks for the valuable assistance we have gotten from the Americorps program.

We have two of the very few Americorps projects that focus on elder respite care.

More than 100 Americorps members provide respite to almost 1,000 clients and caregivers.

Of course, Florida has a higher proportion of older people in its population than any other state.

So our state has developed its own programs.

Our Department's Alzheimer's Disease Initiative provides respite service in all 67 counties in Florida.

We provide both in-home and facility-based services to the caregivers of Alzheimer's victims.

Also, we recently launched a new respite-service initiative called Respite for Elders Living In Everyday Families.

This program places special emphasis on serving unserved or underserved families — particularly low-income families.

RELIEF provides respite on evenings and weekends, when those families have few respite options.

Its sponsor, Sen. Bettye Holzendorf of Jacksonville, told us that this was one of the easiest bills she ever passed.

It seemed every legislator had a caregiver and patient in his or her family.

Just three months after Sen. Holendorf began working on her idea, the program had cleared the Legislature.

In the first nine months, we have enlisted almost 160 volunteers who have provided 36,000 hours of service.

We attribute this program's fast start to the fact that policymakers see the need for caregiver support.

They see the need not in staff studies or research projects, but in their own families and neighborhoods.

And they have been willing to support this initiative for that reason.

While we have had some successes, we can do a lot more to support family caregivers.

Your staff has asked me to identify some of these challenges to effective caregiving.

I've touched on some . . .

Attitudes toward caregivers . . . and funding, of course.

We meet less than 2 percent of the respite need for Alzheimer's in Florida.

We cannot afford to allow this situation to continue.

By spending a few hundred or a thousand dollars to support a family caregiver at home, we may be able to avoid institutionalization at a cost to Medicaid of \$31,000 per year in Florida.

Other challenges emerged from a recent meeting with the Americorps members who give respite and support to caregiving families.

They told heartbreaking stories . . .

. . . Stories of octogenarian caregivers with serious health problems trying to lift and turn and bathe patients bigger than themselves.

. . . Stories of caregivers battling not only the day-to-day challenges of caregiving but loneliness and isolation as well.

But I believe that the most significant barrier lies not in caregiver support . . .

. . . but in the fundamentals of long-term care.

America has no long-term care system today.

We have pieces of long-term care, and some of those pieces do a good job.

But we have no coherent system that supports elders and families as aging increases dependency.

Creating that system as this Nation heads into the Longevity Revolution must be our highest priority.

Caregiver support must be a major part of that system.

Thank you.

Ms. TAKAMURA. Bentley, thank you very much. Rich Browdie from Pennsylvania is our next panelist.

**STATEMENT OF RICHARD BROWDIE, SECRETARY OF AGING,  
DEPARTMENT OF AGING, HARRISBURG, PA**

Mr. BROWDIE. Thank you very much. I guess I have to say something about the demographics of Pennsylvania, to follow suit. Pennsylvania is the State that retains the largest proportion of its native born of any State in the Union. [Laughter.]

And that sort of goes a little bit to the character of the Commonwealth of Pennsylvania. We are a conservative lot, for the most part, and it really tells a little bit of the story behind how the Family Caregiver Support Program came about because I think that is really why people are interested in Pennsylvania's system in this regard.

Let me give you a few features of the program that are important, just for you to understand the basic details. Family Caregiver Support Program does, in fact, provide cash support for out-of-pocket expenses for the kinds of things that we have heard about so much today, up to \$200 a month, depending on a sliding scale, starting at 200 percent of poverty and going up to 380 percent of poverty.

In addition, it also makes available up to \$2,000 per household per lifetime for capital assistance; that is to say, minor renovations for the home to make it possible to assist caregiving and to do other things that would be of a heavy equipment nature.

It was established in eight pilot sites in Pennsylvania in 1987. It became statewide after a State law was passed in 1990, starting the program on a statewide basis, and we now serve about 3,500 people at any one time and about 6,700 people over a year's time, due to case turnover.

The way the system works is that it starts with an assessment that really focuses not just on demonstrating the needs of the consumer, but also of the family, and that was really the whole idea behind the program was to reorient what had been a rapidly developing and relatively sophisticated assessment operation. Pennsylvania has a pretty well-established single point of entry for access to services for older people. But those assessment operations really focused entirely on the consumer, looking at the family exclusively, in terms of being a resource, as opposed to saying what is it that we can do to support the family, so that they can continue to be a resource.

Once care planning is accomplished in which the family, basically, is the focus of the care-planning exercise and the services to be offered, we also make available access to other services through the rest of our aging services system, in addition to connecting people to support groups. And in counties—Pennsylvania has a lot of very rural parts of the Commonwealth—there are locations where there had not been naturally occurring groups, like Alzheimer's Association chapters and others, that were in business. So we basically made it our business to try to create them and make them available where they did not exist.

Counseling and crisis intervention support, that kind of being there to be the care manager when someone has a crisis in their

family or has a problem that they are not prepared to deal with, support with paperwork and all of those other things, insurance, counseling, are all a part of the service system that we operationalized through this program.

I think what is more important is the context in which the program operates now. The program really began out of thinking that was developed in the early and late seventies by Elaine Brody, some research that she had done at the Philadelphia Geriatric Center, which showed a couple of interesting things about people in a project that she was running. First, that families were, in addition to documenting one of the early documentation of the commitment of families to being caregivers, she also was pointing out that families were very prudent users of resources when they had access to those resources; that they were careful about husbanding along a body of resources on behalf of themselves and the person they were providing care to because they wanted to make sure that they had resources for a rainy day or when things would develop if there was a particular problem.

We also, at that time, were developing agency-based case management in a very aggressive way. The consequence was that we were beginning to see how those agency-based systems were not responding to families and, indeed, sometimes there was competition between who was going to be in charge, et cetera.

Having gone through the process of developing the program and raising to importance, in the minds not only of the General Assembly, the public at large, and now our professionals who are in our system, the importance of the family as a caregiving unit and as, perhaps, the focus of what our support should be. It is now beginning to infuse new thinking in the rest of our care management systems.

Basically, what we are trying to do now is to train people so that the resources that we make available in as flexible a way as possible through all of the other programs that we administer through the local area agencies on aging, where the Family Caregiver Support Program is located. All of those programs respond in a somewhat similar fashion in that we use the Family Caregiver Program, not only to serve those for whom it seems to be sort of custom cut, but also use it as a way of modifying the thinking that we use to approach the care planning for a family where the family is going to remain involved, albeit the resources required may go beyond what the Family Caregiver Program can support.

The budget has grown to over \$10 million in the Family Caregiver Program. Pennsylvania has the second-highest proportion of older people, behind our good friends in Florida. Actually, we get a lot of people back from Florida, who are over the age of 75 when it happens, the demographers tell us. [Laughter.]

What that means to us is that this program is helping us learn how to do care management all across our system better. Thank you.

Ms. TAKAMURA. I noted, when Rich was talking, that he mentioned husbanding resources, and since this is a caregiver forum, I think we really should think about "wifing" resources. After all, wives usually have to handle those things. [Laughter.]



Let me invite Leah Eskenazi to the podium. And as she is coming to the podium, I am reminded that cards were distributed to you. We will be taking questions from the audience after the panelists have presented.

I, once again, want to thank our former First Lady, Rosalynn Carter, who has to leave. Thank you for coming, Mrs. Carter.

**STATEMENT OF LEAH ESKENAZI, MANAGER OF SENIOR AND COMMUNITY PROGRAMS, LEGACY HEALTH SYSTEMS, PORTLAND, OR**

Ms. **ESKENAZI**. It is a pleasure to be here this afternoon. I brought pictures, so I will tell you what those are about in just a moment.

I am Leah Eskenazi from Portland, OR, and I am going to stay out of this East Coast competition and talk to you a little bit about the local perspective from Portland, OR. You do have my presentation as a handout, so I am going to go pretty quickly over the information that I have and, hopefully, you will have lots of questions.

Legacy Health System, which is where I am located, includes four-hospital and a Visiting Nurses Association. We started our caregiver services 17 years ago. Family Caregiver Alliance was a good role model and we continue to benchmark with them.

Seventeen years ago, we offered an 8-week education series on chronic illness to the community and 500 people showed up. We knew we were on to something then. The next year we conducted with the Area Agency on Aging a survey of 200 family caregivers, and the number one need was families saying, "If we could just have a break once in a while, we would do fine." So soon after we opened Legacy's In-Home Respite Program.

I am going to start by telling you about our greatest strengths and our challenges. One of our greatest strengths is Oregon's strong Community-Based Services network. It encourages collaboration. Collaboration is an essential component of how we achieve goals. We are currently collaborating with the Alzheimer's Association Oregon Trail Chapter, with the medical school, with local churches, as well as with State and local public agencies. So, even though I talk about Portland, we really work and partner with others throughout the State.

Second, the health care sponsorship has been incredibly valuable and supportive, and it has been long-term sponsorship. Legacy is a respected community health system. It has really helped to have our family resource services and experts onsite. Families trust us. They know we are going to be there. They know our services are not going to go away, so they come and use us, and that makes a real difference. There are all too many services that are not surviving because they do not have the support to continue operating. So families do not trust using them.

Also, caregiver services exists in a low regulation environment in Oregon. Current flexibility of the Federal, State, and local regulations has allowed us to be flexible and to offer affordable low cost, innovative services. For example, our Brookdale model Alzheimer's Day Respite Program. You see some of the pictures over on the side

here. There we are working with local elementary school students and here are visiting medical students.

The day respite programs are staffed with people who have expertise in the arts and in family caregiving. We reserve using licensed health care personnel for those situations where we really need them. Lower personnel costs equal lower fees. Families save countless dollars, and get the services they need.

The greatest challenge, which I'm sure is no surprise to you is that families wait too long to seek help. Second, financial, there are few incentives or resources available to help families. As I mentioned earlier, there are few incentives or resources to sustain caregiver services, especially for small grassroots programs.

Third, communication between health care professionals and caregivers is inadequate. We have spent a lot of time focusing in on this. The increased emphasis on controlling health care costs has definitely reduced the time that physicians can spend with their patients, and physicians know this. They want to spend more time with their patients but it is a real challenge.

Our goal is to be a bridge between the health care system and other formal organizations and informal supports—the family and the caregivers.

So let me show you a model of how we operate. The caregiver and the family surround the middle and, the individual needing care is right in the middle. Around the outside you will see the formal supports; the medical care system, the National and State Aging Services, and then between the family and formal support, the family support services. We know that providing education, support, respite, and information we can help be that link for caregivers has proved it to be a very good model for us.

Today we provide, respite services, information, and referral, education and support services, including over 20,000 hours of respite services a year through in-home and Brookdale model day respite programs.

I am going to jump now to our special initiatives I think that is what you will find especially interesting. The first is our medical student training. Fourth-year medical students who, as a required part of their Neurology rotation, spend time in our Alzheimer's Day Respite Programs and come learn about family caregivers and community resources at the Alzheimer's Association.

There are some folks right there in the photo. They dance, they sing, they have a good time with the participants and staff. We also led them in some didactic training. The comments we get back are just wonderful. They say things like, "I did not know people with Alzheimer's disease could have fun." They have this image that is very traditional and negative. The other thing I just love with medical students, especially the ones who are planning to be ER physicians or OB-GYN, is when they say, "Oh, we are not going to be working with people with dementia or caregivers." We regale them with actual stories about interactions in their chosen field, with this population.

We also have a Caregiver Self-Efficacy Education Program. It is a 6-week caregiver training class with state of the art curriculum. It is based on Kate Lorig's work out of Stanford University, and it is a "train the trainer" model. We are working with caregivers,

their peer trainers, and with professionals. We have conducted nine classes already. The student feedback is incredibly positive. It provides caregivers with a set of tools to care for themselves. It does not train them about tasks for the care receiver. We actually have two caregivers from the first class who was self-diagnosed for depression. With the peer support and education they received in the class, they sought out professional help and received treatment.

Two more initiatives. We have a program where we work with primary care physicians on dementia diagnosing practices and interactions with caregivers. Eighteen focus groups with 78 physicians were covered physicians from Portland, other parts of Oregon, and Cleveland, OH, participated. We are trying to figure out what the communication barrier is between doctors and caregivers, why aren't they able to get done what they need to get done. And what is preventing diagnosis of dementia.

What we found is that doctors have the skills to diagnose. They know the strategies for working with families, but one issue is that sometimes they feel like they cannot do anything to help, so maybe it is really not helpful to diagnose. So we are going to be looking into that issue further.

Finally, our arts exhibit, which is, "Kaleidoscope: An Exhibit Celebrating the Creativity of Individuals with Alzheimer's Disease." It is a beautiful 23-piece intergenerational art exhibit showcasing the creative talents of people with Alzheimer's disease. A lot of people initially say, "Why do you want to do something so depressing?" Once they see the exhibit, it is incredible to see their positive response. People are just amazed at how beautiful the work can be. The exhibit has reached a lot of people, who have not traditionally been involved with caregivers or Alzheimer's. Art is a wonderful medium for bringing a wide variety of people together.

So, on that note, thank you.

[The prepared statement of Ms. Eskenazi follows:]

**Senate Special Committee on Aging**  
**"Easing the Family Caregiver Burden: Programs Around the Nation"**  
**September 10, 1998**

**Leah Eskenazi, Manager, Senior & Community Programs**  
**Legacy Health System - Portland, Oregon**

**Presentation Summary- Local Perspective**

Most people want to follow through on the stated or unstated promise to care for a loved one, but are not prepared to do so. This often leads to a sense of guilt, anger and self doubt. A desire to educate and build confidence in family and friend caregivers led to the development of Legacy Health System's Caregiver Services in Portland Oregon 17 years ago. At that time Legacy offered an 8 week education series on managing chronic illness and 500 people attended the first night! A survey of 200 caregivers the following year conducted by the local Area Agency on Aging indicated that the top need of caregivers was, "to just have a break now and then". Our Respite program was initiated later that year.

**Greatest Strengths of local efforts:**

**1 - Collaboration** - Oregon is strongly committed to community based care which fosters local collaboration. Legacy is currently collaborating on projects with the local Alzheimer's Association, state and local senior services divisions, the Oregon Health Sciences University, Trinity Episcopal Cathedral, other health systems and community based organizations.

**2 - Healthcare Sponsorship** - Long term sponsorship by a respected community hospital with a family resource center and on site experts provides program credibility and promotes caregiver trust. Legacy is the most comprehensive and best know caregiver resource in Oregon. Operating in a managed healthcare environment gives us direct knowledge and opportunities to reduce the burdens faced by individuals with chronic illness and their caregivers.

**3 - Low regulation environment** - The current flexibility of federal, state or local regulations has allowed high quality, low cost, innovative respite and caregiver programs to flourish. For example Legacy's Alzheimer's group respite programs are staffed in part by people experienced in the arts and family caregiving. More expensive healthcare personnel are only used when their level of skill is truly needed, saving consumers countless dollars.

**Greatest challenges:**

**1 - Families wait too long to seek help.** In too many cases, it seems that caregivers die sooner than the people for whom they have cared. Caregivers often delay attending to their own health and well being. Society needs to do a better job of promoting caregiving as a cultural value and the use of organized public and private sector services (formal system) to support family and friends (informal system) who care.

**2 - Financial** - Few incentives or resources are available to help families pay for services, sustain existing public and private sector programs or to encourage increased healthcare participation in this social model of care.

**3 - Communication between healthcare professionals and caregivers is inadequate.** Increasing emphasis on controlling healthcare utilization and cost of care puts a premium on the time spent by health care providers with their patients. Patients are increasingly expected to direct their own care. The challenge is to empower both caregiver and healthcare professional to be more intelligent about caregiving, thus enabling them to bridge the current communication gap.

#### **Legacy Caregiver Services - Core Services**

**Legacy Caregiver Services** is a social services program located in a hospital, that is part of Legacy Health System. Based in Portland, the system consists of four hospital and a VNA. The sole mission of our department is to serve caregivers. The philosophy of Legacy Caregiver Services is embedded in its motto, "You're Not Alone". Our programs are designed as a partnership with caregivers and links the informal and formal systems of care. (See: Family Support Model diagram). The individual is in the center supported by family and friends. With chronic illness the medical care system and other formal services must work with the patient support network to provide optimal support for the individual and family. Legacy's family support model seeks to bridge the informal network and formal systems of care by helping to build competency and self reliance in families and patients, and eliminate barriers to care within the medical care system and others.

The core programs include:

**Information and referral** - The center has a large collection of information about health problems and caregiving, including 1300 books and video tapes, in addition to pamphlets, newsletters and internet access to health information and disease management resources. The center and Respite service receive over 2000 calls/walk-in's a month.

**Education and support** - Community education programs are offered regularly including the Caregiver Series, Understanding Medicare, Legacy/financial issues, strategies for Alzheimer's, stroke and head injury care classes. Access to a wide range of support networks are available through the Center including the Center's coordination of 25 support groups.

**Respite services** - Over 20,000 hours of respite care are provided to families through an In-Home service and at two Brookdale model group respite programs, Trinity Place and St. Aidan's Place. Professional caregiver training classes are offered bi-monthly and a listing of 50-60 private duty caregivers is updated and distribute monthly throughout the community with a hiring guide.

Both quantitative and qualitative data is used to drive program development activities.

Legacy is fortunate to have a Caregiver Researcher on staff, Dr. Linda Boise, who ensures that we are up to date on the needs of caregivers in our community. The staff makes every effort to translate relevant research findings into policy and practice. In addition, Legacy's strong emphasis on Continuous Quality Improvement provides us with a supportive environment to use customer satisfaction and program effectiveness data for decision making.

**Four key Legacy projects:**

1) **By helping families help themselves, the majority of families can best manage their own needs. This core belief led Legacy to develop a 3-year project called the "Caregiver Self-efficacy Education Project".**

- A six week caregiver training class with education book.
- Based on Lorig's (Stanford Univ.) self-efficacy model for chronic care.
- Currently being tested Alzheimer's, stroke, Parkinson's disease caregivers in a train-the-trainer model.
- Pilot test classes and Nine six-week classes completed in Portland area. Nine more classes scheduled to start in October. Comparative data from classes will be analyzed with results prepared by winter.
- A class leader guide and caregiver help book are being prepared for publication.
- We are seeking grant support for regional and/or national dissemination.

One of the pilot class participant, whose husband has Alzheimer's disease, said:

"This was a different kind of program. The focus was on Caregivers [not caregiving tasks]. They didn't let us cry for very long about our problems, but showed us how to cope with our problems, communication with our Receivers, let go of guilt feelings of inadequacy in our caregiving, ... how to recognize signs of depression in ourselves and seek help, reduce stress and problem solve..."

2) **The second key initiative is "Building Caregiver Bridges in a Managed Care World" - This grant supported project builds on current and developing caregiver services activities to enhance the ability of family caregivers to work with health providers, including physician. One component, supported by a National Alzheimer's Association grant, involved investigating the process of clinical assessment and diagnosis for dementia and to identify barriers to proper diagnosis.**

- Eighteen focus groups with 78 Primary Care physicians were conducted in Portland, rural Oregon and Cleveland, Ohio.
- MD's clearly understood Alzheimer's clinical assessment tools and strategies.
- A reluctance to give a diagnosis of Alzheimer's disease was reported for a variety of reasons, including MD perception that since they could not make a difference there was no benefit to making the diagnosis.
- MD's, especially in rural communities appeared more aware of family impact:

"I think the thing that the diagnosis is really about is helping to prepare the family and the patient with that transition from when the patient isn't always able to care for themselves and the family isn't able to -- and the transition to the family not being able to do it. At least we get the family prepared, so if they want to do it, they get the resources so we don't have the situation where you have family bringing in dad or grandpa to the ER, 'I can't take care of my dad anymore,' and they're gone."

- Findings from this study are being disseminated locally and nationally.

**3) A third initiative: Training 4th year medical students. (see photos)**

- Collaborative project with Alzheimer's Association and medical school.
- Students learn about Alzheimer's disease and community resources through on-site participation at St. Aidan's Place Assisted Living, Trinity Place and St. Aidan's Place Group Day Respite programs and at the Alzheimer's Association.
- Required as part of Neurology clerkship rotation.
- Active, positive engagement of individuals with dementia at programs and discussion about community resources is effective in broadening student perception about dementia care options.
- "There is nothing I can do" attitude is addressed and dispelled.
- Project is beginning it's second year of monthly training sessions.

**4) A Forth initiative uses visual arts to educate and show the continuing contribution of people suffering from a dementing illness.**

- Kaleidoscope: An Exhibit Celebrating the Creativity of Individuals with Alzheimer's Disease is a beautiful 23 piece intergenerational art exhibit showcasing the creative talents of people with Alzheimer's disease.
- Created at Trinity Place with the help of local artists, the exhibit was expanded to include work from three other states and is travelling nationally, thanks to a grant from the Brookdale Foundation.
- It is an uplifting, professional exhibit. It helps to raise the self esteem of both Alzheimer's caregivers and care receivers. The exhibit also educates people about Alzheimer's disease from a strengths perspective. (See brochure)

You are welcome to contact me if you are interested in more information about any of Legacy's services or projects. (503)413-6778 or [leskenaz@lhs.org](mailto:leskenaz@lhs.org)



## Facing chronic illness: the family support model and its benefits

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### Abstract

With the aging of the population and the evolving health care system, it is more important than ever before that individuals be actively involved in selfcare activities and that individuals and families receive education and support to help them cope with chronic illness. This article describes a model family support program which operates within a hospital setting to provide information, education, support, and respite services. This model is based on an extensive research base which underscores the value of this model both for the individuals and families involved and for the health care system.

*Keywords:* Family support; Self care; Aging

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### 1. Introduction

Caregiving for an elderly or chronically ill relative or friend is increasingly a role assumed by American families. Contrary to popular belief, Americans do not abandon their elderly or chronically ill relatives. Studies of informal caregiving consistently indicate that 75-80% of care is provided by family members and other informal providers [1], suggesting that the medical care system is dependent on both selfcare by the patient and care provided by families to achieve optimum well-being for individuals with chronic illness.

The danger is not that families will abandon

their ill relatives but that the health care system will abandon its care-givers. The evolving health care system, with managed care emerging as a primary organizing strategy, places increasing emphasis on controlling utilization and the cost of care and puts a premium on the time spent by doctors with their patients. With these changes, it becomes even more important both for affected individuals and their families, as well as for the health care system, to keep chronic illnesses well-managed.

Patients and health care consumers need a place where they will have their questions answered, where they can seek out needed information, and where their spirits and motivations to stay well will be bolstered. A partnership between family members and formal care providers is needed to promote the well-being of

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chronically ill persons or frail older adults and to sustain the family support system. In this article, we present a family support model and describe the Legacy Family Support Services program in Portland, Oregon, which is based on this model. We discuss why this model is important and how it can be implemented within a medical care system.

## 2. The Family Support Model

The Family Support Model recognizes the significant role that self-care and resources from both the informal and formal systems play in promoting optimal health. The concept of the Family Support Model is presented visually in Fig. 1. As shown, the individual is at the center,

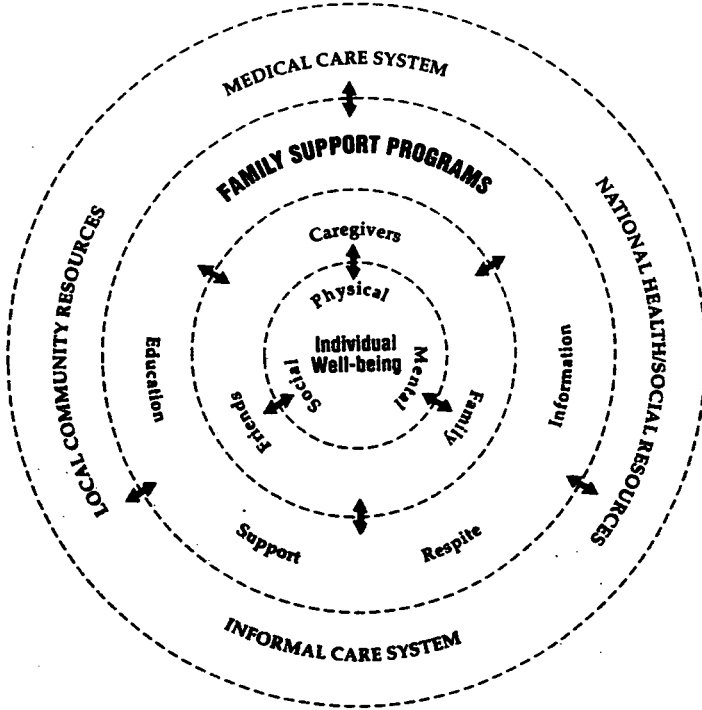


Fig. 1. Family supported model.

surrounded by family and other informal supports. Especially when dealing with chronic illness, the medical system operates in conjunction with the informal support system and community resources. No part of the system is an independent agent, as the well being of the individual depends on support from family, community resources and the medical care system.

The process of maintaining health and responding to symptoms begins with the individual through self-care. Levin et al. [2] define self-care as a process where people function on their own behalf in promoting their health, and in preventing and treating disease. Self-care includes actions to maintain health and prevent future illness, respond to symptoms of possible illness, and manage existing illness conditions. The Family Support Model also responds to the needs of families who are often the primary, or even the sole, source of support for chronically ill or frail individuals. It seeks to link the informal and formal systems so that these resources will complement one another and provide optimum support to the individual and family.

The ultimate goal of the Family Support Model is to build competency and self-reliance in families and patients so that they can effectively manage their own health and any illnesses that happen their way. Except for those patients and families who may need intensive case management, the Model assumes that the majority of families can be empowered to be good care managers. The programs and services of the Family Support Model are based on a broad definition of health such as that developed by the World Health Organization (WHO): 'Health is a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity.' [3].

While the model is described as a 'family support model', we recognize that in modern society 'family' means much more than those persons related by blood or marriage. It includes individuals tied by emotional bonds, i.e. significant others. It also describes an interacting, interdependent system: what affects one member, affects the other(s). Family can be

further described by its roles: as care provider, as social support system, as emotional support system.

### 3. Why a family support model is important

For the first time in American history women, who assume a disproportionate share of the caregiving responsibility, spend an average of 17 years of their adult lives as the mothers of dependent children and 18 years as the daughters of elderly dependent parents [1]. Chronic disease can strike at any age, although as people get older and as our population as a whole ages, chronic illness is becoming more prevalent. Nearly 25% of persons aged 45-64 and more than half of those aged 65 or older, are limited in their activities by at least one chronic condition [4]. With families being more dispersed and more women working, growing challenges face family care-givers.

The healthcare system must find ways to support these families without eroding the special sense of familial commitment and caring that family caregiving demonstrates and without transforming personal care into an impersonal commodity that is merely bought and sold. Providers must strive to develop a shared approach to family support, one that responds to the perceived needs of chronically ill and frail individuals and their family care-givers, that does not usurp their sense of control over their lives, and one that 'helps them help themselves.'

A new interpretation of health is also evolving. Being well is no longer synonymous with being healthy. Being well implies a wholeness and integrity of self in the face of a variety of predicaments, including disease. This shift to a more holistic approach provides opportunities to find better ways to sustain the family's commitment to care.

However health is viewed philosophically, when a patient or family faces chronic illness or frailty, the physician is often looked to for help in where to get community services, in ways to cope with caregiving issues, and for emotional

support [5]. Unfortunately, care-givers are often frustrated with physicians who fail to refer them to community resources or other specialty medical services [6]. The family physician is often the weak link in the referral chain to other services.

Community service providers also have experienced a lack of referrals from physicians' offices. While most physicians regularly refer to home health and meals-on-wheels, only 10% of physicians and their staff know about other family services such as adult day care, mental health programs, support groups or preventive health programs [7]. If the physician is functioning in isolation from the larger community support system, there is no easy solution when he or she suspects that emotional factors affect a patient's poor self-management of an illness, or when poor health of a patient is caused by the everyday stress and fatigue of caring for a chronically ill friend or family member. Problems caused by the stress of caregiving cannot be cured with a prescription or a few days of bed rest. If the physician doesn't know what community resources are available, there is little he or she can do to help the patient or care-giver in these situations.

Rather than attempting to be fully knowledgeable about community services for the chronically ill or elderly, or financing mechanisms for such services, most physicians, especially those in primary care, would prefer to have a place to refer families with chronic illness [8,9]. A family support program can be the place where the medical system and the formal and informal support systems meet. The Family Support Model links families, physicians, and community services into an interconnected system.

#### 4. History of the Family Support Center

The Family Support Center at Legacy Health Systems grew out of a public education program for Parkinsonians in 1981. As the first public offering from the recently founded Neurological Sciences Center at Good Samaritan Hospital and Medical Center, the program, which was de-

veloped with the help of the M.J. Murdock Charitable Trust, was part of the educational mission of the center, along with research and clinical service. The response to an ad in the Portland paper for the program drew over 500 people and the eight-week session had to be offered at two separate times. The need for ongoing support and information led to the formation of the first support group organization. The Willamette-Columbia Parkinsonian Society, or 'Will-Cope', has grown to include dozens of local support groups and a sizeable membership.

Other groups also grew out of other educational series - Alzheimers, stroke, multiple sclerosis. The need for addressing the needs of care-givers soon became apparent in working with these chronic disease populations, and the Care-giver Education Program was developed in 1983. A survey of care-givers conducted by the center in 1982 indicated that 'a break now and then' was the most wished-for service. A subsequent grant from the Meyer Memorial Trust helped to initiate the Care-giver Respite Program and to develop a Family Resource Center and information/referral line. A series of eleven booklets have been written and are distributed nationally to help organizations develop support programs, such as in-home respite, support groups, and special programs for care-givers who also work outside the home.

The Family Support Center is a unique resource for the community. It helped to develop a visible and active Alzheimer's Association; was a founding partner of the Alzheimer Disease Center of Oregon, a collaboration of five healthcare institutions focussed on Alzheimer's research; and helped bring the Medicare Alzheimer's Project, a federally-funded demonstration project, to the hospital.

Against the backdrop of a changing medical and social environment, Family Support Services has continued to reinforce its intent of supporting chronically ill families. The graying of America has heightened interest and concern over what will become of the increasing numbers of frail or dependent elderly. The demographic trends - Oregon has the highest percentage of elderly of any state west of the Mississippi - and

the associated focus on community-based care have forced the State of Oregon to look at the growing needs of families caring for seniors or chronically ill individuals, providing the opportunity for the Family Support Center to work collaboratively with the State to develop outreach and support programs statewide. Other national grants and demonstration projects have been developed with a variety of collaborators, including county government, local agencies, and churches.

### 5. The center today

The hospital context has changed radically over the past decade. The Family Support Center originally supported only neurological patients and families and much of the care-giver activity focussed around dementia issues. Then the program broadened its scope to support all the chronic illness specialties of the hospital. In 1990, the hospital merged with another health system, and the Family Support Center became a system-wide program with resource centers developed at all four of its member hospitals, care-giver training at many locations both within and outside of the Legacy Health System, and support groups meeting in all parts of the city. The original center is still the hub of activity but much of the programming now is outside its walls.

The center offers an easily accessible, pleasant and comfortable place for individuals to come when they have questions about an illness or about caregiving for a close friend or family member who is ill. Because it is located within the hospital complex, people come to the center following a visit with a physician or other health provider or while a family member is an in-patient in the hospital. It provides a kind of safe haven in the hospital setting where their needs, rather than the disease or condition, are the focus of attention.

The basic services offered by the Family Support Center include an information resource library, information and referral service, support groups and classes. The library contains over 900

books, 240 video tapes and numerous brochures on a wide range of illnesses, on preventive and wellness topics, and on caregiving. Visitors may peruse the collection and review video or print materials in the center or borrow materials to take home. Additional books are available for purchase through a cooperative arrangement with a local bookstore which stocks the center with health and wellness books.

Through its I and R service, each month the center responds to over 1500 telephone or walk-in requests for information about community resources and referrals for health and social services. A variety of classes also are offered. These include 'Legal/Financial Planning', 'Strategies for Managing Alzheimer's', 'Understanding Insurance and Medicare', and 'Your Aging Parent: Resources for Help.'

An evening quarterly series offers programs on a variety of issues related to family caregiving. The center also publishes a newsletter for care-givers and collaborates with other organizations to develop and host conferences and special programs.

More than 20 support groups have been nurtured by the Family Support Center over the past 10 years. These support groups, whose memberships now total more than 8000 individuals, cover a broad range of illness conditions, such as Alzheimer's disease, amyotrophic lateral sclerosis, head injury, stroke, epilepsy, etc.

Finally, a respite program offers both in-home and out-of-home group respite services for family care-givers who are looking after individuals with dementia or other disability. The center currently runs two day-respite centers for mild to moderately-impaired persons with dementia, manages an in-home respite program for individuals with either physical or cognitive impairment, and maintains a listing service of individuals who are available to provide privately arranged in-home respite. Currently, the respite services manager is working with a coalition of service organizations and businesses in the African-American community of Portland to establish a multi-service program for minority elders. The program continues to evolve as the needs and context for delivering health services change.

## 6. What are the benefits of the Family Support model?

Although the benefits of the Family Support Center have not been specifically tested, there is a strong empirical foundation for the model. A number of studies have identified the key support needs of families:

- Information – about the disease and about the wide array of issues and resources surrounding it
- Skills – in planning, decision-making, problem-solving, caregiving, and coping
- Respite – from the constant demands and stresses of caregiving and care receiving
- Support – the knowledge that there will always be a place to turn, a resource center, and peer support group, or a friendly voice

What does research show about how these kinds of services improve health and well-being?

### 6.1. Information

Orem points out that learning is a prerequisite to self-care [10]. Up-to-date information is critical both for maintaining health and for managing illness. For those afflicted with chronic illnesses and their family care-givers, having information about the disease helps one to make sense of the situation, accept the illness and, ultimately, to manage it successfully. Information is needed to help individuals recognize and respond to symptoms, monitor physical indicators, utilize community services, and engage in health-promoting behaviors [11].

Patients and families facing different illnesses, such as cancer, heart disease, kidney disease, diabetes or Alzheimer's disease, face both similar and unique issues and stresses. Family care-givers of Alzheimer's families, for example, have identified a range of topics that were 'extremely important' for them, including information about the stages and biomedical aspects of the disease, medications, financial issues, behavioral issues, community services, and diagnostic procedures [12].

Information also enables consumers to make informed choices about health services utilization

and medical procedures and to know when professional consultation is necessary. Information can reduce the anxiety and fear associated with chronic disease and facilitate the recovery process. (For a discussion of relevant research, see Krantz et al. [13].) In sum, information about what is health promoting and about illnesses is an important first step toward responsible self-care and effective use of health care resources.

### 6.2. Education

Educational programs not only can offer information, but also enhance skills and self-efficacy. People with chronic disease and their family care-givers often must take on tasks that require special skills and/or knowledge. For example, they may need to learn how to attend to physical care needs, control pain, and manage the emotional aspects of illness. Care-givers of family members with dementia may have to learn how to manage difficult behaviors, such as catastrophic reactions of their relative to bathing or other daily activities. People with chronic illness also must pay special attention to health-promoting behaviors, such as nutrition, exercise, and relaxation and stress management.

In contrast to simply presenting information, education enhances skills and contributes to psychological adaptation to illness or caregiving. An important principle guiding the programs of the Family Support Center is that of self-efficacy, which emphasizes the importance not just of knowledge, but of a sense of mastery over one's illness conditions and a sense of control over one's well-being. When people have a sense of control over their health, they are more likely to engage in health-promoting behavior, to maintain a more positive attitude about their situation, and to be less likely to experience depression [14].

Efficacy-based education teaches skills needed for self-management, models positive approaches to problem-solving and overcoming difficulties, reinterprets physiological signs and symptoms, and uses persuasion to promote positive self-management [15]. Numerous studies have found a strong relationship between self-efficacy and

health behavior change and maintenance. They offer evidence that efficacy can be enhanced through educational interventions [16]. Thus, a critical role of family support programs is to teach needed skills, and - perhaps even more importantly - to promote people's confidence in their ability to maintain health and manage illness.

### 6.3. Support

People with chronic illness and family members caring for ill relatives are at great risk for depression [17,18]. The individual's perceptions about his or her level of social support can be an important factor in mediating the link between illness and depression [19]. Social support has also been shown to have beneficial effects on morbidity and mortality [20].

While families can be and often are primary supports in sharing the tasks and strains of caregiving, for a variety of reasons people who are care-givers or who are managing their own chronic illness may be reluctant or feel powerless to ask their family for help. The Family Support Center encourages individuals and family care-givers to enlist needed help and support from both the informal and formal system. Family support programs also enhance the ability of family members to be supportive and provide a substitute when family support is not available. Support groups offer an empathetic understanding that family members may be unable to duplicate (only people going through the same problems truly understand the issues and needs). Finally, just knowing there is someone there may be the key to coping with illness. The Family Support Center staff often fill this need.

### 6.4. Respite

There are times when direct services are needed to bolster the family and enable them to continue in their role as primary care-giver. Respite offers this kind of support. The services offered through the Family Support Center are designed to supplement, not replace, the care and support provided by family members. Not all

families providing care for ill or impaired relatives will feel the need for these services, but when extensive care is needed, especially when it involves stressful elements such as caring for a severely demented person, constant care, or dealing with behavioral issues, a break for the care-giver can be essential to the health and well being of both the care-giver and the care receiver. The Family Support Center helps families to problem-solve around the often complex and emotionally stressful decisions regarding where to get assistance from formal or informal sources, and, when necessary, offers supplementary help which maintains the informal caregiving system.

## 7. Benefits for the health care system

In addition to the improved health and enhanced well-being of chronically ill individuals, family care-givers, and other health consumers, the programs described in this article can have important beneficial effects on health services utilization and costs. To a very real extent, the medical care system is dependent on both self-care by the patient and care provided by the family to achieve optimum well being for individuals with chronic illness, cognitive impairment, or functional disability. Research shows that emotional factors such as anxiety and depression increase the number of visits to physicians [21,22]

Research shows that only between 12 and 25% of medical care utilization can be explained by objective disability or morbidity alone [23]. The decision to seek medical care is complex and relates not just to physical symptoms, but also to one's perceptions about the symptoms and to one's attitudes toward illness and medical care. There is significant variation in responses by different people to the same symptoms. If, for example, an individual interprets symptoms to be serious, is uncertain about its potential seriousness, and/or places a medical interpretation on the symptoms, he or she is more likely to seek medical consultation [24]. The 'worried well' syndrome is a familiar notion to physicians. Sometimes, simply providing a patient with in-

formation about his or her symptoms will reduce anxiety and alleviate the individual's need to see a medical professional. Sometimes attending to the psychological components of illness such as depression or anxiety will alleviate the need for a visit to the physician.

Lack of knowledge about services also is a major factor in utilization of non-physician services: knowing where and when to go for help can prevent more costly crisis care later. Thus, interventions to promote knowledge enhance appropriate use. In one study, for example, it was recognized that health education would both increase and decrease utilization, but its hypothesis that the net result of the intervention would be lower utilization was confirmed [25]. In another study, a randomized, controlled trial of self-care educational interventions reduced total medical visits and minor illness visits by 17% and 35%, respectively [26]. Self-care education programs can decrease medical visits, especially for minor illnesses [27,28].

#### **8. Important characteristics of the Family Support Center**

In order for the Family Support Model to function effectively, it must embrace certain important characteristics. These include both organizational characteristics as well as qualities or characteristics of the staff. Organizationally, the Family Support Center must be visible to both the professional medical community and the lay public. The center recently has enhanced its visibility and accessibility by building a window so that the resource library can be viewed from the hall where it is located, and by placing signs and a book drop slot in a strategic location. An unanticipated benefit from these changes was an increase in the number of physicians who drop in seeking assistance with caregiving needs in their own families. This provides an opportunity to demonstrate on a personal level what we can offer their patients.

Location, of course, is not the only key to accessibility. On-going advertising of the center and its programs is necessary both internally

within the medical center and outside to physicians, community service programs and the public through advertising.

In the fast-paced world of medicine, it is critical to stay abreast of the latest developments in medical research, technology and educational approaches. Medical knowledge is advancing at astronomical rates. In order to provide useful information for health consumers, it is critical that printed materials be kept current. While the staff of the center are not medical experts, they must be attentive to new developments in health care. Reading literature on the latest research findings on maintaining health and treating illness is an important responsibility for the staff of the center.

It is equally important to maintain personal communication with physicians. The Family Support Center originally was located in a tertiary facility, and staff worked primarily with neurologists, oncologists, and other specialists. Currently, there is an emphasis on communication with primary care physicians as well. Ways to link with medical clinics programmatically through placement of educational materials in physician offices, and technologically through computers are being explored. The center also maintains a Medical Advisory Committee to maintain communication with physicians.

Technology can be a valuable tool to disseminate up-to-date information to lay consumers. It offers the opportunity to effectively achieve the goal of an educated healthy lay public through the use of the latest in technology and through innovations in educational approaches. In Oregon, for example, a statewide broadcasting technology has developed which allows educational programs to be delivered to rural communities. On a smaller scale, videotapes offer a useful educational medium which individuals can view at the center or borrow for more convenient home viewing.

Staying abreast of state-of-the art educational approaches also helps the center to achieve its goals. The center's interest in efficacy-based education, for example, derives from our participation in and monitoring of patient and caregiver education research. The principles of ef-

ficacy-based training are woven into the programs available through the center, as well as defining the staff's approach to working with individuals and families.

The center continues to monitor its efforts to insure that it accomplishes its objectives. The Family Support Center has utilized both university-based researchers and a staff researcher to carry out program evaluations and research relevant to its mission. The staff researcher has studied the psychological and program barriers to help seeking for care-givers of dementia patients. Understanding these barriers has helped to insure that the center tailors its program to reach its target audiences.

How staff and volunteers relate to and work with the consumers of the center also is a key to its success. It is very important when working with families to understand the process they go through in adapting to an illness and/or one's role in helping an ill family member. Taking on the role of care-giver is not easy for most people. It involves several critical transition points including acknowledging the infirmity of the individual; accepting responsibility to provide physical care; making care decisions with or for the person, especially if dementia is involved; and arranging for formal services and/or institutionalization for their loved ones. These decisions are often fraught with a great deal of conflict and emotional turmoil.

Experienced staff and volunteers understand that individuals need time and on-going support in order to confront and deal with these issues emotionally and practically. Developing a relationship over time is an important component of providing support for families coping with chronic illness. The staff member can be a valued contact person whose support and knowledge may not be needed for long periods of time, but for whom the patient or family care-giver is grateful if a special need arises. Time allows trust to build and information to be provided to families in small doses and in timely fashion. The on-going relationship the center maintains with families offers the opportunity to deliver the message of ways to maintain health and utilize both formal and informal support through a

variety of mechanisms, including newsletters, one-to-one contact, and classes, all of which reinforce the philosophy of the center.

The professional is consultant rather than manager of care or maker of care decisions. It is important that providers always view the care-giver (or patient) as the person in charge. The philosophy of Legacy Family Support Services is embedded in its motto, 'You're not alone.' The center provides families with the tools they need to be active and respected partners in their own or their affected family member's care while they are empowered to advocate and manage the quality of their own lives in the process.

## 9. Conclusions

As more and more people face chronic illness or frailty, a place within the health care system to address the needs of individuals and families becomes even more critical to sustaining their optimum health and psychological well being. Family support programs help consumers make informed choices regarding when and where to get help, enable them to take responsible care of themselves, enhance knowledge of how to stay well, bolster informal support systems, and provide essential support for maintaining a positive attitude.

There is substantial evidence that the Family Support Model will reduce the costs of medical care by enhancing the effective use of medical services and reducing visits for minor illnesses. With the current changes in healthcare the value of a family support program has taken on new meaning. As the system continues to evolve in the effort to improve its efficiency and effectiveness, the Family Support Center will continue to meet the changing healthcare needs of the elderly and of individuals with chronic illness. Helping families help themselves now fits even better.

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Ms. TAKAMURA. Thank you, Leah, for bringing the photographs, also.

Our final panelist for this afternoon is Connie Ford who is vice president for Product Development and Services for AdultCare, which is situated in Deerfield Beach, FL.

**STATEMENT OF CONNIE FORD, RN, MPA, VICE PRESIDENT,  
PRODUCT DEVELOPMENT AND SERVICES, ADULTCARE,  
DEERFIELD BEACH, FL**

Ms. FORD. Thank you and good afternoon. I am both thankful and honored to have the opportunity to participate in today's event and to share with you some of the innovative ways that AdultCare, a Fortis Company, is committed to making a difference in the lives of family caregivers.

On a personal note, I am a health care professional who is educated at the Johns Hopkins Hospital. Although I have a broad health care delivery and systems perspective, it was not until our company began to focus on the caregiver that I became aware of the serious issues surrounding family caregiving. Because these issues impact so many lives I have become personally and professionally dedicated to finding ways to help and advocate for caregivers.

The mission of AdultCare is to assist individuals and their families in making informed choices that lead to a better quality of life throughout the aging process. Information, education, advice, and support services are provided to members who are struggling with the dilemmas of elder care, as well as planning for or attempting to understand their own aging process. The provision of service is typically over the phone, and it is usually followed with printed material that is specific to identified needs.

More information about AdultCare, its history and services, is in a handout. If you do not have one, I will be happy to supply one at a later time.

This afternoon, though, we are directing our attention to programs that are easing the family caregiver burden and, therefore, I would like to focus on this work that AdultCare is doing.

We recognized that in order to best serve caregivers we needed to better understand them. We gathered information from many sources and also initiated our own research among the 6,500 U.S. Fortis employees. To date, two employee surveys have been conducted approximately a year apart. Thirty percent of Fortis employees are active caregivers and another 6 percent expect to be soon. The survey findings were utilized to create solutions to better meet employee needs and to reduce the impact that caregiving is having within the Fortis family of companies.

AdultCare developed its unique Productive Aging Program for Fortis' long-term care insurance policyholders and their families. This comprehensive service was initiated because long-term care is much more than just a financial issue. Fortis is a caregiver-friendly company. Its long-term care insurance policies feature caregiver training, personal care advocacy, and respite, all in addition to planning, prevention, problem solving, and positive support, which are the core components of the Productive Aging Program.

Fortis Long-Term Care is a corporate partner with the National Family Caregivers Association. A little more than a year ago, the NFCA and AdultCare began an intervention study to show whether or not information, consultation, and resource services provided by AdultCare make a significant difference in the lives of NFCA member caregivers. A preliminary preview of the midpoint measuring appears quite promising, and we look forward to sharing these results early in 1999.

Simultaneously, we, as a company, have been moved by the findings of the initial survey that was the basis for determining the active and control groups in the intervention study. In spite of the tremendous physical and psychological challenges they face daily, NFCA members who are primarily intense caregivers continue to persevere. They are a remarkable, yet commonly unrecognized and unrewarded, human resource in America. Today, I also have distributed a copy of "Caregiving Across the Lifecycle: An NFCA/Fortis Report." And, again, I will be happy to get you copies if you do not get one.

In addition to providing research and participating in a collaborative relationship with the NFCA, AdultCare practices its philosophy of being an active public/private partner by assisting other organizations. Materials on caregiving developed by AdultCare and reviewed by the National Alliance for Caregiving have been given to the National Council on Aging, and they are currently in their Web site under Family Care Resources. Selections from our Caregiver series are in the handout, and they include some information on tax relief for caregivers.

Locally, AdultCare is actively participating in community solutions. Members of our senior management team serve on different boards, including disease-specific organizations such as the Parkinson's and the statewide Alzheimer's Disease Initiative with Mr. Lipscomb.

Furthermore, AdultCare has fully supported an effort to provide volunteer services to persons who are homebound and/or their caregivers. Funded by a Robert Wood Johnson grant we helped to submit, Boca Raton Interfaith in Action was formed as a multi-generation initiative of support and assistance to the unified efforts through the unified efforts of religious organizations, community agencies, and dedicated people. A brochure with more details on this project is also in the handout, and this was created and people became very much aware that even in Boca Raton there are caregiving issues.

Finally, AdultCare is seeking ways to reach out and to advocate on behalf of caregivers through its Web site, publications, conferences, and all forms of media. A column, on your behalf, has been created in Today's Caregiver magazine in an effort to provide feedback to caregivers about pertinent legislation and what they can do to communicate their needs and concerns.

So, in conclusion, Adultcare and Fortis Long-Term Care are consistently and continually trying to understand and respond to needs of caregivers. We seek to collaborate as an active and valuable partner in developing greater awareness of caregivers and issues, as well as programs that provide assistance and solutions.

**As consultants, educators, and advocates, AdultCare seeks to improve the lives of a great American treasure—the family caregiver.**

**Thank you.**

**[The prepared statement of Ms. Ford follows:]**

## **U.S. SENATE SPECIAL COMMITTEE ON AGING**

### **"EASING THE FAMILY CAREGIVER BURDEN: PROGRAMS AROUND THE NATION"**

**AdultCare, Inc., a Fortis Company**

*The mission of AdultCare is to assist individuals and their families in making informed choices that lead to a better quality of life throughout the aging process.*

**PRESENTATION**

**Connie Ford, RN,MPA  
Vice President**

GOOD AFTERNOON. I AM BOTH THANKFUL AND HONORED TO HAVE THE OPPORTUNITY TO PARTICIPATE IN TODAY'S EVENT AND TO SHARE WITH YOU SOME OF THE INNOVATIVE WAYS THAT ADULTCARE, A FORTIS COMPANY, IS COMMITTED TO MAKING A DIFFERENCE IN THE LIVES OF FAMILY CAREGIVERS.

ON A PERSONAL NOTE, I AM A HEALTH CARE PROFESSIONAL WHO WAS EDUCATED AT THE JOHNS HOPKINS HOSPITAL. ALTHOUGH I HAVE A BROAD HEALTH CARE DELIVERY AND SYSTEMS PERSPECTIVE, IT WAS NOT UNTIL OUR COMPANY BEGAN TO FOCUS ON THE CAREGIVER, THAT I BECAME AWARE OF THE SERIOUS ISSUES SURROUNDING CAREGIVING. BECAUSE THESE ISSUES IMPACT SO MANY LIVES, I HAVE BECOME PERSONALLY AND PROFESSIONALLY DEDICATED TO FINDING WAYS TO HELP AND ADVOCATE FOR CAREGIVERS.

THE MISSION OF ADULTCARE IS TO ASSIST INDIVIDUALS AND THEIR FAMILIES IN MAKING INFORMED CHOICES THAT LEAD TO A

BETTER QUALITY OF LIFE THROUGHOUT THE AGING PROCESS. INFORMATION, EDUCATION, ADVICE AND SUPPORT SERVICES ARE PROVIDED TO MEMBERS WHO ARE STRUGGLING WITH THE DILEMMAS OF ELDERCARE AS WELL AS PLANNING FOR, OR ATTEMPTING TO UNDERSTAND, THEIR OWN AGING PROCESS. THE PROVISION OF SERVICE IS TYPICALLY OVER THE PHONE, AND IS USUALLY FOLLOWED WITH PRINTED MATERIAL THAT IS SPECIFIC TO IDENTIFIED NEEDS.

MORE INFORMATION ABOUT ADULTCARE, ITS HISTORY AND SERVICES IS IN YOUR HANDOUT.

THIS AFTERNOON WE ARE DIRECTING OUR ATTENTION TO PROGRAMS THAT ARE "EASING THE FAMILY CAREGIVER BURDEN". THEREFORE, I WOULD LIKE TO FOCUS ON THE WORK THAT ADULTCARE IS DOING IN THIS PARTICULAR ARENA.

WE RECOGNIZED THAT IN ORDER TO BEST SERVE CAREGIVERS, WE NEEDED TO BETTER UNDERSTAND THEM. WE GATHERED INFORMATION FROM MANY SOURCES AND ALSO INITIATED OUR OWN RESEARCH AMONG THE 6500 US FORTIS EMPLOYEES. TO DATE, TWO EMPLOYEE SURVEYS HAVE BEEN DONE APPROXIMATELY 18 MONTHS APART. THIRTY PERCENT OF FORTIS EMPLOYEES ARE ACTIVE CAREGIVERS AND ANOTHER SIX PERCENT SOON EXPECT TO BE. THE SURVEY FINDINGS WERE UTILIZED TO CREATE SOLUTIONS TO BETTER MEET EMPLOYEES NEEDS AND TO REDUCE THE IMPACT THAT CAREGIVING IS HAVING WITHIN THE FORTIS FAMILY OF COMPANIES.

ADULTCARE DEVELOPED ITS UNIQUE PRODUCTIVE AGING PROGRAM FOR FORTIS LONG TERM CARE INSURANCE POLICYHOLDERS AND THEIR FAMILIES. THIS COMPREHENSIVE SERVICE WAS INITIATED BECAUSE LONG TERM CARE IS MUCH MORE THAN JUST A FINANCIAL ISSUE. FORTIS IS A "CAREGIVER FRIENDLY" COMPANY. ITS LONG TERM CARE INSURANCE POLICIES FEATURE CAREGIVER TRAINING, PERSONAL CARE ADVOCACY AND RESPITE, ALL IN ADDITION TO THE PLANNING, PREVENTION, PROBLEM SOLVING AND POSITIVE SUPPORT COMPONENTS OF THE PRODUCTIVE AGING PROGRAM.

FORTIS LONG TERM CARE IS A CORPORATE PARTNER WITH THE NATIONAL FAMILY CAREGIVERS ASSOCIATION (NFCA). A LITTLE MORE THAN A YEAR AGO, THE NFCA AND ADULTCARE BEGAN AN INTERVENTION STUDY TO SHOW WHETHER OR NOT INFORMATION, CONSULTATION AND RESOURCE SERVICES PROVIDED BY ADULTCARE MAKE A SIGNIFICANT DIFFERENCE IN THE LIVES OF NFCA MEMBER CAREGIVERS. A PRELIMINARY PREVIEW OF THE MID-POINT MEASURING APPEARS QUITE PROMISING. WE LOOK FORWARD TO SHARING THE RESULTS EARLY IN 1999.

SIMULTANEOUSLY, WE AS A COMPANY HAVE BEEN MOVED BY THE FINDINGS OF THE INITIAL SURVEY THAT WAS THE BASIS FOR DETERMINING THE ACTIVE AND CONTROL GROUPS IN THE INTERVENTION STUDY. IN SPITE OF THE TREMENDOUS PHYSICAL AND PSYCHOLOGICAL CHALLENGES THEY FACE DAILY, NFCA MEMBERS WHO

ARE PRIMARILY INTENSE CAREGIVERS, CONTINUE TO PERSEVERE. THEY ARE A REMARKABLE YET COMMONLY UNRECOGNIZED AND UNREWARDED HUMAN RESOURCE IN AMERICA. TODAY I HAVE ALSO DISTRIBUTED A COPY OF "CAREGIVING ACROSS THE LIFE CYCLE: AN NFCA/FORTIS REPORT".

IN ADDITION TO PROVIDING RESEARCH AND PARTICIPATING IN A COLLOABORATIVE RELATIONSHIP WITH THE NFCA, ADULTCARE PRACTICES ITS PHILOSOPHY OF BEING AN ACTIVE PUBLIC/PRIVATE PARTNER BY ASSISTING OTHER ORGANIZATIONS. MATERIALS ON CAREGIVING, DEVELOPED BY ADULTCARE AND REVIEWED BY THE NATIONAL ALLIANCE FOR CAREGIVING, HAVE BEEN GIVEN TO THE NATIONAL COUNCIL ON THE AGING FOR USE IN THE FAMILY CARE RESOURCES DIVISION OF THE NCOA WEB SITE. SELECTIONS FROM OUR CAREGIVER SERIES ARE IN THE HANDOUT.

LOCALLY, ADULTCARE IS ACTIVELY PARTICIPATING IN COMMUNITY SOLUTIONS. ALL MEMBERS OF OUR SENIOR MANAGEMENT TEAM SERVE ON A VARIETY OF BOARDS INCLUDING DISEASE SPECIFIC ORGANIZATIONS SUCH AS PARKINSON'S AND THE STATEWIDE ALZHEIMER'S INITIATIVE. FURTHERMORE, ADULTCARE HAS FULLY SUPPORTED AN EFFORT TO PROVIDE VOLUNTEER SERVICES TO PERSONS WHO ARE HOMEBOUND AND/OR THEIR CAREGIVERS. FUNDED BY A ROBERT WOOD JOHNSON GRANT WE HELPED TO SUBMIT, BOCA RATON INTERFAITH IN ACTION WAS FORMED AS A NEW MULTI-



GENERATIONAL INITIATIVE OF SUPPORT AND ASSISTANCE THROUGH THE UNIFIED EFFORTS OF RELIGIOUS ORGANIZATIONS, COMMUNITY AGENCIES, AND DEDICATED PEOPLE. A BROCHURE WITH MORE DETAILS ON THIS PROJECT IS IN THE LAST SECTION OF YOUR HANDOUT.

FINALLY, ADULTCARE IS SEEKING WAYS TO REACH OUT TO AND ADVOCATE ON BEHALF OF CAREGIVERS, THROUGH ITS WEB SITE, PUBLICATIONS, CONFERENCES AND ALL FORMS OF MEDIA AVAILABLE. A COLUMN, "ON YOUR BEHALF" HAS BEEN CREATED IN TODAY'S CAREGIVER MAGAZINE IN AN EFFORT TO PROVIDE FEEDBACK TO CAREGIVERS ABOUT PERTINENT LEGISLATION AND WHAT THEY CAN DO TO COMMUNICATE THEIR NEEDS AND CONCERNS.

IN CONCLUSION, ADULTCARE AND FORTIS LONG TERM CARE ARE CONTINUALLY AND CONSISTENTLY STRIVING TO UNDERSTAND AND RESPOND TO THE NEEDS OF CAREGIVERS. WE SEEK TO COLLABORATE AS AN ACTIVE AND VALUABLE PARTNER IN DEVELOPING GREATER AWARENESS OF CAREGIVERS AND ISSUES AS WELL AS PROGRAMS THAT PROVIDE ASSISTANCE AND SOLUTIONS FOR CAREGIVING. AS CONSULTANTS, EDUCATORS AND ADVOCATES, ADULTCARE SEEKS TO IMPROVE THE LIVES OF A GREAT AMERICAN TREASURE...THE FAMILY CAREGIVER.

THANK YOU.

Ms. TAKAMURA. Connie, I would like to thank you for sharing all that information with us. I would actually like to thank each and every panelist.

We have a few minutes during which we can entertain questions from the audience, many of whom are themselves experts. So whether it is a statement or a question, I invite your participation. Let's see if there are any comments or questions that come to mind. I know I have at least three.

This is a question for any panelist. We have heard several times today that it is crucial that health care professionals receive training in caregiver education in geriatric medicine and exposure to older Americans. How do you suggest we ensure that this occurs?

Susan and Bentley, you both made some comments about professionals; Susan from a nursing perspective, and Bentley was talking about doctors being core to a team.

Mr. LIPSCOMB. First of all, that I think it is, while I would not characterize it as a waste of time to go for everybody else and leave out the doctors, they are the ones that drive the system as a general rule and, unless you get them, it is going to be a rough road to travel for the rest of them. So I would do that.

We went to the legislature for 5 years in a row saying mandate the M.D. schools to put a basic geriatric track in the curriculum. They steadfastly refused to do so because the dean said their students were not interested in treating old people. So this last year we finally got an incoming speaker who decided it was important. So he chose the one university that had a research capacity and said, "Would you like to have a medical school?" and they said, yes, and so now we are creating the Ford M.D. School, which will be focused on primary care and geriatric medicine.

So what you need is somebody like the speaker you heard at lunch, who takes it on as a personal challenge to get it done, and then it will probably happen. But as was mentioned in the testimony before the committee this morning, there are 142, I think, medical schools in the U.S. and nine of them have a geriatric track in their basic curriculum. So that tells you where we are in this process. It is a major, major problem in terms of education and policy change, and it is something we are going to have to deal with.

Ms. FRIEDMAN. I agree. when you are dealing with an older person, very often they believe the doctor's opinion is infallible. If doctor says X or Y, that is the way they are going to go, regardless of what their caregiver thinks or knows.

However, because it is so difficult to impact the medical profession, particularly at the training level we are focusing upon funding training of other professionals on the frontlines of care, particularly home health aides. Our JVS program trains home health aides in caregiver relations. It is also choosing people for this program who are mature adults, who have some personal experience. I think you start by educating homecare providers, and allied professionals. We are now actually looking at a proposal, which is examining what is called the infusion method of training, something that has been done with sexism and racism and now, ageism. The goal is to take professional programs and to infuse aging services issues and education into social work schools, allied professions

curricula. I think you cannot just wait for it to happen with the doctors. I think you need to work at all of the different levels.

Ms. TAKAMURA. As someone who taught both in the School of Medicine and School of Social Work, I am going to make some comments about that. Susan.

Ms. REINHARD. I think you have to sneak it in. We have been working with the Medical Society, University of Medicine and Dentistry, the Board of Nursing any way we can, and you have to find an issue that is sexy to them. It could be cardiac surgery, just as you were saying, you have to find something. The ER physicians have no clue they are going to have somebody with Alzheimer's disease. You start having meetings with them and start to introduce the material to them, and if you can, get the board of medical examiners or especially the Medical Society, to buy into this. Right now I am working with them on pharmaceutical products and how we want to change the way seniors are getting too many medications. We are actually putting a system in place, where a senior will go in, and if the medication is too much, the system will not pay for it. It is called a hard edit. This gives me entree to talk to every doctor's group that I can, and then I can start talking about seniors, and then I can start talking about their family caregivers. But I think you have to do it constantly and everywhere you can.

Ms. TAKAMURA. Thank you. Connie.

Ms. FORD. I would just like to comment that there has also been a growing trend in physician house calls and physician home care, and there is an American Academy of Homecare Physicians, and I think that they are ones that are very motivated to respond to caregiver needs.

Ms. TAKAMURA. Leah.

Ms. ESKENAZI. Well, just to comment, not necessarily on developing geriatric training programs, but it has been interesting what we have found having a Resource Center at the hospital, a Family Resource Center, that we are realizing doctors have families too. So, just recently, I am noticing that we have a lot of Baby Boomer doctors, and they are starting to care for their parents, and so they are starting to seek out. And I'll tell you, when it starts hitting them personally, we are starting to get more interest. So that has helped us to educate through a few doctors reaching their professional groups and then they have been the vehicle for us to educate or like a clinic group of doctors.

So we have kind of gone the other way. We have gone from the individual doctor to their groups that they are working with. And then, of course, with the medical students, it has been an incredible experience, and I would encourage you to try to make those efforts, in terms of reaching the medical schools in your community. But we did work through the Neurology Department, so maybe a different group.

Ms. TAKAMURA. Again, as someone who taught in the School of Medicine and also the School of Social Work back in Hawaii, Bentley, your comments are well-taken—but I think we also need to recognize that there is a tremendous need for nurses, and social workers, and allied health professionals because they oftentimes see older persons more frequently.

It is a concern however, that many programs across the country are pulling their geriatric training programs back because educational institutions are unable to support specialty studies, given their budgets. Perhaps in Florida you can, but not in all places across the country.

Mr. LIPSCOMB. No. We never suggested to train geriatricians. What I want and what I said to the legislature, if my dad goes into the emergency room at 2 in the morning, I want to know that the family practice physician, the internist or the ER doc that he or she is going to run into at that point in time has some idea of what an older person is.

Ms. TAKAMURA. Yes, I agree with you. In a meeting a week ago, I met with representatives from three of our professional associations. I asked them to take back to their associations the fact that the number of months or years dedicated to professional training has not been extended, but the body of knowledge has increased. It is extremely difficult to get more content into an already full curriculum.

Obviously, this is another area for discussion. We have a few more questions. This question is a very compelling one. It is one that a lot of people have thought about. Since caregivers often do not self-identify, how can you reach them to let them know about your programs?

Mr. BROWDIE. We will just take a first shot because I am sure there are all kinds of good ideas.

What we found is that other gatekeepers to family contact are the most, if you will, profitable for us to go through—clergy, physicians, practices, pharmacies, and other related health professionals. I would like to say that the hospitals have been a productive area for us. The discharge planners remember for a week or two, but their lives are so bedeviled by the time pressures, that it really is not quite as effective. We have had great success in working with other community gatekeepers that wind up being very effective. These are people that knock on their door all of the time, and they really do not know what to do.

Ms. KELLY. We have found that we have to continually market and we have to use the media all of the time to put the message out. This is a continual effort, and it is really one of the barriers to service because you do need to have outreach efforts to educate families that are funded on an ongoing basis.

We find that when families contact us the first time, about over half have never contacted another formal social service program prior to giving us a call. Our main sources of referral are from health and social service agencies. We make repeat calls, hold in-services, and send materials routinely. It is a big effort, and it has to be built into the budgeting process for a program.

Ms. REINHARD. I agree with the earlier statements, but I think that it is one thing to outreach and it is another thing to make sure people know where to call. We have got so many different numbers out there; you know, call the day-care center, call this one. Our goal is to have one number for all senior services and plaster it everywhere. And when you call that one number, the answer will go to that county that the person called, and it will be a local person talking to them. So they only have to remember one number for

anything to do with senior services. I believe Bentley already has this in Florida, perhaps, but it has to be simple.

Mr. LIPSCOMB. Yes. We just have 1-800-96-ELDER.

Ms. FRIEDMAN. I also think we need to use these faith-based communities that I was trying to talk about as quickly as I could at the end of my presentation. I think that they are an excellent access point for older people and for caregivers. In the project that we have been funding with synagogues, for instance, we have found that older people will go and talk to their minister or their rabbi, et cetera, before they will go to a social service agency because that is like talking to family.

So I think that we need to work with the interfaith coalitions that exist and really try to get the word out that way, as well.

Ms. FORD. Well, and even in addition to people who are caregivers, who identify themselves as caregivers, it is hard to get them to recognize that programs are for them. Our whole system is so patient-centered that it has taken us a while, and even in the intervention study, to let caregivers know that, no, this is for you.

Ms. ESKENAZI. On that same line, I think we have given people the name "caregiver," and they may not identify themselves that way. So a lot of the programs that we offer, legal and financial training, Medicare, deciphering the Medicare system, et cetera, we do not say you have to be a caregiver to come. But once they get there, we tell them that is who they are. So it is sort of a—it is our way of educating them, in a way.

Ms. TAKAMURA. There is a question for Connie Ford.

Connie, you mentioned in your presentation that you received a Robert Wood Johnson grant. The question from the audience is, is not your organization a for-profit organization?

Ms. FORD. Our organization is a cost center of Fortis Long-Term Care. The grant was received by the Community Interfaith Coalition, which is a not-for-profit organization in Boca Raton, and myself and others of our staff helped to write the grant using Fortis or AdultCare resources to get this program off the ground. But we have no receipt of the funding, and all of our services are volunteer.

Ms. TAKAMURA. This is a question directed at Bentley. I am going to abbreviate the question and welcome any of the panelists to respond.

It seems that family caregivers can teach policymakers a lesson; that is, that they really need to provide care no matter what the bureaucratic obstacle might be. Are you saying that we in Government should not only offer support, but that we should also remove obstacles too by integrating our health and social services for the elderly?

I probably should have abbreviated it even further.

Mr. LIPSCOMB. Ask it again. [Laughter.]

Ms. TAKAMURA. All right. So the question is, if you look at system change, should we be offering support, and be doing a better job of integrating our health and social services for our older people?

Mr. LIPSCOMB. I do not see that as being the issue. I think we are doing that, and I cannot go anywhere where I do not see my counterpart in any of the 50 States trying to do that or the area

agencies trying to do it at the local level. But you cannot put square pegs in round holes, and we have got the best acute care system in the world when it comes to medicine and treating people. You go see the doctor. The doctor makes you well. The doctor sends you home.

That does not happen in long-term care. Many times the client is at the high point when they walk through the door, and from that point on they go steadily downward, so what you are trying to do is maintain them or make them as comfortable as you can. We do not have a system that is set up to deal with that, and that is why the deans of the schools of medicine do not want to fool with long-term care because it does not fit into their game plan. It does not fit into their medical students' game plans because these people do not get well. You do not cure things like Alzheimer's and emphysema, and chronic hypertension, and all of the kinds of things that the caregivers have to cope with.

So we need a system that is logical, and evolved, and makes sense on a continuum to take care of those people and supports those caregivers, and it is going to have to basically be a separate system.

We have not mentioned all day today the fact that the Federal programs contribute to the mass confusion out there. I have seen no old people come into my purview that have this half of them as Medicare and this half of them as Medicaid, but that is the way we have to relate to them because the two systems are not integrated. You cannot treat them as a whole person. You have to treat them based on the funding flow from the particular system that is paying for it, and it just does not work.

Now, we have got some waivers in our State—I am sure Rich probably has or Susan has. I know Minnesota does, Arizona does—to try to put the pieces together. But these programs were created in 1966. Unless I missed something, a lot has changed since 1966, particularly the age of the people we are dealing with right now. And so maybe it is time to rethink the whole legal base of this thing and the system base of this thing and come up with something that makes more sense in the environment that we are dealing in today.

Ms. TAKAMURA. Would any of the panelists like to add to that?

[No response.]

There is another question from the audience.

The question makes the point, first of all, that there certainly is a diversity in the range of services out there in the community, both public and private. The question is how are you working together with the private sector to ensure that they also are able to provide services to people who, perhaps, can make use of them?

Ms. REINHARD. I think that is a great question. I do not pretend that New Jersey is out there on the cutting edge on this, but that is where we are going to start looking—on what are employers doing, not a small program, but what is their level of consciousness about the Baby Boomers that work for them, maybe are them? The productivity data we have got this morning is compelling. What do they want to do? How can we partner with them? So, in about 2 weeks, we have a meeting with the New Jersey Business and In-

dustry Association to start brainstorming around this area. I do not have any answers, and I would love to know if anyone does.

Although I can say in terms of working with individuals and using their own private resources, that is something that has to be done very, very carefully. I do not think we should just look at you are Medicaid or you are not. I think, of course, efforts to do sliding scale fees are important. The area agencies are struggling with how can you have cost share and the dollars that come from the Older Americans Act? But we should not just put people in these little corners, and part of our trouble is that programs are organized into those little pots of money, and it is difficult to pull them all together. In our State, we are trying to do that through the single-point-of-entry system and break down the barriers between the funding, but that is a different issue than trying to get corporate dollars or other kinds of private dollars.

Ms. FORD. Well, and just as Bentley had said, that things have changed since 1966. They have in the employer segment too, and many of the larger companies are providing some caregiver support services, but it is the smaller companies that are really being impacted, and that is the area that needs to be addressed.

When I went to the Chamber of Commerce looking for support in funding for our Interfaith and Action Project, I was told, "Caregiving? I have never heard of that," and I have 2,000 employers.

Mr. LIPSCOMB. Yes.

Mr. BROWDIE. Actually, we have a fair number of employers who use our local agencies as technical assistance resources, really, in designing programs and also trying to design fits between publicly funded benefits and employer-based benefits. But as you just indicated, the big issue are the small employers who really do not feel that they are able to mount anything like an extensive program, and they are bumping into overtaxed publicly funded systems. So the relationship kind of goes like, "Well, gee, we could really work out a nice deal if we did not have a waiting list or you did not have the financial barriers that you have as a corporation."

Ms. FRIEDMAN. When I worked for the New York City Department for the Aging, we started something called Partnership for Elder Care in 1983 with some of the major corporations. But what the continuing issue was, and this is the major corporate level, but I am sure it applies for smaller businesses, is that you need to have a long-distance capability.

The more than 600 area Agencies on Aging across the country certainly should have that kind of capability as a network to be able to help a New York City base employee a caregiver help mom in Missouri. As the program in New York City evolved, one of the issues for it was to start developing that because large corporations demanded it. We are a mobile society, any business, any small business that you are going to work with is going to need that as well.

Ms. TAKAMURA. Bentley.

Mr. LIPSCOMB. About 2 years ago we came to the conclusion that my colleagues up here are saying. That is I do not know why we assume that the business community does not have to be educated the same as everybody else, but they do. And so we started making

a conscious effort to go talk to Economic Development Councils, to talk to Chambers of Commerce, to talk to different kinds of groups.

We even put out specific printed materials that talk about what is the elder market in the State of Florida; why should you be concerned about it; what do the demographics look like; how much is it going to cost you to take care of these people that you are luring down here to retire—you know, different kinds of questions like that, that they had never thought about before because it never dawned on anybody that there might be a contingent liability associated with some of these people where folks were saying, "Come on down," and they were by the hundreds of thousands. So we do not have as many people doing that any more now, and I think they are very receptive. They are a lot more receptive than the deans of the medical schools are, I can tell you that much. [Laughter.]

Ms. TAKAMURA. I have a question here is that is directed to the committee staff. It asks about or notes that Alzheimer's disease is not recognized as a disease requiring skilled nursing care, hence homecare, nursing home costs for Alzheimer's patients are not covered by Medicare. Of course, the question is, is any legislation in place to allow Medicare to contribute to nursing home or homecare for Alzheimer's patients? The follow-up question is what can caregivers do to expedite this legislation?

I am going to ask the individual who posed this question to meet after the forum with the staff who are here. I would like to see if we can meet our obligation to leave this room by 4 o'clock.

Another question is one directed to Secretary Browdie, about his program. I will ask that the individual who raised the question to meet with Rich after the forum, because it is a very specific question.

Let me wrap the forum up this afternoon with two questions that are a little difficult, but worth considering.

The first one is what do you do when the person who is sick or who needs long-term care is alone and depends upon friends who are not as, perhaps, committed as family members? Oftentimes these are individuals who are in denial about their illness, wait too long to get in the appropriate care, and as a result of that, decline even more rapidly.

Does anyone want to take that one on? Connie. Susan, go ahead.

Ms. FORD. I think that that is a really difficult question, and that is one of the, I guess, advantages for knowing what community other volunteer efforts and what other community support services are available.

I know that through the National Federation of Interfaith Volunteer Caregivers they have done some really amazing work in providing care such as that, and it works the other way around too. We had a call just the other day from California, where a woman had taken in a friend who had Alzheimer's who she thought was going to live a short time and now it is 4 years later, and she is going out of her wit's end and does not know what to do.

Ms. REINHARD. I was going to say, we run into this a lot, particularly with Adult Protective Services, which is also a part of our department. And balancing protection versus independence; recognizing that people are adults and are independent decision makers. It



really is intensive work with the individual and family, if you can find them, and certainly friends—assuming that you think they need more help than they want to receive or they need to move. We have found, in those circumstances, usually a peer, an age peer does better in talking with the senior than a professional staff person.

Do you want to add to that?

Floor Question. I really feel nobody has mentioned the power-of-attorney for adults. I think it is very important to educate older people to be sure that they have that and that gives you a tool.

Ms. TAKAMURA. Power-of-attorney?

Floor Question. Power-of-attorney for health care.

Ms. TAKAMURA. Power-of-attorney for health care. Yes, Bentley.

Mr. LIPSCOMB. I think the first question you have got to ask is how much money does the person have? If they have got financial resources, you go one direction. If they do not have financial resources, then you have to go another direction. And, again, if they have a power-of-attorney, they have dealt with it. But if they do not, then what you have got to do is go to court and get a guardian of the person and the property, and then that person can do it. If they have no resources, there is no point going through that step because, you know.

Then you have to decide if they qualify for nursing home care. If they do, then that is probably—well, what else are you going to do with them? Somebody, you know, you might get a person that takes them in for 4 years, but that is not the norm. That is an exceptional kind of case, where somebody is willing to make that kind of sacrifice. Most of the time we basically take the point of view, if it is less expensive to support them in the community, we support them in the community. At the point it costs more to take care of them in the community than it does to put them in a nursing home, they go in a nursing home.

Ms. TAKAMURA. Perhaps, Bentley, to step back even further, perhaps as a nation we have to do a better job of preparing everyone for the possibility of long life. A very good friend of mine has kiddingly said to a group of our friends that she has decided that we will all live together at her home—it is very spacious. She has invited our hairdresser to also share the house with us. [Laughter.]

So is her form of planning. We all need to plan.

Let me move to a final end-of-forum question. It is about an end-of-life issue. Can any of you speak about plans in the work to address end-of-life care as it relates to caregivers?

Ms. REINHARD. I am not sure what you mean. As it relates to caregivers? Do you mean how to help them work with the family member at the time?

Ms. TAKAMURA. I am not quite sure. It is a pretty general question, about end-of-life care, which many people feel has not been given enough attention—hospice and other forms of end-of-life care.

Floor Question. Working with the Center to Improve Care for the Dying, part of what we are saying is, as the numbers increase, the complexity and the volume is going to become significant, and we do not have caregiver forces to prepare for that. So it is working with private area direct-care managers with health care systems. How else can we step up—

Ms. REINHARD. So you mean preparing family caregivers to provide care at end of life.

Floor Question. Well, it is looking at what kind of legislation policy do we need to have in place in order to support these persons as the complexities increase.

Ms. REINHARD. Well, I speak for New Jersey. End-of-life decisions, end-life-care is a very, very large and important issue in New Jersey. This is home of the Karen Ann Quinlan, Paul Armstrong, a RWJ Foundation funded support study, a follow-up with Comfort Care and, of course, as you know, there is a whole new grant proposal that states have recently submitted—I think it was in June or July—for a more policy-oriented approach on how you are going to deal with end-of-life issues to open up that dialog with families, with professionals, with policymakers. So I think it is multiple strategies.

I think in terms of nurse delegation, that very specific area, trying to work with boards of nursing is an issue in every State. We have it in our State, but only in assisted-living and in foster care, not homecare. So it seems to be setting-specific at this point. I think it is going to have to be put in the whole context of that protection concept again and letting go. There is a great deal of fear, particularly if you are talking about narcotics.

We are in our State talking about allowing nurses, nurse practitioners, to prescribe narcotics in the home, in addition to physicians. That is another whole area. So there is lots going on, but I cannot say there is any one answer.

Ms. TAKAMURA. It is a very important, evolving conversation.

I am going to close this forum by first of all, mentioning to you that there is a national phone number you can call in case you need to locate caregiving support. That is 1-800-677-1116. This is the number for the Elder Care Locator.

I also would like to, once again, thank Senator Breaux and Chairman Grassley, as well as the members of the committee, for making this forum and the hearing this morning possible. Special thanks to Ken Cohen, Jill Greenley, Ted Totman, all of the staff directors and key staff for Senators Grassley and Breaux, and certainly all of the rest of the committee staff, many of whom I know are here.

Finally, I would like to thank the panelists and, along with them, two of my own staff—Moya Bendit-Thompson, who is a Director of Legislation and Public Affairs for the Administration on Aging, and Don Grantt, who is an aging specialist.

I really do want to thank all of you for staying until nearly 4 o'clock. It has been a long day, but family caregiving is an extremely important issue. It affects every one of us in this room.

Certainly as we give care to family members, the question that looms in the back of all of our minds is who will care for me? So the best job that we can possibly do is to make sure that we have truly humane, responsive, accessible, services in place.

Thank you so much, once again, to the Senators who made this forum possible and to the committee and their staff. Thank you all for coming.

[Whereupon, at 3:59 p.m., the committee was adjourned.]

A P P E N D I X

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*Specially Prepared For*  
SENATE SPECIAL COMMITTEE ON  
AGING  
FORUM

## U.S. SENATE SPECIAL COMMITTEE ON AGING

### *"EASING THE FAMILY CAREGIVER BURDEN: PROGRAMS AROUND THE NATION"*

#### **AdultCare, Inc., a Fortis Company**

*The mission of AdultCare is to assist individuals and their families in making informed choices that lead to a better quality of life throughout the aging process.*

*Connie Ford, RN, MPA  
Vice President*

AdultCare is a unique company dedicated to specializing in caregiving and elder issues throughout America. It provides members who are struggling with the dilemmas of eldercare as well as understanding their own aging process, with information, education, advice and support services. Among the members and families that AdultCare serves are Fortis Long Term Care insurance policyholders and Fortis employees in the United States. Members are from many generations, as persons reach out for themselves or concern about a loved one, especially an older loved one.

#### History

AdultCare was founded in 1992 in response to the rapidly growing needs of persons of many generations seeking guidance for dealing with the issues surrounding aging, caring for their parents and the complexities of caregiving.

Fortis Long Term Care, an insurance industry thought leader and innovator, completed the acquisition of AdultCare early in 1997. At this time AdultCare focused on the development of its unique *Productive Aging* Program along with an information library; expanded provider network; information systems support and Fortis employee caregiving and elder issues programs.

The mission of Fortis Long Term Care is to assist families in preserving their financial and emotional independence. The role of AdultCare is to directly augment this mission through the provision of its information, consultation and referral services. Long term care insurance policy holders—and their family members—receive unlimited use of AdultCare services...*Productive Aging*...from day one of policy purchase.

### Identification of Service Need

A survey of 6500 Fortis employees was conducted in November 1996. It showed that there were many active caregivers for someone over the age of 50 and in need of AdultCare services. A repeat and expanded survey was conducted a year later. These findings have been used to further meet employee and corporate requests.

As reported by the Harvard School of Public Health in 1996, "The population most at risk of needing long term care services...knows little about the options for long term care other than nursing homes... They remain extremely uninformed..."

As a market innovator, Fortis Long Term Care developed unique long term care insurance policies with special caregiver features including: caregiver training; personal care advocacy; and respite care...all in addition to the *Productive Aging* Program. Fortis Long Term Care subsequently became a corporate sponsor of the National Family Caregivers Association (NFCA) and AdultCare has worked closely with the NFCA and has recently produced a report detailing the impact of caregiving on these members. A copy of the report accompanies this document.

### Evolving Trends

Member participation in AdultCare services is varied, since each situation comes with its own set of circumstances. In fact, the majority of callers initiate the conversation with a request that often does not reflect their real needs or available options. AdultCare believes, just as the 1997 National Alliance for Caregiving/AARP Final Report portrayed, 38% of caregivers surveyed, "did not know what they didn't know." Some members are true planners and do call in plenty of time to obtain information now to make wise decisions for the future. However, most members require more immediate assistance and call for advice relative to current problem solving situations; a few require ongoing counseling. A small percent of members have made decisions but now need provider referrals and community based resources to execute their plan.

Many requests are for ways to allow older persons to remain at home and manage their affairs. There are often Medicare or other insurance concerns. Frequently, members are not sure how to navigate the health care system or advocate on behalf of another. AdultCare offers family conference calls for those who are having difficulty in decision making and need a neutral third party. Confidentiality is also a primary concern. For example, if a member and then the spouse calls, there is no mention that the other has been spoken with, even if it is about the same subject or

person. There is never any limit to the number of calls a member can make. The service is one of convenience as a one-stop resource.

AdultCare's research is finding that certain persons require an active rather than reactive support approach. This is especially true for caregivers who, if depressed, have all they can do to make it through the day, much less take time for themselves. As shown in other research, AdultCare also finds that proactive mailing of information can help people in their decision making and stress management.

Finally, while not fully developed at this time, another category of persons has been identified. These are people who need "special handling". They are individuals who are so overwhelmed and/or under such stress that their ability to absorb information is limited. The amount and type of information that is explained or sent to them is reduced and staged. The follow up protocols for these callers are also more frequent.

### Productive Aging

As mentioned earlier, Fortis understands that long term care is more than a financial issue. Aging and its surrounding issues impact family members and all caregivers, not just the policyholder. *Productive Aging* is designed with four major components:

- ◆ Planning – for the future while encouraging family members to do the same.
- ◆ Prevention – to assist in postponing or even preventing a need for future interventions.
- ◆ Problem Solving – ideas and options for dealing with challenges as they arise.
- ◆ Positive Support – to help cope with the changes and stresses of caregiving and aging.

The services include:

- ◆ Information - accessing the AdultCare comprehensive library and database, thereby saving time and effort as resource advisors research a particular issue or concern.
- ◆ Education – assistance in gaining greater understanding of complex legal, financial and insurance issues as well as government entitlements, Medicare and Social Security.

- ◆ Advice - obtaining referrals to eldercare providers, products, services and community based resources nationwide.
- ◆ Support - talking to experienced advisors about issues ranging from wellness to caregiving.

Selections from the library are included in a subsequent section of this handout.

### AdultCare and Other Long Term Care Insurance Companies

AdultCare has not sought additional relationships with a long term care insurance company nor do we have financial agreements with any referral provider. This allows staff to be totally objective in the delivery of information and resources. There are no hidden business agendas, only proprietary business rules that govern the quality of the information in the databases and therefore the quality of the referrals that are given.

### AdultCare is Unique

AdultCare is the only company focused on the caregiver, specialized in caregiving and elder issues and national in scope. AdultCare has taken the time and effort and has spent the resources needed to better understand family caregivers. Its several collaborative relationships with nonprofit organizations are active rather than passive. AdultCare is a needs-driven, front line or participatory partner. This is true for relationships developed both nationally and locally. This philosophy of active public/private partnering contributes to the uniqueness of AdultCare, the services it provides and its value as a partner. Examples of the collaborative relationships include:

1. National – National Family Caregivers Association (NFCA). An initial trial was done with AdultCare to learn if the services offered would be of help to NFCA members. Preliminary results were positive however, the true value needed to be measured. An Intervention Study was then designed. AdultCare developed the survey instrument, conducted the survey, prepared and recently published the document, "Caregiving Across The Life Cycle: A National Family Caregivers Association/Fortis Report". The NFCA/Fortis Intervention Study is now in its final months. Preliminary interim findings look promising; final results will be shared by the end of the first quarter of 1999.
2. Local – Boca Raton Interfaith in Action. An employee of AdultCare spearheaded this new organization. It is a multi-generation, volunteer effort

to provide support and assistance to homebound individuals and/or their caregivers through a unified effort of religious organizations, community agencies and dedicated people. In-kind support is demonstrated through use of support services, mailings for meetings, surveys of the community, scheduling flexibility for involved employees and office space for a student practicum.

Most recently, AdultCare conducted a regional survey of family caregivers to determine interest and desire for an Elder Hostel program of education and relaxation for caregivers. In addition to AdultCare and Elder Hostel, the partners include the National Alliance for Caregiving and the National Family Caregivers Association.

Another unusual forum to provide solutions to caregivers has been through a relationship with *Today's Caregiver* magazine. AdultCare staff time and support resources are used to produce a new regular column, "On Your Behalf" that was created to provide feedback to caregivers about caregiver legislative issues and their status. Again, this was established in response to a need...a need verbalized by caregivers from around the country who, especially during today's speedy information age, have difficulty understanding why government change is slow.

Thus, AdultCare has demonstrated a significant effort to not only understanding the issues facing the family caregiving community but also to contributing to solution oriented programs and services.

#### Private Sector Interest in Caregivers

Since the inception last year of the Fortis *Productive Aging* Program, some long term care insurance companies now also offer a similar feature. There is no other company, however, that has done the research and has the extent of information, expertise, understanding and services as that offered by AdultCare.

As family caregivers are gaining greater public attention and are recognized as often being the health care decision-maker, there is little wonder that the private sector is seeking avenues to capitalize on opportunity. The concern is that as a potentially vulnerable group...family caregivers...may fall prey to many of the deceptive techniques that have permeated the home and health care industry. This risk increases as decisions may be forced during a time of crises. While the increased use of the Internet allows access to information, there is no guarantee that the information received is timely, objective or accurate.



The *Productive Aging* Program provides two booklets; *Planning and Prevention*, to every new Fortis Long Term Care insurance policyholder. The booklets encourage getting organized, staying healthy and exploring options before a crisis occurs so that wise decisions can be made.

Summary

AdultCare, a Fortis company, is unique. It offers information, consultation and referral and specializes only in caregiving and elder issues. Locally and throughout the nation, AdultCare consistently demonstrates caring and dedication through quality programs, research, collaboration and advocacy. For additional information contact Connie Ford: 1-800-235-3999 ext. 122 or e-mail [Connie@adulthoodcare.com](mailto:Connie@adulthoodcare.com).

***Information Library Selections***

***Planning***  
***Organizing Paperwork***

***Prevention***  
***Health and Wellness***

***Problem Solving***  
***Long Term Care-Nursing Home Guide***

***Positive Support***  
***Building Inner Strength***



# Productive Aging


## ORGANIZING PAPERWORK

Legal and financial issues are private topics for most families and, therefore, seldom discussed. When it is necessary to take over some of the legal or financial work of another family member, discussion is essential. In fact, it is preferable to talk about these issues before a crisis occurs. Families should think about whom would take over the paying of bills and maintaining financial commitments, when a parent or other family member is incapacitated. Preplanning allows all options to be reviewed and wise decisions made. The following is an overview of medical care issues, a discussion of typical property documents and home equity conversions that are useful to caregivers. This information is not designed to take the place of legal advice. Each situation is different and needs individual attention. A vital information checklist is also enclosed. If you have questions regarding any of these issues, we encourage you to consult an attorney or competent financial advisor. There are professionals in both these fields who specialize in elder issues.

### Medical Care Issues

**Advance Directives:** Everyone has the right to accept or refuse medical treatment. An individual's wishes can be followed in legally binding documents known as an *advance directive*. These documents were mandated by the federal government in 1991. An advance directive is a statement of an individual's treatment choices. They are called advanced directives because they are issued in advance of the time that the decisions must be made. These directives become effective when persons can no longer make a decision for themselves. For example, when an individual is taken to a hospital in a coma, the presence of the advance directive will make his/her treatment wishes known. There are two forms of advance directives: the health care durable power of attorney and the living will. Keep original forms in a safe place where family members can get them. Also, copies should be given to health care professionals, lawyer, clergy, and family members. If these documents should be canceled or revoked, it is important to notify the persons who have received copies. Advance directives are:

**Living Will:** A living will is a document stating a person's wishes concerning life-sustaining treatment. It instructs the doctor on treatment acceptance or rejection. Examples of life-sustaining treatments are cardiopulmonary resuscitation (CPR), mechanical respirators, renal dialysis, experimental medication and procedures, and artificial feeding. It may also ask direction about donating organs and tissues should death occur. States vary in their regulations for living wills.



**Healthcare Durable Power of Attorney:** This document authorizes a designated other person to make decisions about medical care, when an individual is unable or does not want to make those decisions for him/herself. The person named will act on the individual's behalf during all planning and treatment meetings of the health care team providing care. The individual who initiated it may revoke this document at any time.

**Euthanasia:** Advances in medical technology have prolonged life, but in many instances that has meant prolonged suffering. Advanced directives have assured that individuals may make their rejection of life-prolonging treatments known before a crisis occurs. The word euthanasia comes from the Greek, meaning painless, happy death. It is important to distinguish between passive euthanasia, which is the withholding of treatment to allow for death, and active euthanasia, which is a direct or assistive action to allow death to occur. Without the prior and written direction, the withholding of treatment can become mired in legal and moral issues. National organizations can provide information of many aspects of these issues.

### **Property Issues**

**Living Trust:** This is the transfer of ownership of financial assets out of the individual's name and into the name of a trust. A living trust is what is known as a revocable trust. This means that it can be changed or canceled and ownership is returned to the individual. The individual being named as trustee and beneficiary maintains control of the trust. Trust assets do not go through probate upon death. Distribution of assets is, therefore, named in the trust documents.

**Will:** A document that directs the transfer of ownership of assets after death. These assets are transferred under the supervision of the probate court. Probate is a legal procedure for settling an estate. A will can also be used to direct assets into a trust for management by a trustee. The trustee is obligated to manage the trust and its proceeds for the benefit of the beneficiaries. Most states have laws regarding the distribution of property among surviving relatives, when death occurs without a will.

**Durable Power of Attorney:** A legal authorization for a designated other person to manage financial assets. The document details the exact responsibilities and limits for management, such as check writing and selling property. It can be effective on signing or at some future time, if an individual becomes incapacitated and unable to manage his/her own affairs.

**Guardian or Conservator:** A court appointed individual, who assumes most of a disabled person's civil and legal rights for that person's protection. The powers are

granted, for that person's protection, and are subject to the direction of the court. This is generally due to a chronic health condition or disease that results when a person is no longer able to manage financial resources, physical health or personal safety.

**Viatical Settlements:** The term "Viatical settlement" comes from the Latin word *viaticum* meaning "provisions for a journey." Viaticum were supplies Roman soldiers were given in preparation for journeys into battle, ostensibly, journeys from which they might not return. Similarly, a viatical settlement provides an individual with resources for the final months of life. A viatical settlement allows individuals facing life-threatening illnesses, such as cancer, severe heart disease, AIDS, Alzheimer's disease or other conditions, to sell their life insurance policy to a third party for cash, while they are still able to use the money. There are no restrictions on how funds from a viatical settlement can be used. The purchaser of the life insurance policy then becomes the beneficiary and is responsible for making all future premium payments to keep the policy in force. Another insurance related financial option is accelerated death benefit (ADB). This is included as a rider in some life insurance policies. The federal government enacted legislation effective January 1, 1997 that exempts accelerated death benefits and viatical settlements from federal income taxes under certain circumstances. At this time fifteen states have regulations for licensing or registering policy buyers. For more specific information, please contact the Viatical Association of America (800-842-9811).

**Home Equity Conversion:** Home equity conversions allow the elderly to receive additional income, while they in their home. There are several options available:

*Reverse mortgages:* Monthly payments are made to the homeowner based on the amount of equity in and value of the home. The loan amount is repaid at a future date when the homeowner no longer resides or sells the home. The property may be sold at any time. Proceeds are retained that exceed the amount needed to pay off the mortgage. Homeowners cannot be forced to move or to sell their homes.

*Deferred payment loans:* A long-term, secured loan under which repayment is deferred until the sale of the property.

*Sale/Leaseback conversions:* The owner sells the home to an investor while retaining the right to live in the property for life. In this type of arrangement, one becomes a renter in his/her own home. The purchase price is paid as a lump sum plus fixed monthly amounts, based on the seller's life expectancy. If the seller dies before the full loan is repaid, the loan balance is paid to the estate. Payments to the seller should be from a secured source of funds.

*Home equity loans and credit lines:* Banks and brokerage houses make loans or extend credit on the basis of a second mortgage against the property.



Be advised that the options mentioned above should be thoroughly discussed with family members, financial advisors and/or attorneys. There may be tax consequences, impact on the estate and heirs, or an effect on eligibility for other federal and state assistance.

Today, many people remain healthy, active, and alert due to several factors, among which include healthier life styles, planning for the future, and advancing medical knowledge. The "Productive Aging" program is available to assist in pursuing goals for a quality life. For additional information that may be of assistance to you and your family, Resource Advisors are a phone call away.

### **Contributing Resources**

A Consumer's Guide to Aging, David H. Solomon MD and David Ruben MD  
"Age Page" of the National Institute on Aging  
"Aging Network News"  
American Association of Retired Persons  
National Alliance for Caregiving  
The American Bar Association  
The Kentucky Bar Association

*Productive Aging is committed to providing accurate and timely materials and resources to help individuals make wise decisions. Provider referrals are offered based upon identified needs. Research is ongoing and updates are included when appropriate. Decisions should always be made following a thorough review of the materials, on site provider visits and individual requirements. Telephone numbers are current as of printing. Productive Aging materials and resources are not recommendations or endorsements and are not intended to replace professional care or advice.*

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## VITAL INFORMATION CHECKLIST

While your relative is in good health, it is advisable to sit down and discuss the paperwork needed to provide and coordinate the assistance he/she may require in the future. Families often have trouble talking about money and personal matters. Such conversations may bring about feelings of jealousy, independence, self-esteem, and privacy. It is important to keep an open line of communication to overcome these barriers. You may want to take this opportunity to gather and prepare these papers for yourself and share information with everyone in your family. This may help other relatives realize the importance of preplanning, if they have not already done so. As a caregiver you may be asked to provide information about your relative to service agencies and health care professionals. Consequently, you may want to inventory all legal, financial, and insurance documents. Please refer to the checklist.

### Legal Documents

Locate and make copies of documents and keep in your files. Make sure originals are kept in a safe place. If the record has been lost, request a duplicate.

DOCUMENT	LOCATED	COPIES
Birth Certificate	_____	_____
Citizenship Papers	_____	_____
Social Security Card	_____	_____
Marriage License	_____	_____
Divorce Decree	_____	_____
Military Records	_____	_____
Passports	_____	_____
Will	_____	_____
Living Will	_____	_____
Power of Attorney	_____	_____



Health Care Power of Attorney \_\_\_\_\_

Legal Agreements \_\_\_\_\_

Other \_\_\_\_\_

**Financial Documents**

Locate and make copies of documents to keep in your files. List Account #, name, and telephone.

	ACCT#	Name and Telephone
Checking Account	_____	_____
Savings Account	_____	_____
Retirement Account	_____	_____
Income Tax Returns	_____	_____
Stock Certificates	_____	_____
Savings Bonds	_____	_____
Certificates of Deposit	_____	_____
Real Estate Deed/Title	_____	_____
Automobile Title	_____	_____
Investment Income	_____	_____
Other Income	_____	_____
Mortgage Statement	_____	_____
Property Tax Statement	_____	_____
Lease Agreement	_____	_____
Hospital Bills	_____	_____



- Doctor Bills \_\_\_\_\_
- Utility Statements \_\_\_\_\_
- Telephone Bills \_\_\_\_\_
- Credit Card \_\_\_\_\_
- Other Debts \_\_\_\_\_

**Insurance Documents**

Locate and make copies of documents to keep in your files. List Policy #, name and telephone number.

	<b>Policy #</b>	<b>Name and Telephone</b>
Auto	_____	_____
Homeowner/Renters	_____	_____
Life Insurance	_____	_____
Medicare	_____	_____
Medigap	_____	_____
Medicaid	_____	_____
Long-Term Care	_____	_____
Disability	_____	_____
Liability	_____	_____
Other	_____	_____

NOTES



# Productive Aging

## HEALTH AND WELLNESS

Most people believe that good health is necessary for a full and satisfying life. Poor health from disease or injuries can rob an individual of independence and purpose and leave pain and dependence in its place. However, there are those persons who suffer with disabilities and chronic diseases but remain independent in spirit and continue to lead full and rewarding lives. How are these individuals able to lead a satisfying life without good health?

### What Is Health?

*Health* is defined in Taber's Cyclopedic Medical Dictionary (1993) as a condition in which all functions of the body and mind are normally active. This definition is appropriate for the medical community, as it allows the development of a standard of health that can be measured. The *statistical standard* is based on the average of such indicators as blood values and blood pressure levels, and an individual is expected to fall within these normal levels. When the standards are not met an investigation is initiated to determine the reason. The *ideal standard* is based on how the individual's systems and organs function measured against the ideal. Taber defines *disease* as the presentation of a group of specific, clinical signs, symptoms, and lab findings that are abnormal. This definition of disease, as a specific set of findings, relates to the Taber definition of health, but is health a lack of abnormalities? Doesn't health seem to imply a more positive state of the body and mind? The World Health Organization (WHO) has stated that health is a state of complete physical, mental, or social well-being and not merely the absence of disease or infirmity. The inclusion of *well-being* seems to expand the idea of health to include a sense of appreciation for life. The concept of health among the Greek physicians was closely related to man as being inseparable from nature. It was believed that man could strive for perfection, and that to be unhealthy was to be less perfect. At times in history, health has been considered a virtue similar to morality and prosperity. In the modern era of practical medicine, health is regarded as the absence of signs and symptoms of sickness or disease, disregarding the expansiveness of the WHO definition. The concept of well-being is, however, being addressed by many persons and health care professionals around the country as inseparable and therefore essential to health.

**What Is Your Idea of Health?**

Individuals should develop an idea of health. Take some time to think about what health means to you. Is it to be free of disease? Is there an ideal state of functioning where body, mind, and spirit are fully active and free? Is there a feeling of health...a feeling of positiveness and an appreciation for life? What is your idea of health?

**What Is Wellness?**

Wellness is considered an enhancement of health and well-being. It has been defined as a process of healthier living and growing in appreciation of yourself, others, and your environment. Wellness is taking care of oneself or self-care: mothers have been talking about it for centuries. The prevention of sickness with "spring tonics" and the use of folk medicine and home remedies are part of all families and cultures. Taking care of one's self includes public health measures to increase community and environmental health. In today's complex society, many new scientific findings concerning treatments, nutritional needs, risk factors, and disease prevention are announced on a routine basis. Sometimes these announcements are "cure-alls" and do not accurately represent the facts. Taking care of one's self today requires knowledge and commitment. It is more than remembering Mother's admonition to "put on that sweater or you'll be sure to catch pneumonia." Wellness is an active approach to health that is based on physical, mental, and social principles. This includes such activities as eating healthful foods, exercising, reducing bodily and environmental risk factors for chronic disease, and taking care of one's financial resources. Wellness can also be thought of as the ability to maximize one's state of being, whatever that state may be. This idea of wellness helps to explain how individuals can maintain a full and rewarding life despite chronic disease or disability.

**What Is Your Idea of Wellness?**

Individuals should develop an idea of wellness. Take some time to think about what wellness means to you. Is it following your doctor's orders? Is there an ideal state of well-being? Is there a plan that guarantees results if you eat this and don't eat that or you walk a mile and laugh a lot? What is your action plan for wellness? Will it help you develop the ability to maximize your life?



### **What Is the "Productive Aging" Idea of Health and Wellness?**

"Productive Aging" recognizes the ability of the individual to make sound, informed choices, and supports this ability and the activities required to maximize health. The feeling of well-being, which comes from planning and preparing for the future, preventing disease and injury, problem solving with knowledge and confidence, and the positive support of family, friends, and community is the reward of living in a proactive, wellness way. The wellness approach to life can be adopted at any age and at any stage of physical condition. A study reported by Dr. Maria Fiatarone involving frail elderly in a nursing home showed that even a minimum of 8 weeks of chair exercises 3 times a week increased their muscle strength and ambulation. Smoking is another example of how behavior change can increase wellness. Damage to the body, which has accrued from years of smoking, is not necessarily permanent. Louis Sullivan, a past Secretary of Health and Human Services, has stated that, "even if one has smoked for nearly half a century, stopping now will add years to your life, as well as life to your years. Your body can repair much of the damage smoking has done, if you stop." It is never too late to make a commitment to feel better and increase your enjoyment of life.

### **What Is the Active Approach?**

The following activities are important for a healthful lifestyle. Each individual should develop his or her own plan and then initiate and maintain a program based on preferences for food, exercise, stress reduction, and having fun.

**Remember** that wellness is an individual commitment to maximize one's own state of being.

- Control stress
- Control weight
- Develop new and nurture existing friendships
- Eat a more healthful diet
- Exercise on a regular basis
- Have some fun every day
- Limit alcohol consumption
- Plan for the future
- Prevent accidents
- Protect your skin from the sun

- Stop smoking
- Volunteer your talents
- Wear a seat belt

Today, many people remain healthy, active, and alert due to several factors, among which are healthier life styles, planning for the future, and advancing medical knowledge. Think about making a commitment to better health through the wellness approach. The "Productive Aging" program is available to assist in pursuing goals for a high quality life. For additional information that may be of assistance to you and your family, Resource Advisors are a phone call away.

### **Contributing Resources**

Taber's Cyclopedic Medical Dictionary, Clayton Thomas MD

The Healthy Seniors Workbook, edited by Barbara Lambesis

The Idea of Health, Judith A Smith

The Wellness Book, Herbert Benson, MD

Who? Me? Exercise? Sara Harris and Olga Hurley, RPT

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# Productive Aging

## LONG-TERM CARE: NURSING HOME GUIDE

Approximately 30 percent of persons in the U.S. can expect to spend some time in a long-term care facility. Admission to these facilities may be for rehabilitation after hospitalization or for long-term placement due to the need for skilled nursing services. Choosing a nursing facility is one of the most important and complex decisions in family caregiving. Planning ahead is one of the best ways to ease the difficulty of this decision. This is not generally feasible during a time of unexpected serious illness and hospitalization. However, discharge from the hospital requires a medical social worker to provide placement services that are appropriate both financially and medically. These services are beneficial for the short-term response to acute illness, but cannot take the place of family decision making for long term or permanent placement. When the caregivers and care recipient determine that care at home is no longer possible, then a choice must be made to assure the best setting to meet the care needs.

Feelings of anger, guilt, and resentment are common to both caregivers and the care recipient. These feelings may come from the role reversal of children caring for a parent (or other older adult), from feelings of dependency, fear of abandonment, time restraints and perhaps, simple exhaustion. Planning ahead should begin before the need for long term care is suspected. The exploration and use of services (such as adult day care, community programs, personal care assistance, or live-in help) as care needs increase is a realistic method to expand effective caregiving. With this experience of planning and utilization behind them, it may be easier for care recipient and caregiver to assess the need for higher levels of care in a more open and realistic manner. Open communications allow the family to recognize and share feelings rather than conceal them. When care has been provided without the assistance of others, or the care recipient is unable to take part in decision making, it is possible to seek the support and guidance of the health care team, support groups, and friends.

### What is a Nursing Care Facility?

Nursing homes are specially licensed health care facilities that provide inpatient nursing and rehabilitation or restorative (restores an individual to their highest level of functional ability) services to patients who require continuous care, but not hospital based acute care services. Residents are provided with round-the-clock medical supervision and nursing care. Nursing care is defined as intermediate or skilled. Intermediate care refers to basic nursing and personal care services;



skilled care includes rehabilitation and sub-acute services. Sub-acute care is generally used to describe a physically separate unit in a nursing facility that provides services for Alzheimer's disease, dementia, head injuries, AIDS, or other conditions which require specialized assistance (ventilation, IVs, TPN, dialysis). Some nursing facilities offer only intermediate or skilled care while others offer both. An individual may enter a nursing facility to receive continuing care for multiple long-term conditions or to recover from an illness or injury after being treated in a hospital. Certified nursing facilities must meet federal as well as state requirements.

#### **What Are the Services Provided?**

Services include: nursing care services; rehabilitation services for injured or disabled persons; personal care services, socialization and recreational activities, and specialized care, such as ventilator or infusion therapy. Typical care provided is: assistance with bathing, dressing and eating; preparation of special diets; administration of medicines; wound care dressings, care and treatments prescribed by a physician, occupational and recreational therapy, and social services to assure that patient rights and responsibilities are maintained. Many facilities also offer pastoral care.

#### **Who Provides the Services?**

**Administrator:** Administrators are licensed by each State Board of Examiners for Nursing Home Administrators. The administrator is responsible for managing the facility. Some larger nursing facilities may have an assistant administrator. Administrators must also meet standards required by the Federal Nursing Home Reform Act.

**Medical Director:** The Medical Director is a physician who gives advice to the Administrator, Director of Nursing and attending physicians on medical questions and policies. The Medical Director provides physician services when a resident's attending physician is unavailable.

**Director of Nursing:** In most states, the Director of Nursing Services must be a registered nurse (RN). The Director of Nursing has responsibility for the nursing care rendered. This is usually done by scheduling rounds, coordinating nursing with other resident services, recommending the number and types of nursing staff to be employed, providing nursing staff training, and participating in quality assurance.

**Nurses:** Nursing facilities are required to have licensed nurses, on duty, around-the-clock, including RNs, each day, for at least one shift-seven days a week. The

charge nurse is a RN or licensed practical nurse (LPN) who supervises nursing on a floor or wing of the facility. The medication nurse administers medications and is supervised by the charge nurse. In some facilities, one person may perform the functions of a charge nurse and medication nurse.

**Nursing Aide:** Working under the supervision of an RN or LPN, the nursing aide bathes, dresses, assists in feeding, assists with resident activities and changes linens. Nursing aides complete a training program, pass a competency test, and meet hiring criteria to work in a nursing facility. Certified nursing aides (CNA) are placed on the nurse aide registry maintained by the State Board of Nursing.

**Social Worker:** The social worker helps residents and families with their social service needs. The social worker serves as the facility's resource for making referrals to providers in the community. He or she may set up a resident or family council to discuss concerns or plan special events for the residents in conjunction with the activities director. In nursing facilities with 120 or more beds, a qualified social worker must be employed full-time.

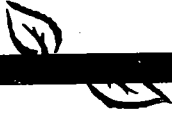
**Activities/Recreation Director:** The activities or recreation director develops, schedules, and conducts activities to meet the needs and interests of all residents. These activities encourage residents to enjoy themselves by promoting independence, providing learning opportunities, and socializing with other residents. The activities director must be a qualified therapeutic recreation specialist.

**Therapists:** Therapists who provide services in nursing facilities include physical, occupational and speech therapists. The physical therapist helps to retain or restore functioning in the muscles of the hand, arms, legs, feet, back and neck through exercises or treatments. The occupational therapist maintains, restores, or teaches skills to improve resident's manual dexterity and hand-eye coordination. The speech therapist helps residents overcome swallowing and speech problems.

**Pharmacist:** A pharmacist may be employed by the nursing facility or work under a contract. The pharmacist provides direction to the nursing facility on the methods and procedures for storing, administering, disposing and keeping records of drugs.

**Food Service Personnel:** The food service personnel develop menus, prepare and serve food, and make sure residents get the proper diet. The food service supervisor approves menus and dietary policies and procedures and discusses diets and food preferences with residents. If not a licensed dietitian or a graduate of a college level food and nutrition program with two years' experience, the dietary supervisor must consult with a dietitian with these qualifications.





### What Is the Cost?

The cost of care in a nursing facility is usually based on the amount and type of care an individual receives. Many nursing facility residents use more than one method of payment. As a general rule, facilities have a daily rate covering room, board and some basic services. There are charges for additional services and amenities. To the extent that cost enters into the placement decision, it is important to obtain the facility's current (and projected) rate schedules. In addition to paying privately, the following may help cover the costs of nursing facility care:

**Medicare:** Medicare is the federal health insurance program for people 65 or older and certain disabled people. Medicare pays part, but not all, of hospital and other health care expenses for persons who are eligible. Medicare has two parts: hospital insurance (Part A) and medical insurance (Part B). Medicare, Part A covers services you receive in a hospital or skilled nursing facility or from a facility, health agency, or hospice program. Medicare, Part B covers some physician and outpatient services, medical supplies, and other services not covered by Part A. Medicare, Part A may help pay for your care in a Medicare-participating (certified) skilled nursing facility (Medicare does not pay for custodial care) when the following specifications are met:

- The medical condition requires daily special nursing or specific rehabilitation services that can only be provided in a skilled nursing facility.
- Admission in a hospital at least three days in a row (not counting the day of discharge) before entering a skilled nursing facility.
- Admission to a facility within a short time (generally within 30 days) after discharge from an acute hospital.
- Nursing care in the skilled facility is needed for the medical condition that was treated in the hospital.
- A physician certifies that skilled nursing or skilled rehabilitation services are needed on a daily basis.

When the stay in a skilled nursing facility is covered by Medicare, Part A helps pay for a **maximum** of 100 days in each benefit period, but only if skilled nursing care or rehabilitation services are needed for that long. If discharged from a skilled facility and then readmitted within 30 days, the three-day stay in the hospital is not required. When some of the 100-day benefit is left, and skilled nursing or rehabilitation services are needed on a daily basis for a condition treated during the previous stay in the facility, Medicare will reimburse some of the costs of care. In each benefit period, Part A pays for all covered services for the first 20 days in a

skilled nursing facility. For days 21 through 100, Part A pays for all covered services except for \$95.00 a day, the coinsurance cost per day in 1997.

Medicare, Part B helps pay for covered services received from health care professionals in the office, in a hospital, in a skilled nursing facility, at home, or any other location.

Part A covers the following major services:

- Semiprivate room (two to four beds in a room)
- All meals, including special diets
- Regular nursing services
- Physical, occupational, and speech therapy
- Medications
- Blood transfusions
- Medical supplies such as splints and casts
- Use of appliances such as a wheelchair

Some services NOT covered under Part A include:

- Personal convenience items that are requested such as a television or telephone
- Private duty nursing care
- Any extra charges for a private room, unless it is determined to be medically necessary
- Any services that are not provided by the facility and included in its bill

**Medicare Supplemental Insurance (Medigap):** This is a private health insurance option, which, if purchased, supplements Medicare coverage. It generally pays for the non-covered costs of Medicare covered services only, such as; hospital deductibles and physician copayments, and does NOT pay for long-term care services. Medicare regulations are complex. Questions that pertain to an individual situation should be addressed with the social worker at the nursing facility. The case will be reviewed and options can be discussed when appropriate.

**Medicaid:** Medicaid is a joint federal/state program administered by the state to provide medical assistance to low income persons. For persons who qualify, Medicaid can help pay for care in a Medicaid certified nursing facility. Each state has different eligibility requirements, but all states have strict limits on the income, assets, and other financial resources a person may have and still qualify for Medicaid. In most states, if income is less than the private-pay rate, an individual may be eligible for Medicaid. Monthly income, including Social Security payments, Supplemental Security Income, and pension benefits, will be sent directly to the



nursing facility. Medicaid pays the difference between that income and the Medicaid rates. (States allow each resident to keep a small monthly personal-needs allowance of at least \$30.)

To be eligible for Medicaid, remaining assets are limited and vary from state to state. Many residents spend their assets ("spend down") and spend themselves into poverty, as defined by Medicaid, in less than 12 months. Federal rules offer some protection for spouses who remain at home. In 1995, provision was made to maintain assets of up to \$75,000 and to retain monies, monthly, from the spouse's pension and Social Security.

Medicaid is the principal source of public financing for long-term care. Not only does the program spend about 40% of its total budget on nursing home care each year, but a majority of the residents (6 out of 10) receive Medicaid assistance.

Medicaid is a complex program and each state has administrative discretion. Therefore, no two programs are alike. Services and eligibility criteria vary from state to state and may change from year to year. For the most up-to-date information on Medicaid, it is best to contact the county department of social services, welfare office or health department. Also, the social worker at the nursing facility should be able to answer questions concerning eligibility and allowances.

**Veteran's Administration:** Nursing care in a VA or a private nursing facility is provided for veterans who are not acutely ill and not in need of hospital care. VA may, but is not mandated to, provide nursing care, if space and resources are available in its own facilities. Veterans may be asked to provide an income eligibility assessment. Questions should be addressed to the nursing facility social worker.

**Private Insurance** (including long-term care insurance): Some Medicare supplementary insurance policies, often referred to as "Medigap" insurance, can provide a source of payment for care services in a nursing facility. Long term care insurance is a type of policy covering nursing home care and can include home health care coverage as well.

## CONSIDERATIONS IN CHOOSING A NURSING FACILITY

The National Citizen's Coalition for Nursing Home Reform has identified 7 features of a good nursing home. They include:

- Consistent and responsive ownership
- Stable well-trained staff
- Community interaction
- A philosophy of resident-centered care
- A mission to eliminate restraints or to use them only when no individualized care plan works for the resident
- Teamwork between management and staff
- Respect and advocacy for resident rights

Obtain the advice of a health care professional, hospital social worker, discharge planner, or care manager to determine what level of care is necessary.

Ask the family physician or other health care professional to recommend placement considerations. Different professionals may recommend a particular facility. Any recommendation should be given special consideration, however, it is still important to consider all factors in your final selection.

Hospital social service departments, friends, neighbors and clergy may suggest facilities. AdultCare can also provide a list of facilities that meet certain standards in the desired location.

The final choice should be a family decision that includes the care recipient. The adjustment is less emotionally painful when all contribute, even minimally, in the choice of the new residence.

Consider a location that is convenient for visits by family and friends. These visits will contribute greatly to the adjustment necessary to maintain quality of life in the new residence.

With the list of possible facilities, begin the screening process over the phone. (If you requested AdultCare's list of facilities in your family's area, this step is completed.) Some initial areas that need to be addressed include:

- Levels of care that are provided and therapies available.



- Medicare/Medicaid certification. This qualifies the facility for reimbursement under these programs.
- Approximate cost per day
- Location and out door accessibility
- Bed availability
- Federal, state or Joint Commission on Accreditation citations or fines for abuse, neglect, safety violations, or inadequate patient treatment such as over/under use of medications, therapies, physician visits, or the provision of poor meals and inadequate fluid intake
- Action taken to correct the situation and length of time needed to comply to regulations.
- The county State Ombudsman's office provides information on citations or complaints. Call them to verify the facility's account of resident care.

Choose at least three facilities from the list that best meet the family's needs. Telephone the person in charge of admissions to schedule a personal visit.

Visit several times at different hours of the day or evening. Some visits should be unannounced so a true picture of the facilities daily routine can be seen. Also, visit at mealtimes to see if the food is varied, well prepared, and served attractively. Notice if residents, who may have a difficult time eating, are assisted. The time will vary, but plan on 1 1/2 to 2 hours for a visit.

Use the Questions to Ask section that follows this page. Before reviewing or visiting a home, check with the state's Office of the Long Term Care Ombudsman. These offices provide help and information regarding long-term care facilities. The latest survey report on facility, complaints against facility and results and conclusions of complaints should be made available on request.

Since the nursing facility contract or financial agreement is a legal contract, be certain to understand it thoroughly. It may be wise to have a lawyer review the agreement before signing.

#### **What Are the Questions to Ask?**

These questions are helpful to ask when visiting a nursing facility. They can also be used to assess the care that is being given in the facility on an ongoing basis. If AdultCare provided a list of referrals, many of these issues have already been addressed. If this is the case, it may be helpful to concentrate on more personal matters of concern to the family.

**Credentials**

Does the facility have a framed, posted license from the State Department of Health?

Does the administrator have a current license from the State Board of Examiners for Nursing Home Administrators?

Is the facility certified to participate in Medicare and/or Medicaid?

**Safety**

Is the facility hazard free?

Are the rooms well lighted?

Are there handrails in hallways and grab bars in bathroom?

Is the furniture sturdy?

Are the floors non-skid?

Is the building equipped with smoke detectors, sprinkler system and emergency lighting?

Are there written emergency evacuation plans and fire drills?

Are the exits clearly marked and unobstructed?

**Facility**

Is the atmosphere pleasant?

Does the facility look clean and orderly inside and out?

Is it free of unpleasant odors?

**Resident's Rooms**

Can residents have personal items and decorations?

Do the rooms provide privacy?

Are rooms and bathrooms wheelchair accessible?

Are there private areas available when family and friends visit?

**Dayroom/Activity Room**

Is there a printed activity schedule?

Is there group as well as individual activities?

Are outside trips available?

Are there activities available for bedridden residents?

Does the activity director interact with residents in a caring, creative manner?

**Food Service**

- Are meals tasty, nutritious, and attractively presented?
- Are menus posted weekly?
- Are special diets available?
- Are the dining room and kitchen clean?
- Who assists residents that can't feed themselves?
- How does the staff assure adequate fluid intake?

**Services**

- Is regular and emergency medical attention available?
- Is there an arrangement with a hospital for transfer of a resident in an emergency?
- Are pharmaceutical services available?
- Can arrangements be made for residents to worship as they please?
- Are physical therapy and rehabilitation services offered?
- What laundry services are available?

**Staff**

- Are employees courteous, helpful and respectful to residents and family?
- Is there adequate staffing at all times?
- Does staff have proper certification and follow state guidelines?
- Do employees interact well with the residents?
- Do you hear laughter and see affection displayed between staff and residents?

**Residents**

- Do residents appear to be well cared for and content?
- Are residents well groomed and appropriately dressed?
- What is the incidence of pressure wounds (bedsores) of residents?
- Is the Statement of Patient Rights posted?
- Is care provided for special needs, such as Alzheimer's?
- Is the resident and family encouraged to participate in the care plan?
- Is the resident and family informed of any changes in physical or financial status  
or of incidents which may occur to the resident?
- What is policy on physical restraints?
- What is policy on chemical restraints (the use of certain drugs)?

**General**

Is location convenient to family and friends?

Are outside areas provided for residents to sit or walk?

Is there a security system to prevent confused residents from wandering off the grounds? Or a fenced-in area?

Can married couples share a room?

Does the contract clearly state what services and goods are and are not included in the basic fee?

Are residents provided with monthly, itemized statements of services and fees?

Do the resident's assets remain in his or her control or that of the family?

**A Final Note**

Caregiving responsibilities will continue to be felt, even when a family member becomes a nursing home resident. It is difficult to relinquish the care of a loved one to strangers, even though, realistically, that may be the best course of action.

Today, many people remain healthy, active, and alert due to several factors, among which include healthier life styles, planning for the future, and advancing medical knowledge. The "Productive Aging" program is available to assist in pursuing goals for a quality life. For additional information that may be of assistance to you and your family, Resource Advisors are a phone call away.

**Contributing Resources**

A Consumer's Guide to Aging, David Solomon MD and David Ruben MD.

National Institute on Aging

U.S. Department of Health and Human Services

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# Productive Aging

## BUILDING INNER STRENGTH

It is the gift of inner strength that allows one to continue in situations that might otherwise be considered impossible. It is that intangible fortitude that often develops with challenging circumstances. It is called on in both the best and the worst of times. Inner strength, the core of the human soul, is dynamic—part of something of which character and spirituality are made. Learning how to nourish this spiritual health force will assure that inner strength is present when facing yet another of life's trying events.

### Helping Yourself Build Inner Strength

Life goals and objectives usually change as one ages. As these changes become apparent, it is helpful to revisit values and beliefs making sure that new goals and objectives are consistent with current values and beliefs. Renewing or enhancing one's appreciation for life allows feelings and challenges to be put in perspective, perhaps to gain new insight into the meaning of life. Among opportunities that touch this aspect of life are:

- ◆ Setting aside time for prayer, meditation, or spiritual readings
- ◆ Remaining true to one's values and spiritual inclinations
- ◆ Opening up to experiences through nature and other life mysteries, art, music, or reading great books.
- ◆ Reviewing obligations, expectations, abilities and alternatives to use talents and maximize well-being
- ◆ Evaluating the use of time by keeping a journal or reviewing daily activities to assure that the use of time is consistent with values and beliefs.
- ◆ Focusing on the small miracles of life on earth
- ◆ Using a sense of humor to enhance the ability to cope with crisis and tragedy

### The Art of Affirming Life

Another method of building inner strength is through affirmation. Affirmation is a learned skill that is accomplished by focusing on individual goodness and daily living. Such statements as "I do my very best" and "Every day is precious" are examples. An individual may sustain feelings of self worth and the meaning of life through an active approach that includes:

- ◆ Maintaining contact with one's spiritual truth through prayer, meditation or other personal expression.



- ◆ Remembering each person is unique and special.
- ◆ Thinking of things in a positive manner.
- ◆ Visualizing happy situations, circumstances and thoughts.
- ◆ Making positive affirmations for one self and others.
- ◆ Verbalizing these affirmations throughout the day.
- ◆ Making statements in the present tense.
- ◆ Doing things that produce good feelings.

Sometimes it may be difficult to affirm one's self, especially during a time that stress seems to take over. When this happens, the focus needs to shift to managing that situation.

### **Helping Yourself to Manage Stress**

Studies show that effective personal stress management is a key element in the ability of an individual to handle difficult situations and anxiety. The more that is understood about the stress and its impact on the individual, the more likely one can learn how to deal with it. Take time to consider which methods of easing stress personally work. The suggestions listed below are effective "stress managers" for some:

- ◆ Turn to a higher power: Participate in activities such as prayer, meditation, reflection on spiritual readings, or religious practices, and other fellowship opportunities.
- ◆ Develop a mind image: A specific technique in visualization is to create a quiet scene, such as a place in the country, the mountains, or the seashore. For many people this provides a retreat that is always available.
- ◆ Engage in physical activity: Release the pressure of anger, tension, or nervousness through exercise or physical activity. Physical exercise relieves that "up tight" feeling and creates relaxation. Remember the body and mind work together.
- ◆ Share the stress: Talk to someone about concerns and worries. If the problem is private and/or complex, consider joining a support group or seek professional help from a psychologist, psychiatrist, social worker, or mental health counselor.
- ◆ Acknowledge and accept limits: When a problem seems beyond control and cannot be changed at the moment, don't fight the persons or situation. Learn to accept the difficult—for now—until a future time when it can be changed.

- ◆ Take care. Get enough rest and eat well. When irritable and tense from a lack of sleep or from not eating properly, there is less ability to deal with stressful situations. If stress repeatedly keeps away sleep, professional help may be indicated.

### The Art of Relaxation

In addition to managing stress, relaxation techniques are also a recommended strategy for regaining balance and relieving stress. Relaxation becomes a state of body and mind that allows you to stand back or be removed from the physical and emotional reactions of a situation. It is similar to the feeling of release and calm that proceeds sleep. Learning to practice relaxation techniques brings peace to the inner self and allows one to experience just *being*. Investigate the following methods and consider discovering which works the best.

- ◆ Prayer or meditation
- ◆ Audio and video tapes that teach imagery for relaxation
- ◆ Music for visualization and relaxation
- ◆ Yoga, or tai chi
- ◆ Deep breathing techniques

Today, many people remain healthy, active, and alert due to several factors, among which include healthier life styles, planning for the future, and advancing medical knowledge. Learning how to nourish one's self to maintain spiritual health will help assure that inner strength is present when facing occasions and tasks that impact the foundation of every day life. A strong foundation, firm with inner strength, is more likely to remain solid whatever the life challenge one is given.

The "Productive Aging" program is available to assist in pursuing goals for a quality life. For additional information that may be of assistance to you and your family, Resource Advisors are a phone call away.

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***Caregiver Series Selections***

*Caregiving*

*Caring for the Caregiver*

*Caregiver Activities*

*Tax Benefits for Caregivers*



# Productive Aging

## CAREGIVING

The provision of adequate care to meet the needs of older Americans is a growing concern to family members and health professionals. The health care status of the elderly can deteriorate quickly, requiring rapid intervention of the health care team. This may mean emergency admission to a hospital or intensive care at home. Family members may have difficulty responding to a new situation, particularly if long-standing care patterns will need to be changed. Decisions often need to be made on the spur of moment and without adequate information. Conflicting responsibilities, distance, financial concerns, and unresolved family problems will influence the decision making process. Special skill and knowledge is required to make these decisions and provide care when and how it is needed. Today, family members are able to develop this skill and knowledge with the help of many community resources.

### What Is Caregiving?

Caregiving has come to mean more than "giving care". It is used today to designate the care given to elderly persons with chronic conditions, which impair the elder's ability to function independently. This care is generally provided at home, but may also be the "extras" provided by a friend or family member to a person in a nursing home or other facility. The tasks performed may include: running errands, driving, shopping, cleaning, laundry, cooking, handling finances, bathing and dressing, providing medical treatment, such as wound care, or managing medications. The care needs may range from requiring supervision or assistance to total care. Care is most often provided at home, as most individuals desire to remain in their own familiar environments. It is generally believed that care at home provides the best opportunity to maintain or enhance well-being through the sense of security and social stability of remaining in one's own place.

### When Should Caregiving Begin?

How much is already being done? Studies of caregiving report that 60 % of persons over 55 years of age are responsible for at least one daily activity for their parent (s). Planning for the care of family members who are becoming frail, suffer from multiple chronic disease, or mental impairments should begin before the need is immediate. With time to plan, decisions concerning the future can be based on sufficient information about medical condition and prognosis, family and community resources, and financial realities.

It is helpful to know the following:

- The name and telephone number of all health care providers
- The medical conditions and treatment plans, which includes medications and /or special diets or activities
- Where vital information about bank accounts, wills, and insurance is kept
- Community agencies and other resources that assist in caregiving

Planning for caregiving must include all the participants. Open communications between parents and children, spouses, and other significant persons will assist in developing a fair and realistic plan of care. It is important that each family member be as involved as possible not only in planning, but in the implementation of the care plan. Long distance caregivers may be able to do such things as organize medical bills or prepare and file state and federal income taxes.

### **Who Is a Caregiver?**

The vast majority of the elderly who need assistance with daily activities remain at home. Only 5% of older Americans reside in nursing homes. Spouses, family members, friends, neighbors, paid helpers, and volunteers provide caregiving. The spouse remains the primary caregiver as long as that is physically and emotionally possible. When the time comes that other assistance is required, it is generally a daughter or daughter-in-law that takes over the primary role. In some instances, caregivers have taken over the role unexpectedly and without preparation. This may be a temporary activity, until the family can respond with more permanent solutions to the need for care. Each family situation is unique. The extent of participation will vary. Some families will be able to share caregiving tasks, both financially and personally, because they live in the same geographic area. Other family members who live at a distance may take on other tasks. Special challenges exist when living at a long distance or being an only child who assumes this role alone. But, no caregiver is alone today. Many community and private agencies are available to help with the myriad of occasional and everyday tasks. These agencies are available to supply either paid or volunteer specially trained home care providers, classes and training, education, products which assist with self-care activities, and support groups.



### **Who Requires Care?**

A caregiving experience usually begins in a crisis but may come on gradually. It begins in earnest when a family member or friend becomes too ill or incapacitated to care for themselves, or a spouse who has been the primary caregiver for many years and can no longer continue in that role. The individual who receives care is known as the care recipient; those that provide care are the caregivers. When possible, the care recipient must be considered in all care planning and decision making. A once independent person can become overwhelmed with feelings of helplessness and anger, when they are dependent on others for personal care. Recognizing these feelings, open communications, and a sense of humor will do much to maintain dignity and self-respect. Recipients most often include those individuals:

- Who live alone
- With a history of falls
- With dementia or other severe declining mental functions
- With chronic mental illness
- With stroke or other physically limiting conditions such as rheumatoid arthritis
- With neurological diseases
- With multiple chronic diseases
- With severely impaired vision
- With developmental disabilities returning to a home environment

### **Both Care Recipients and Caregivers Require Care.**

The commitment in time, energy, and the learning of new skills can be daunting. Caregiving is often physically and emotionally exhausting and caregivers must learn to take care of themselves. It is helpful to:

- Know your own physical and emotional limits
- Seek help with problems and care provision
- Take time out for yourself

Caregiving should include all family members, the health care treatment team, and community resources to assure that the plan of care is implemented. Keep in mind that the knowledge and skills involved can be learned from professionals and other caregivers.

### **Continuing Care**

The needs and circumstances of both care recipient and caregiver will change over time. Acute illnesses, finances, and additional responsibilities are factors that will have an impact. The care recipient's physical or mental health status may wax and wane or his or her wants may change, necessitating new arrangements. Caregivers may become ill, spouses may be transferred, or other family or job duties may limit time and energy. The wants and needs of both the care recipient and caregivers over time will require updating the plan of care. This may mean additional help at home, an assisted living apartment, or finding placement in a nursing facility. Assessment of the recipient's physical or mental status, his/her desires for continuing care, home environment, and caregiver needs should be made periodically by the family and health care team.

As Americans age it is important to consider what lies ahead in our own active and longer lives. Planning for the caregiving of family members or spouses should be part of that consideration. Whether your needs are in the future or present, "Productive Aging" can help make planning and caregiving a manageable and fulfilling responsibility. We stand ready to provide you with additional information and resources to enhance the well-being of you and your family. Resource Advisors are a phone call away.

### **Contributing Resources**

National Alliance for Caregiving  
The American Society on Aging  
The 36 Hour Day, Mace and Rabins  
The National Institute on Aging

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# Productive Aging

## CARING FOR THE CAREGIVER

Caregiving is an art, not a science. A person is not born with a caregiver gene; it is a learned, evolving experience. When is a person a caregiver? A universally accepted definition of caregiving does not currently exist. Some define caregiving as a direct, hands-on experience. Others consider organizing paperwork or paying bills long distance to be caregiving. Whatever the definition or the scope of the services provided, the role of caregiver implies that one's life has been impacted. Recent surveys indicate that many more people than ever expected serve as caregivers. One report issued by the National Alliance for Caregiving in the spring of 1997 states that individuals in more than 22 million households are involved in caregiving for someone over 50 years old. The National Family Caregivers Association reports that the number of caregivers in all households totals at least 25 million people. These staggering statistics have tremendous financial implications for the family, society, business, and government. If individuals were not providing these non-reimbursed caregiving services, who would provide the care? Who would pay? The impact of caregiving services translates monetarily into what some estimate to be \$300 billion annually! **Caregiving is of value!**

### Paying the Price

However willingly caregiving activities are performed, as more time passes for the caregiver, balancing life's priorities may become an increased challenge. Forty percent of the caregivers recently surveyed by The National Family Caregivers Association agreed that a combination of isolation, changing family dynamics, and the loss of leisure time were the most burdensome aspects of caregiving. How is it possible for the millions of people who are caring for older family members, spouses and/or younger family members to balance this responsibility with working and with enjoying some time for themselves?

As a care recipient becomes more dependent, the physical demands placed upon the caregiver increase. Many caregivers suffer from a lack of sleep, develop poor eating habits, and jeopardize their health while trying to provide a high degree of physical caregiving. Learning proper techniques for bathing, lifting, and assisting is time well spent by the caregiver in order to prevent injury—to either party.

A caregiver may also experience physical symptoms as a result of emotional stress. These symptoms may include: fatigue, headaches, depression, sleeplessness, or feelings of being overwhelmed. Feelings of resentment are a good indicator that more is being done than can be managed. Fortunately

caregivers can take many pro-active approaches in order to remain as positive and healthy as possible.

### What Are the Active Approaches?

- Learn as much as possible about the disease/condition and the treatment plan. Think of the health care provider as a member of the team—the first line for information and advice.
- Seek help from others—be aware of physical and emotional limits so that help may be arranged when it is needed. Get to know community resources—agencies, church or other religious organizations, senior centers, and support groups.
- Take time out—have some quiet time at home or visit with a friend. Make a commitment to take time for personal well-being. Try listening or playing inspirational music, writing, or gardening—there are many ways to get in touch with spirituality and nature.
- Grant personal credit for committing to care for another person; this is a major life challenge. Adults require a different type of care than children require—not only are they bigger in size but they are also used to independence. The role of parenting is re-enacted through caregiving although the care recipient may be an adult. It is important to recognize the changing roles and responsibilities that caregiving brings to the *entire* family.
- Eat well-balanced meals and get adequate sleep and exercise. Consider joining a gym and “letting off some steam.” A caregiver’s body needs proper attention in order to remain—or become—strong and healthy.
- Express feelings. Joining a caregiver support group to talk about your experiences as a caregiver may be a welcome outlet. Support group involvement also provides a lot of good ideas for problem solving. Writing in a journal or diary may also be helpful.
- Master stress reduction techniques. Some of these include:
  - ◆ Relaxation exercises. (These can be listened to on audio-tapes.)
  - ◆ Yoga. (This is a stretching exercise that is done in combination with deep breathing.)
  - ◆ Meditation. (Involves focusing thoughts on one object at a time.)



- ◆ **Mental imagery.** (When the imagination recreates a place that is peaceful and relaxing—revisit it often when time out is needed.)
- Consider *respite care* for some temporary time off. Relief care may be funded through a volunteer organization, through insurance reimbursements, or by private payment. Take a well-deserved break. Assisted living facilities and some nursing homes offer in-facility respite services on a bed-available basis. The "Productive Aging" program can provide resources wherever they are needed.

### **Spiritual Stress**

In addition to physical and emotional stress, caregiving may also challenge one spiritually. Chronic and debilitating illnesses that rob families of a loved one's former self can shake beliefs and values. Questions may be asked such as, "Why has this happened?" or "What have I done to deserve this?" These feelings of being a victim and losing control may impact one's inner strength and well-being. Finding areas of life where things are controllable—where things are predictable—may be helpful. Discussing feelings with a religious leader, a family member or friend, or joining a support group may provide relief and understanding. Remember, these emotions are felt by many others. Caregivers need time to themselves, time which is free from worry over the well-being of the care recipient, and time to search for meaning during this passage of life.

### **Caregiver's Bill of Rights**

#### **I have the right:**

- To take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my relative.
- To seek help from others even though my relative may object. I recognize the limits of my own endurance and strength.
- To maintain facets of my own life that do not include the person I care for just as I would if he or she were healthy.
- To get angry, be depressed, and to express other difficult feelings occasionally.
- To reject any attempt by my relative to manipulate me through guilt, anger, or depression.
- To receive consideration, affection, forgiveness, and acceptance for what I do for my loved one for as long as I offer these qualities in return.

- To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my relative.
- To protect my individuality and my right to make a life for myself that will sustain me during the time when my relative no longer needs my full-time help.
- To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired older persons in our country, similar strides will be made toward aiding and supporting caregivers.

—Jo Horne

### Looking Forward

Remembering happier times and missing the companionship of an equal partner can lead to overwhelming feelings of loss and isolation. One way to cope with these feelings is by finding and using resources. Keep in mind that you have a partner in caregiving work at "Productive Aging." Resource Advisors are a phone call away.

### Contributing Resources

Caregiving—Helping an Aging Loved One, Jo Horne

National Alliance for Caregiving

National Council on the Aging

National Family Caregivers Association

"The Baltimore Longitudinal Study of Aging: With the Passage of Time"

The National Institute on Aging

The National Institutes of Health

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# Productive Aging™

## CAREGIVER ACTIVITIES

Some caregivers perform specific tasks with varying frequency ranging from once a month to daily. These tasks may include providing transportation, grocery shopping, household chores, bill paying, or cooking. Others provide direct personal assistance. More than half of all caregivers help with at least one Activity of Daily of Living such as bathing, dressing, transferring, ambulating, toileting, or continence.

### Helpful Hints for the Caregiver

Caregiving is complicated work. It involves not only the task of *doing*, but also the task of *coping* with the many challenges that arise when taking care of another person. Caregivers develop and learn skills that cannot easily be replaced. Here are some suggestions to help alleviate or prevent potential problems that arise when providing care.

- Both the caregiver and the care recipient benefit when they know what to expect. Understanding what physical and emotional problems/limitations are present and can be anticipated allows planning together for present and future needs.
- Keep the lines of communication open and on an adult-to-adult level. Keep in mind that the need to depend on someone else to accomplish activities that previously were done independently is a source of stress to care recipients.
- Establish a daily routine. Try to do things the same way and at the same times every day such as dressing, bathing, eating, sleeping or taking medications. Follow as many of the recipient's old routines as possible (any change in routine is a potential source of stress).
- Provide a safe environment, clear walking areas, and install safety devices.
- Allocate time for activity. Easy chores can provide feelings of personal control and accomplishment. Light exercise is important for mental and physical health as well as preventing restlessness. Provide fun activities such as card playing, watching videos, or listening to music.
- Try and picture what life is like from the care recipient's perspective. Consider creating shared activities and opportunities for making choices.
- Do what needs to be done. Doing more or less than necessary robs an individual of dignity and self worth.
- Make things easy. Lay out clothes in the order the person puts them on. Prepare meals that are simple to make and easy to eat.
- Organize a journal for medication management that contains a chart of what medicine to take, when to take it, how to take it, and if the medicine was taken.

- Crush pills and mix them into soft foods such as applesauce if there is difficulty swallowing or reluctance to take medications. Some medicines are available in liquid form that can be blended with fruit juices to mask the taste.
- Learn to give physical care such as transferring or bathing safely and efficiently. Caregiver training classes may be offered at a local hospital, community college, or through a support group.
- Limit caffeine and prevent daytime napping if there are problems with getting to sleep. Herbal teas or warm milk may have a calming effect. Singing quiet songs, relaxing games, or giving a massage may also help with sleeplessness. It may require a lot of experimentation to find a technique that works. The use of sleeping or tranquilizing medications may induce unpredictable responses so careful consideration is warranted.
- Provide opportunities to use the toilet before and after meals and immediately before going to bed. It is normal for both the care recipient and caregiver to feel embarrassed or awkward during times of incontinence. These feelings are reduced when caregivers remain calm and reassuring during difficult times.
- Make bath time relaxing by playing soft music in the background. Bathing is a very personal and private activity. Wait and try again, if there is objection to bathing. Sometimes unspoken objections result in aggressive behaviors. The care recipient may be feeling uncomfortable and vulnerable at this time.
- Avoid aggressive behavior by explaining what is going to be done before doing it. If the behavior develops, take a deep breath and a "time out" for 2 or 3 minutes. Look to see if you can figure out what event led to the outbreak, and what might be done differently next time.

Remembering happier times and missing the companionship of an equal partner can lead to overwhelming feelings of loss and isolation. One way to deal with these feelings is by finding and using the resources that are needed by the caregiver. Keep in mind that you have a partner in caregiving work at "Productive Aging", Resource Advisors are only a phone call away.

### **Contributing Resources**

Caregiving: Helping an Aging Loved One, Jo Horne

National Alliance for Caregiving

National Council on Aging

National Family Caregivers Association

The National Institute on Aging

The National Institutes of Health

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# Productive Aging

## TAX BENEFITS FOR CAREGIVERS

The valuable services provided by caregivers are currently not well recognized in the form of tax benefits by the U.S. government. Some caregivers provide hands-on service to the care recipient, others financial assistance and still others a combination. The present Internal Revenue Service (IRS) tax code permits no deduction for volunteer work, inside or outside the family. However, any financial contributions made by caregivers can have positive tax consequences. When the right facts are present, a caregiver can claim a dependent; qualify for a lower tax rate as a head of household; and/or deduct medical expenses paid on behalf of the care recipient.

### Dependent Parents

One determinant to the amount of income tax a taxpayer owes is the number of dependents that are claimed. The more dependents, and therefore deductions, the lower the amount of taxable income will be. A parent or parent-in-law may be a dependent even when not living in the same household as the taxpayer. The dependent's gross income must be low; (Social Security benefits do not count as gross income for this purpose) and the taxpayer must furnish at least half of the dependent's support annually. When the parent or in-law lives with the taxpayer, then the fair market value of the lodging that the taxpayer provides is considered as support. On the other hand, if the wage earner moves in with the dependent and lives rent-free, the value of that lodging becomes income for the wage earner. Admission to a hospital or move to a nursing home is considered only a "temporary absence" in determining the dependent's home. For tax purposes, health insurance premiums are considered support even though health insurance benefits are not counted in determining income. Benefits received under either Medicare Part A or Medicare Part B are also not considered as income.

An individual who is claimed as a dependent loses some tax benefits on his or her tax return. It is wise to check with a tax advisor about the tax status of the whole family in this situation. When the parent or in-law is claimed as a dependent, records must substantiate the amount that is spent on support. When an employer asks for a W-4 form each year (to determine the number of withholding exemptions), it is wise to claim an extra exemption when there is reason to believe that the parent or in-law will be named as a dependent.

### **Multiple Support Agreements**

A multiple support agreement is a contract made by brothers and sisters (or in-laws) who contribute to a loved one's (often a parent or other relative) financial well-being. The whole group jointly provides at least half of the financial support, and each member of the group is able to claim a dependent when he or she provides half of the elder's support single-handed. The multiple support declaration determines which group member is allowed the dependent claim.

There are two requirements. First, the person who claims the dependent must contribute at least 10% of the support personally. Second, everyone else in the group who contributed 10% or more of the support must sign an IRS Form 2120, agreeing NOT to claim the loved one as a dependent. The IRS wants to make sure that the same person is not claimed as a dependent by two, three, or five relatives. It will exclude even a valid dependency deduction when the other members of the group do not make the waiver of the deduction. It is acceptable for the group to sign a new agreement each year, "rotating" the dependency deduction, as long as only qualified people take the deduction.

### **Head of Household Status**

Another factor in the amount a taxpayer pays is his or her "filing status." Married people who file a joint return are charged lower tax rates than single taxpayers that have the same amount of income. Head of household status is in the middle: tax rates are higher than joint return rates, but lower than the rates for a single taxpayer. Taxpayers who qualify as heads of households also get a higher standard deduction than their single counterparts. A head of household is unmarried (single, divorced, or widowed) and maintains a household where any dependent person lives more than half the year. The dependent and head of household don't have to live together, as when the taxpayer pays for a separate household for a dependent parent. The household that the taxpayer maintains could be a nursing home. For example, if the taxpayer pays more than half the cost of keeping the parent in a nursing home, the taxpayer qualifies for head of household status. However, a person who has waived the right to claim the dependency deduction under a multiple-support agreement is not allowed to claim a dependent in order to file taxes as a head of household. When a tax return is filed, the IRS has the right to send the taxpayer a Form 4752 in order to collect information to substantiate the taxpayer's entitlement as head of household.





### **Deducting Medical Expenses**

When a parent or in-law is dependent, a tax deduction for medical expenses paid on his or her behalf may be taken. In fact, one may qualify for this deduction even if the individual is not a dependent for other tax purposes, as long as at least half of his or her support and medical bills are paid. It is typically not possible to deduct all the medical expenses that are paid. The medical expense deduction is the total amount of all medical expenses (and expenses of other dependents), minus expenses that are reimbursed by insurance or other pay out and are greater than 7.5% of Adjusted Gross Income. When there is a multiple support agreement, only the person who is entitled to the dependency deduction is allowed to deduct the medical expenses. Only what was paid personally, not amounts paid by the other siblings who signed the multiple support agreement are allowable. Those other siblings can not deduct the medical expenses they paid, either, because he or she is not their dependent. Participants may agree that the person who gets the dependency deduction will pay all the medical expenses (and keep records documenting the payment), whereas the rest will earmark their financial contributions for meeting additional needs.

Thanks to a 1996 federal law, the Health Insurance Portability and Accountability Act, it is now clear that "qualified" long-term care services count as medical expenses that can be added to the pool of potentially deductible expenses. Qualified expenses include the provision of care, treatment, or therapy for a person who needs assistance with at least two basic daily tasks (like dressing and eating), or who needs constant supervision due to Alzheimer's Disease or other cognitive impairment. When medical expenses are paid directly to the provider no gift tax is incurred no matter how large the amount. But if the money is given to the dependent, a gift tax may be due when the amount exceeds \$10,000 to one person in a given year.

### **The Dependent Care Credit**

Responsibility for a parent or in-law is often combined with the holding of a full-time job. This may necessitate the hiring of an aide or companion to take care of the dependent during the workday, which could result in a tax credit allowance. A tax credit directly reduces the amount of income tax one pays; a deduction just reduces the amount that is used to calculate tax obligations. The dependent care credit is between 20 and 30% of expenses; the higher the income, the lower the percentage of the creditable expenses that can use in the calculation. The maximum amount that can be considered is \$2400 for one dependent, \$4800 for

two or more (for instance, two small children and also a dependent parent); so the maximum credit for one dependent is \$720 (30% of \$2400). For the caregiver to qualify for this credit, the care recipient must either be a dependent of the caregiver, or would be a dependent except that his or her income is too high. The individual must also be unable to cope with his or her basic needs, or need constant supervision to avoid danger to him or herself and/or other people.

Helping parents financially can yield tax benefits. When the role is financial support (rather than hands-on care) the person who helps is still considered a caregiver. The tax benefit is maximized when the parent has little income apart from Social Security, and the caregiver is a single person in a high tax bracket. It often takes sophisticated advice to take advantage of rightful tax provisions.

Today, many people remain healthy, active, and alert due to several factors, among which include healthier life styles, planning for the future, and advancing medical knowledge. The "Productive Aging" program is available to assist in pursuing goals for a quality life. For additional information that may be of assistance to you and your family, Resource Advisors are a phone call away.

### **Contributing Resources**

Dana Schilling, Esq. (contributing author)

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***Supporting Attachments***

*“A Profile of Caregivers”*

*Boca Raton Interfaith in Action*

*“On Your Behalf”*

# A Profile of Caregivers

In the spring of 1994, NFCA conducted its first Caregiver Member Survey. The results were illuminating, and professionals and caregivers alike were very interested in the results. This past summer, a second NFCA Caregiver Member Survey was conducted with funding from one of our National Corporate Partners, Fortis Long Term Care Insurance, and technical know-how and logistical support from Fortis subsidiary AdultCare.

There are several factors that make this survey noteworthy. First of all, it had a remarkable response rate of 35%. Secondly, it is one of the very few surveys of caregivers from all across America and all across the life cycle, thus shedding light on the common aspects among the members of the caregiving population. Thirdly, it is a survey of a group of individuals, many of whom are providing an intense level of caregiving, who have reached out for support. Finally, it is significant because it is a survey of individuals of whom over 60% have been caregiving for five years or more.

Here then is a snapshot view of NFCA's members in the summer of 1997, based on our first preliminary analysis. Additional information and analysis will be available shortly.

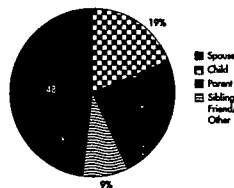
## Who We Are: A Brief Synopsis

<b>SEX</b>			<b>KIDS AT HOME</b>	
Female	82%		Yes	23%
Male	18%		No	77%
<b>MARITAL STATUS</b>			<b>EMPLOYED</b>	
Married	74%		Yes	47%
Single	12%		No	53%
Divorced/Widowed/ Separated	14%		<b>EMPLOYED FULL TIME</b>	
<b>AGE</b>			More than 31 hrs/wk	71%*
20-35 years	6%			
36-50 years	34%			
51-65 years	36%			
66-80 years	22%			
Over 80 years	2%			

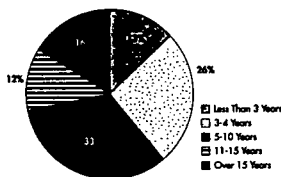
\* % of those working

<b>WHERE CAREGIVING IS DONE</b>	
Caregiver's Home	80%
Care Recipient's Home	8%
Nursing Home	6%
Assisting Living Facility	2%
Other	4%

## FOR WHOM DO YOU CARE



## HOW LONG HAVE YOU BEEN A CAREGIVER



## HOW MUCH LONGER DO YOU ANTICIPATE YOU WILL BE A CAREGIVER?

Less than 5 years	25%
5-10 years	31%
11+ years	44%

(Continued on page 8)



### What is Boca Raton Interfaith In Action?

Boca Raton Interfaith in Action is a multi-generation volunteer effort to provide support and assistance to homebound individuals and/or their caregivers living in Boca Raton. The mission of BRIA is to maintain dignity, independence and a better quality of life for homebound individuals and their caregivers through a unified effort of religious organizations, community agencies and dedicated people.

### Who Do We Serve?

- Individuals at home who need assistance in order to maintain their independence
- People without family or friends nearby to provide support and care
- People suffering from chronic pain, illness or the effects of aging and frailty
- People recently home from the hospital and in need of support
- Caregivers of persons in these situations

### What is the Interfaith Volunteer Support Services Program?

This program recruits and trains a network of caring volunteers who are linked with those in need and provide gifts of service such as:

- ✓ Friendly visits
- ✓ Transportation
- ✓ Shopping/running errands
- ✓ Light housekeeping
- ✓ Yard work
- ✓ Meal preparation
- ✓ Telephone assurance
- ✓ Reading/writing
- ✓ Respite care

### Who are the Volunteers That Provide the Service?

- Neighbors helping neighbors
- Generous caring people who share a responsibility for helping others
- People of all ages and denominations

***Boca Raton Interfaith In Action provides services to residents of Boca Raton regardless of age, race, sex, marital status, religion or ethnic background.***

**Boca Raton Interfaith In Action, P.O. Box 811525, Boca Raton, FL 33481-1525 (561) 391-7401**

- I would like to contribute to this effort to improve the quality of life for the homebound living in Boca Raton.
- I would like to volunteer my time
- I know someone who would benefit from your program
- I have enclosed my gift in the amount of \$ \_\_\_\_\_

Name: \_\_\_\_\_ Phone: \_\_\_\_\_  
Address: \_\_\_\_\_  
City: \_\_\_\_\_ State: \_\_\_\_\_ ZIP: \_\_\_\_\_

Please make checks payable to *Community Interfaith Coalition, BRIA*  
All donations are tax deductible.

Boca Raton Interfaith in Action  
P.O. Box 811525  
Boca Raton, FL 33481-1525



**Together We Can Make A Difference**

- Encourage and support those with special needs to continue to live independently through our presence and services
- Brighten someone's day with a visit to break the loneliness
- Ease someone's burden by doing the shopping or helping to prepare a meal



*Thanks to our special founding friends...*

AdultCare, Inc.  
 AME Church  
 American Cancer Society  
 Boca Raton's Promise for Youth  
 Center for Information & Crisis  
 First Church of Christ Scientist  
 First Presbyterian Church  
 First United Methodist Church  
 Good Shepherd Lutheran Church  
 Manor Care Health Services  
 New Hope Church  
 Personal Care Managers  
 Ruth Rales Jewish Family Services  
 St. Gregory Episcopal  
 St. John of San Cataldo Church  
 Temple B'nai Torah  
 Temple Beth El



*Generations Helping Generations*

**An Interfaith Volunteer Support Services Program**

*Founding Sponsor*  
**Community Interfaith Coalition**

*Initial Funder*  
**Robert Wood Johnson Foundation**

Boca Raton Interfaith in Action  
 P.O. Box 811525  
 Boca Raton, FL 33481-1525  
 (581) 391-7401

## On Your Behalf

by Connie Ford

# The Family Medical Leave Act

I have just returned from the First International Conference on Caregiving held in London, England. While healthcare delivery systems vary widely from country to country, the issues and impact on the lives of caregivers are the same. The United States, however, is behind England and most recently, Australia, in achieving legislative recognition and meaningful national support of caregiving and caregivers.

America's only federally mandated legislation that supports caregivers is the Family Medical Leave Act (FMLA) which became effective August 5, 1993. The intent of the legislation is to recognize that more employees today are juggling workplace demands with family care responsibilities and provides a way to preserve an employee's job and economic security while fulfilling increasing demands of family care. This Act applies to companies that employ 50 or more persons within a 75 mile area. Many of our caregivers are employed and meet the eligibility criteria of working for their company for at least 1 year and over 1,250 hours during the last 12 month period.

### How does the FMLA help employed caregivers?

It allows eligible employees to take up to 12 weeks of unpaid leave per year for certain family health reasons without jeopardizing their employment status. Recent surveys show that many caregivers do not realize that the law does not have to be taken all at once. It can be broken up in whatever time segments are most

beneficial to the employee, including using a few hours per week. The time requests need to be pre-arranged, approved and may require justification with medical certification.

### There are three circumstances for using this leave.

- 1) For the care of the employee's child which includes birth, placement for adoption or foster care.
- 2) For the care of the employee's spouse, son, daughter or parent who has a serious health condition.
- 3) For the employee's own health condition which inhibits his or her job performance.

### Conditions layed out by FMLA

- When you use this leave, your employer must maintain your regular medical insurance coverage. Premiums may later be collected, only if you don't return to work.
- When you return to work, if your exact job is not available, an equivalent position must be granted to you with the same compensation.
- You also do not forfeit any previously accrued benefits.
- If your state has a law which is more favorable to you, then the state law prevails. The FMLA sets minimum employer standards.

While this law is in place, according to a 1996 Labor Department report, only 16.5% of employees have taken advan-

tage of their right to this leave; another 3.4% needed to but couldn't afford to be without pay. The 1997 National Alliance for Caregiving random national survey reported that 11% of employed caregivers used this benefit.

There are several reasons, in addition to monetary, that this leave is underutilized. Only about 55% of today's employees qualify under this mandate to grant unpaid family leave. Not all employees understand their entitlements or are encouraged by their managers to use this benefit. Many caregivers and their supervisors do not realize the time flexibility the law allows. Also, caregiving of today extends beyond the core family unit that this act recognizes. Caregivers who assist grandparents, in-laws, significant others, friends and other relatives do not qualify for FMLA benefits.

The 1993 FMLA is at the very least a start on behalf of caregivers in our country. The coverage needs to be better communicated to employers and employees, expanded and updated. The experiences of England and Australia, and their willingness to share information can now be used as a starting point in this country toward developing legislation for family caregiving in the United States and throughout the world. It remains our responsibility, individually and collectively, to get results to recognize and provide meaningful support for today's caregivers! ■

If you would like the exact wording of the Family Medical Leave Act... or any federal legislation, call your U.S. Representative or one of your U.S. Senator offices. You will find their phone numbers listed in your local phone book. Or write to them at:

Senator _____	Hon. _____
U.S. Senate	U.S. House of Representatives
Washington, D.C. 20510	Washington, D.C. 20515

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# **Options for Supporting Informal and Family Caregiving**

**A POLICY PAPER**

**The American Society on Aging**

*August 1997*

**Funded by The Pew Charitable Trusts**

# **Options for Supporting Informal and Family Caregiving**

## **A POLICY PAPER**

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## EXECUTIVE SUMMARY

One of the major challenges of the twenty-first century will be to provide accessible, affordable, and quality long-term care to the growing numbers of frail older people. Currently, federal cutbacks in health and human services are having a profound effect on the ability of states to develop long-term-care systems that are responsive to consumer needs. States must now assume greater responsibility for shaping the financing, eligibility, coverage, and delivery systems that provide long-term care.

At the same time, policymakers are beginning to recognize the critical role of families in the provision of long-term care and are addressing family-related matters that historically were thought to be too private for a public response. In fact, decision makers—in both the public and private sectors—are becoming personally affected by caregiving because they themselves are providing care to older parents, spouses, and other relatives and friends.

Policymakers have a strong interest in maintaining the strength and durability of family and informal caregiver networks as the primary providers of long-term care. Caregiver support is increasingly becoming a priority for many state governments because of the high costs of *not* taking any action.

The motivation to bring about change is present in every state, driven by economics, values, and, of course, politics. States have two main incentives for providing caregiver support and expanding home and community-based care options as part of a long-term-care system: The first is a matter of *values*, the strong preference of older people to remain at home, in their communities, with their families, for as long as possible. The second is driven by *economics*, the desire to control the rising costs of long-term care, particularly for nursing homes.

While strengthening the role of families in long-term care can produce cost savings for states and is generally the preferred option expressed by individuals, emphasizing this role also can place severe strain on family caregivers. Therefore, it is crucial in any long-term-care strategy to provide support services for caregiving families.

This paper provides a common starting point for both policymakers and consumer advocates to shape a state policy agenda that recognizes and supports the central role of families in the provision of long-term care to frail and disabled older people. The paper highlights key issues and facts about family and informal caregivers and makes the case that states should want to invest in programs that support and strengthen family care. Key strategies for action by both state policymakers and advocates are summarized to assist in the development of family caregiver support policies.

### Families, Not Institutions, Are the Major Providers of Long-Term Care

- Families provide 80 percent of all care at home and are commonly referred to as "family caregivers."

- The term *caregiver* refers to anyone who provides as-

sistance to someone else who needs it to maintain an optimal level of independence.

- The availability of family caregivers is often the deciding factor in whether a loved one can remain at home or must move to a more costly nursing home.

### Nearly All Public Opinion Polls Show That Long-Term Care Is a Powerful Family Issue

- Polls show that the majority of Americans support a publicly financed long-term-care program that includes home- and community-based options as well as nursing home care.

- Families worry about the catastrophic costs they could face if a family member should need long-term care.

- While older people overwhelmingly prefer home-care to nursing home care, it is the cost of nursing home care that most affects the economic security of the family.

### Demographic and Social Trends Will Affect Family Care in the Future

- Long-term-care costs may more than double in the next 25 years. At the same time, the population is rapidly aging, and the American family is changing.

- By 2030, when the baby boomers reach age 65, approximately one in five Americans will be at least 65—or about 70 million older people, more than *twice* their number in 1995.

- Five social trends may affect the supply of caregivers in the future: (1) increasing divorce and remarriage rates; (2) increasing geographic mobility; (3) decreasing family size; (4) delayed childbearing; and (5) more women in the workplace.

### Research Shows That Caregiving Often Exact a Heavy Emotional, Physical, and Financial Toll

- Many caregivers experience immense stress and feelings of burden, high rates of depression, and feelings of anger and anxiety.

- Caregiving can adversely affect one's physical health and ability to continue providing care—leaving two impaired persons, rather than one.

- The emotional and physical strain of caring for a frail older relative is often exacerbated by worries over paying for care, particularly for nursing homes.

- The financial impact of caregiving takes a particular toll on family members when it affects their ability to work. Research has shown that some caregivers must quit their jobs to give care, while others experience increased absenteeism, lower productivity at work, lost career opportunities, and loss of future earnings.

### The Costs of Care Are an Economic Burden for Most Families

- Medicare does not cover long-term care, private insurance is expensive and limited in coverage, and out-of-pocket costs are high.

- Middle-class families are hit the hardest.

- An institutional bias still drives long-term-care spending.

- Despite older peoples strong preferences for home and community-based services, long-term-care dollars are overwhelmingly spent on nursing home care.

- The cost of nursing home care—averaging about \$40,000 a year per person care for—is beyond the means of most people.

#### Policymakers Are Beginning to Recognize the Critical Role of Families in the Provision of Long-Term Care as a Way to Help Control Rising Costs of Care

- Four main policy strategies currently support caregiving families: (1) direct services (e.g., respite care); (2) financial incentives and compensation, including direct payments and tax incentives; (3) the cash-and-counseling model; and (4) employer-based mechanisms.

- Research has shown that most caregivers prefer services to dollars.

#### State-Funded Caregiver Support Programs Are Diverse and Dependent Upon Individual State Priorities and Resources

- No comprehensive list of state-funded caregiver programs exists because of the fragmentation of services and variations in eligibility, mode of delivery, and scope of services.

- Respite care is the service most typically funded by state governments.

- Two successful programs stand out in terms of scope, service package, and funding; these can be replicated by other states: Californias Caregiver Resource Centers and Pennsylvania's Family Caregiver Support Program.

In the near future, the demands placed on family and other informal caregivers are likely to escalate, affecting nearly every American family. This paper shows that *caregiving is not just an aging issue, it is a family issue and a policy issue*. It is vitally important for consumer advocates to seize the policy agenda and urge states to develop family caregiver support policies to protect families from the financial and emotional bankruptcy that often is the cost of long-term care.

Finally, advocates should arm themselves with the facts. They should use this report and should focus attention on the two major recommendations for state action:

- The need to recognize and strengthen the central role of families in the provision of long-term care.

- The need to shift the focus and incentives in long-term care away from institutional care to home and community-based care.

Strengthening the role of families is both *cost-effective and compassionate* public policy. We can no longer afford not to act—our own future and that of our parents, grandparents, and children depends on it.

## INTRODUCTION

As we rapidly approach the twenty-first century, Americans are increasingly being faced with the challenges of providing long-term care to the growing numbers of people with chronic illnesses and disabling conditions. The future looks very unlike the past. Indeed, a number of societal dynamics—demography, healthcare financing, family structure, and medical advances—have pushed long-term care to center stage at the national, state, and local policymaking levels.<sup>1</sup>

Who are the major providers of long-term care in the United States? Contrary to popular belief, *families, not institutions, are the major providers of long-term care, providing some 80 percent of care.* Often at great sacrifice, families strive to keep an impaired relative at home, avoiding more costly institutional care. Indeed, the availability of informal and family caregivers is often the deciding factor determining whether an impaired individual can remain at home or must move to more costly nursing home care.

Research has shown that about 90 percent of dependent community-dwelling older people receive care from family, friends, and neighbors; about one-quarter use a combination of formal<sup>2</sup> and informal<sup>3</sup> care; and only 9 percent rely exclusively on formal care.<sup>2</sup>

Public and private expenditures for long-term care—now estimated at more than \$108 billion—are projected to more than double in the next twenty-five years.<sup>3</sup> The greatest population growth will be for those aged 85 and over—the most rapidly growing elderly age group and those most in need of long-term care.

Long-term care often involves the most intimate aspects of peoples lives: personal hygiene, getting dressed, using the bathroom. Other needs may involve household tasks such as preparing meals or using the telephone. Most people who need long-term care live at home or in the community. Of the 12.8 million Americans estimated to need long-term-care assistance, only about 2.4 million live in institutional settings such as nursing homes.<sup>3</sup> Most, but not all, are older people: Approximately 57 percent are people aged 65 and older (7.3 million); 40 percent are working-age adults aged 18 to 64 (5.1 million); and 3 percent are children under age 18 (400,000).<sup>3</sup>

The term *family caregiver* is now part of the American vocabulary, in large part because of the aging of the population and the increased attention to health and long-term-care issues in the mass media. *Caregiving, however, is not just an aging issue; it is a family issue and a policy issue.*

Today, policymakers are addressing family-related matters that historically were thought to be too private for a public response. In fact, decision makers—in both the public and private sectors—are becoming *personally affected* by caregiving because they themselves are providing care to older parents, spouses, and other relatives and friends. By the year 2005, baby boomers will become a majority of those aged 50 to 74. The baby boom leaders

in their 50s and 60s will bring with them a better understanding of today's family issues.<sup>4</sup>

At the same time, the American family is changing rapidly. Increasing numbers of women in the labor force, increasing geographic mobility, high incidence of divorce and remarriage, and delayed childbearing may strain families' capacity to provide care in the twenty-first century. These dramatic trends mean not only that there will be fewer family caregivers available, but that those who do care for disabled older people will have even less support from other family members than is the case now.<sup>5</sup>

Although it has been suggested that families might reduce their caregiving efforts if publicly funded long-term-care services were available, there is little evidence to support this claim.<sup>6</sup> Caregiver support is becoming a priority for many state governments because of the high costs of not taking any action. Several state programs now formally acknowledge the goal of reducing caregiving strain and complementing informal care so that families are able to continue providing long-term-care assistance.

This paper provides a common starting point for consumer advocates to shape a state policy agenda that recognizes and supports the central role of families in the provision of long-term care to frail and disabled older people. The paper highlights key issues and facts about family and informal caregivers, summarizes the state-of-the-art knowledge about caregiver support programs and emerging trends, and makes the case for why states should want to invest in programs that support, rather than supplant, family care.

### Talking Points

- Families, not institutions, are the major providers of long-term care, providing some 80 percent of care.
- The availability of family caregivers is often the deciding factor in whether an individual can remain at home or must move to a more costly nursing home.
- Long-term-care costs may more than double in the next twenty-five years. At the same time, the population is rapidly aging, and the American family is changing.
- Caregiving is not just an aging issue; it is a family issue and a policy issue.
- Caregiver support is becoming a priority for many state governments because of the high costs of not taking any action.
- Advocates can and must make the following case: To support and strengthen the role of families and other informal caregivers is *cost-effective* and *compassionate* public policy.

<sup>2</sup>*Formal care* is defined as care provided by professionals, paraprofessionals, or volunteers associated with a service system who provide care at home, in community agencies, or in institutions or residential facilities.

<sup>3</sup>*Informal care* is defined as care provided without pay by family, friends, or neighbors.

## WHAT THE AMERICAN PUBLIC THINKS ABOUT LONG-TERM CARE: A POWERFUL FAMILY ISSUE

Polls show that the majority of Americans support a publicly financed long-term-care program that includes home- and community-based options as well as nursing home care. Indeed, how Americans view long-term care influences how they vote.<sup>8</sup> Close to half (46 percent) are more likely to vote against their member of Congress if he or she votes for health reform legislation without long-term care.<sup>9</sup> Nearly seven out of ten Americans (69 percent) prefer a publicly financed long-term-care program similar to Social Security or Medicare.<sup>8</sup>

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Mrs. G, a 58-year-old manager in the State Department of Transportation, has cared for her 83-year-old father, a stroke survivor, in her home for the past three years. Last summer she took a leave of absence from her job to care for her father after he fell and broke his hip. Her immediate fear was that Dad would have to go into a nursing home—*not* what she or her father wanted. The prospect was both heartwrenching and a financial nightmare. However, Mrs. G was lucky enough to find an adult day program and caregiver resource center in her community to help keep her father at home. With this support, Mrs. G has been able to return to work and continue caring for her father.

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Survey after survey and nearly all public opinion polls show that long-term care is a major issue of concern for American families. A 1996 national survey found that nearly 90 percent of Americans believe that providing long-term care is a *big problem*, and 59 percent have a family member or friend who has needed long-term care. Of these respondents, 53 percent provided hands-on care and 25 percent provided financial assistance to help pay for that care. This survey also found that long-term care is an intergenerational issue, touching younger as well as older people. Fifty-two percent of respondents born after 1965 have a friend or relative who needs long-term care. Of these younger people, 44 percent have provided hands on care, and one in five has provided financial help.<sup>9</sup>

Another recent survey found that one in five Americans over age 50 are at high risk of needing long-term-care services during the next twelve months.<sup>10</sup> Families worry about the catastrophic costs they could face if a family member should need long-term care. In a 1997 national survey, 69 percent said they are worried about paying for long-term care.<sup>11</sup> In a 1993 Gallup Poll, two out of three respondents said that long-term-care costs were a major concern for the future.<sup>12</sup> While older people overwhelmingly prefer home care to nursing home care, it is the cost of nursing home care that most affects the economic security of the family. When told of

the yearly cost of nursing home care, 72 percent recognize that the cost is beyond their means.<sup>13</sup> Four out of ten (42 percent) would not be able to pay for one year of nursing home care at a cost of \$40,000 a year, and another one-third (34 percent) would run out of money in two years.<sup>9</sup>

These public opinion polls and surveys point to two overriding concerns. First, Americans who need long-term-care services are likely to face serious financial difficulty in paying for that care. Second, limited public funds pay for home and community-based services, which most older people prefer. Clearly, long-term care is a powerful family issue. Action must be taken to do the following:

- Recognize and strengthen the central role of families in the provision of long-term care.
- Shift the focus and incentives in long-term care away from institutional care in nursing homes to home and community-based care.

## PROFILE OF INFORMAL AND FAMILY CAREGIVERS

Here is a profile of informal and family caregivers:

### Definition

The term *caregiver* refers to anyone who provides assistance to someone else who needs it to maintain an optimal level of independence.<sup>14</sup> Families provide the vast majority of care and are commonly referred to as "family caregivers." Caregivers may or may not live with the care recipient. The way the term *family caregiver* is defined by policymakers affects significantly the type of services provided and the cost of providing them.<sup>15</sup> For example, some state-funded respite programs limit eligibility to family members living with the person needing care (e.g., a spouse). In this case, family members who assume major care responsibilities but do not live with the impaired person (e.g., adult children) are excluded from respite assistance.

### Prevalence

Estimates vary on the number of caregivers in the United States, depending on the definition used:

- Nearly one out of every four U.S. households (23 percent, or 22.4 million) provides care to a relative or friend aged 50 or older.<sup>16</sup>
- About 15 percent of U.S. adults care for a seriously ill or disabled family member.<sup>17</sup>
- About 13.3 million people—7 percent of U.S. adults—are spouses or adult children of disabled older people and have the potential responsibility for their care. Of these, about 85 percent (or 11.4 million) are adult children.<sup>18</sup>
- About 7.3 million people are informal caregivers, defined as spouses, adult children, other relatives, and friends who provide unpaid help to disabled older people living in the community. Of these, about three-fifths (or 4.2 million) are spouses and adult children, and the re-

maintaining two-fifths (3.1 million) are other relatives, friends and neighbors.<sup>13</sup>

#### Who Are the Caregivers?

**Gender.** Caregiving is largely a women's issue. Nearly three out of four (72 percent) caregivers are female.<sup>14</sup>

**Age.** The average caregiver is 57 years old. However, more than one in three caregivers are older adults themselves: one quarter are between 65 and 75 years old, and another 10 percent are at least 75 years of age.<sup>15</sup> One recent national survey found that 46 was the average age of caregivers of people 50 years of age and older.<sup>16</sup>

The median age of employed caregivers of the elderly is 45 years old; 28 percent are under 35 years of age and 15 percent are at least 65 years old.<sup>17</sup>

Women in their 50s are more likely than older women to experience two or more caregiving episodes. These women are more likely than women in their 60s and 70s to live with the care recipient.<sup>18</sup>

**Relationship to care recipient.** An estimated 85 percent of caregivers are relatives of the care recipient.<sup>19</sup>

In general, if the care recipient is married, the primary caregiver will be the spouse; otherwise adult children, typically adult daughters, will assume the caregiving role.<sup>20</sup>

Nearly 23 percent of caregivers are wives, 13 percent are husbands, 29 percent are adult daughters, and 9 percent are sons. The remaining 26 percent are siblings, grandchildren, other relatives, and friends or neighbors.<sup>21</sup>

Older generations also care for younger generations. Increasing numbers of mid-life and older women have primary responsibility for their grandchildren and great-grandchildren. Differences are evident by cultural group, with 12 percent of African American children living with grandparents, compared to 5.8 percent of Hispanic children and 3.6 percent of white children.<sup>22</sup>

**Living arrangements.** Nearly three-fourths of caregivers live with the care recipient.<sup>23</sup>

Between 20 percent and 40 percent of caregivers are in the "sandwich generation," with children under age 18 to care for in addition to their disabled older relative.<sup>24</sup>

One-third of primary caregivers assume major care responsibilities because they live closer to the care recipient than other family members.<sup>25</sup>

Nearly 7 million Americans, or 3.5 percent of the U.S. adult population are long-distance caregivers (those who live a distance of one hour or more from the older adult needing assistance). The average travel time for these caregivers to reach their relative is four hours.<sup>26</sup>

**Ethnicity.** In the coming decades, the older population and their families in the United States will be more ethnically diverse.

Within the United States, recent research focusing on ethnic diversity among caregivers indicates both similarities and differences in the caregiving experience. It is clear, however, that across all ethnic groups family care is the most preferred and relied upon source of assistance.<sup>27</sup>

Growing evidence indicates that differences among African American, Asian, Hispanic, and white caregivers

are less pronounced than differences within the groups. Similarly, research suggests that group differences may be more related to the length of time since immigration than to specific ethnic background.

**Employed caregivers.** Between one-third and nearly two-thirds of caregivers are also employed outside the home.<sup>28,29</sup> This trend is likely to continue as women continue to enter the labor force.

Between 7.4 percent and 11.8 percent of the workforce is involved in providing care for an older person.<sup>30</sup>

An estimated 9 percent of caregivers quit their jobs to provide care. For adult daughters, this number rises to 12 percent.<sup>31</sup>

**Caregiving tasks.** Unlike most formal service providers, families provide care at night, over weekends, and on demand. Studies have found that from 53 percent to 69 percent of people with dementia are out of bed most nights—waking the caregiver and requiring supervision.<sup>32,33</sup>

Two-thirds (66 percent) of caregivers assist older people with activities of daily living (ADLs).<sup>34</sup> Of these, 19 percent assist with one daily living task, 15 percent assist with two, and one-third (33 percent) assist with three or more.<sup>35</sup>

Three out of four caregivers help with grocery shopping, transportation, and housework, and about 66 percent prepare meals or manage finances. Half help administer medications.<sup>36</sup> These tasks are known as instrumental activities of daily living (IADLs).<sup>†</sup>

**Time spent caregiving.** The duration of caregiving can last from less than a year to over 40 years. The majority of caregivers provide unpaid assistance for one to four years; 20 percent however provide care for five years or longer.<sup>37</sup>

Eighty percent of caregivers provide unpaid assistance seven days a week.<sup>38</sup> On average, caregivers provide personal care assistance and household maintenance chores for 18 hours a week. Some 48 percent give care for eight hours or less, while 21 percent provide help for nine to 20 hours per week, and 14 percent give care for 21 hours per week or more. Eleven percent provide round-the-clock care.<sup>39</sup>

Time spent caregiving varies by type of impairment. One statewide study of caregivers of cognitively impaired adults found caregivers spending an average of 13 hours per day providing care—more than a full-time job outside the home.<sup>40</sup>

#### Who Is Being Cared For?

Almost 100 million people in the United States have one or more chronic conditions.<sup>41</sup>

\*Activities of daily living (ADL) include bathing, eating, walking, and other personal care activities.

†Instrumental activities of daily living (IADL) include preparing meals, grocery shopping, using the telephone, managing money, taking medications, doing housework, and other activities of independent living.



Nearly 40 percent of older people living in the community—12 million people aged 65 and over—are limited by chronic conditions. Of these, three million (or 10 percent of older people) are unable to perform ADLs. Additionally, an estimated 1.5 million older people needing long-term care live in nursing homes.<sup>28</sup>

"While you love them more than anything in the world, it's a seven-day, twenty-four-hour-per-day job. You give up almost everything—seeing friends, part-time job, just being able to jump in the car and do household errands. Your life is never your own again."

(67-year-old wife caring for her husband, who has Parkinson's disease)

Long-term-care needs increase dramatically with age. The need for assistance with at least one ADL is under 3 percent for those less than 65 years of age but increases dramatically with age from 9.3 percent for ages 65 to 69 years, to 10.9 percent for ages 70 through 74 years, 18.9 percent for ages 75 through 79 years, 23.6 percent for ages 80 through 84 years, and 45.4 percent for those 85 years of age and older.<sup>29</sup>

An estimated 10 percent of people 65 years of age and older, and nearly half of those 85 and older, suffer from Alzheimer's disease. People with Alzheimer's disease or another dementing illness can never safely be left alone and often require round-the-clock care.<sup>3</sup>

#### Demographic and Social Trends Affecting Family Care in the Future

Various demographic and social trends will affect family care in the future.

**Demographic trends.** The magnitude of the aging of America is enormous and will challenge every sector of our society by the middle of the twenty-first century. At the turn of the century in 1900, 75 percent of the U.S. population died before the age of 65. Today, over 70 percent of the population live beyond age 65.<sup>30</sup> *At every age, people are likely to have more older people in their families today than in the past.*<sup>30</sup>

The older population, that is, those people 65 years of age or older, numbered 33.9 million in 1996, or 12.8 percent of the U.S. population—about one in every eight Americans.<sup>31</sup> This population will continue to grow, with the most rapid increase expected between the years 2010 and 2030 when the baby boom generation reaches age 65. By 2030, one in five Americans, or an estimated 70 million, will be at least 65 years of age—more than twice the number in 1995.<sup>31</sup>

Minority populations are projected to increase to 25 percent of the older population in 2030, up from 13 percent in 1990. Between 1990 and 2030, the white population is estimated to increase by 91 percent, compared with 328 percent for older minority groups, including Asians (643 percent), Hispanics (570 percent), African

Americans (159 percent), and American Indians and other groups (294 percent).<sup>32</sup>

Not only is the older population increasing, but it is rapidly getting older. In 1996, people reaching age 65 had an average life expectancy of an additional 17.7 years (19.2 years for females and 15.5 years for males).<sup>33</sup> Those people 85 years of age and older are the most rapidly growing elderly age group. In 1996 those 85 and older numbered 3.8 million, or 10 percent of the older population.<sup>33</sup> *By 2040 there will be almost four times as many people over 85 as there are today.*<sup>33</sup>

As the population ages, the number of people with chronic conditions requiring long-term care will increase dramatically. Over the next 25 years, the number of people with chronic impairments is estimated to increase by 35 million people to 134 million Americans.<sup>33</sup>

One of the cruelest chronic conditions of old age is Alzheimer's disease, a progressive neuro-degenerative disease. The prevalence of Alzheimer's disease and related dementias rises dramatically with age, particularly for those aged 85 and older. Today, about 4 million Americans are afflicted with Alzheimer's disease. It is estimated that by the year 2050, more than three times as many people—or 14 million Americans—could have this devastating disease.<sup>33</sup>

**Social trends.** A number of changing patterns of family life may affect the continued ability of families to provide care for impaired older family members. Among the trends are the following: (1) increasing divorce and remarriage rates; (2) increasing geographic mobility and more long-distance caregivers; (3) decreasing family size; (4) delayed childbearing, which may increase the size of the "sandwich generation," that is, those caring simultaneously for children and their parents or other older relatives; and (5) increasing female labor force participation. Despite these trends, which could affect the potential pool of family members available to provide care, *caregiving is likely to remain an intrinsic part of the experience of American families well into the twenty-first century.* Research has shown that even when the primary caregiver is no longer able to provide care, another relative, usually someone from the same or the next generation, steps in to take over caregiving responsibilities.<sup>34</sup>

Ultimately, social trends affect the supply of caregivers, while demographic trends increase the demand for caregiving as the population ages and becomes more likely to need long-term care. In the twenty-first century, the demands placed on family and other informal caregivers are likely to intensify dramatically, affecting nearly every American family.<sup>35</sup>

#### Talking Points

- Almost 100 million people in the United States have one or more chronic conditions. Over the next twenty-five years, this number is expected to increase to 134 million Americans.

- Nearly one in four U.S. households is involved in caring for a relative or friend aged 50 or older.

• Caregiving is largely a women's issue. Some 72 percent of caregivers are female, mostly wives and adult daughters.

• The average age of a caregiver is 57. More than one in three, however, are older themselves (65 years of age and older).

• Caregiving can last from less than a year to over forty years. Some 80 percent of caregivers provide unpaid assistance seven days a week.

• People are likely to have more older people in their families today than in the past.

• By 2030, when the baby boomers reach age 65, one in five Americans will be at least 65, for a total of about 70 million older people, more than twice the number in 1996.

• Five social trends may affect the supply of caregivers in the future: (1) increasing divorce and remarriage rates; (2) increasing geographic mobility; (3) decreasing family size; (4) delayed childbearing; and (5) more women in the workplace.

• In the twenty-first century the demands placed on family and other informal caregivers are likely to escalate, affecting nearly every American family.

Mr. and Mrs. J live in upstate New York. Mr. J is a 74-year-old retired painter who quit his job five years ago to care for Mrs. J, age 66, who has Parkinson's disease. They had to sell the house that they had lived in for twenty-five years and move to an apartment because Mrs. J could no longer climb the stairs. They get little outside help; only someone who comes to clean once a week. Their two adult children live in California. While the children call frequently and each visits about three times a year, they are busy with their own careers and young children. Mr. J suffers from high blood pressure. His greatest worry is that something will happen to him and he will no longer be able to care for his wife.

#### EFFECTS OF CAREGIVING: WHAT DOES RESEARCH TELL US?

Caregiving affects people in different ways. No two caregivers are alike. However, there are common themes in the way caregiving affects the family and other informal caregivers. Research has shown that providing care to older people often exacts a heavy emotional, physical, and financial toll. Caring for an older relative is not the same as childrearing, since children usually continue to gain independence and self-sufficiency. In contrast, family caregivers of older people face the painful, inevitable deterioration of their loved ones, leading ultimately to greater debilitation or death. Prolonged caregiving has negative effects on the emotional and physical health of

caregivers, even though it is willingly undertaken and often a source of great personal satisfaction.<sup>17,18</sup>

#### Emotional Toll

A body of research has shown that many caregivers are emotionally strained by the responsibilities of providing long-term care to a disabled older relative or friend. Caregivers experience a sense of burden<sup>19</sup> and very high rates of depression (up to 68 percent).<sup>20</sup> Family caregivers are more depressed than age-matched controls in the general population<sup>21</sup> and are more apt to feel anger and anxiety.<sup>22,23</sup> A number of studies have shown that caregiver emotional distress increases as the care recipient's level of functional impairment becomes more severe.<sup>17,24,25</sup> Disruptive behaviors associated with dementia are particularly distressing for families.<sup>1,27</sup>

Not surprisingly, the stresses of caregiving are more severe for those, like the spouse, who live with the care recipient. While men and women are affected similarly, women appear to experience higher levels of distress.<sup>22,26</sup>

#### Physical Toll

Caregiving often leads to increased susceptibility to health problems.<sup>28,29</sup> For example, heavy lifting and turning, frequent bedding changes, dressing, bathing and helping the person use a toilet or dealing with incontinence can put physical strain on caregivers.<sup>30</sup> One-third of caregivers report themselves to be in fair-to-poor health, a much higher percentage than the general population.<sup>31</sup> The majority of family caregivers are over the age of 50 and at risk for experiencing physical health problems of their own.<sup>19,32</sup> Studies show lowered immune function<sup>33</sup> and nearly double the normal use of psychotropic drugs.<sup>34</sup> Recent research suggests that caregivers physical health problems are the result of ongoing stresses from their caregiving role.<sup>35</sup>

#### Financial Toll

The emotional and physical strain of caring for a frail older relative is often exacerbated by worries over paying for care. Some caregiving spouses forego paying out-of-pocket for any help at home because they are anxious and concerned about how they will pay for extended care in the event their husband or wife requires costly nursing home care. Other older spouse caregivers who live on fixed incomes cannot afford to pay for help, even though that help could make the essential difference in their ability to continue care.<sup>3</sup> Studies show that about one-third of caregivers report family incomes in the poor to near-poor range, and a sizable number of families have adjusted family incomes below poverty level—more than families of the same age group with no caregiving responsibilities.<sup>1,36,37</sup>

The financial impact of caregiving is most apparent for family caregivers when it affects their ability to engage in and perform effectively at work. Between one-third to nearly two-thirds of caregivers now work outside the home.<sup>38,39</sup> This trend is expected to increase as a result

of more women in the labor force and longer life expectancies.<sup>12</sup> In California, 43 percent of family caregivers under the age of 65—those most likely to be in the labor force—juggle work, family, and caregiving responsibilities. Among those caregivers not working, 28 percent had quit their jobs to provide care for a family member.<sup>13</sup>

Studies have shown that employees caring for older relatives experienced more conflict between the competing demands of work and family than did co-workers who did not have caregiving responsibilities.<sup>14,15</sup> Negative effects have included time lost from work (absenteeism, taking time off without pay, reducing work hours), lower productivity while at work, quitting a job to provide care, lost career opportunities, and lower future earnings.<sup>16</sup>

### Talking Points

- Caregiving exacts an enormous emotional toll. Research has shown that many caregivers experience immense stress and feelings of burden, high rates of depression, and feelings of anger and anxiety.

- Caregiving can adversely affect one's physical health and ability to continue providing care—leaving two people impaired, rather than one.

- The emotional and physical strain of caring for a frail older person is often exacerbated by worries over paying for care, particularly nursing home care.

- The financial impact of caregiving takes a particular toll on family members when it affects their ability to work. In one study, 28 percent of non-working caregivers had quit their jobs to provide care. Others experience increased absenteeism, lower productivity at work, lost career opportunities, and lower future earnings.

### COSTS OF CARING: THE ECONOMIC BURDEN

Long-term care is a major expense for many older people and their families. Three main issues underscore the importance of examining the costs of care:

- *Medicare does not cover long-term care.* Contrary to popular belief, Medicare pays for short-term, subacute nursing care; it does not cover the costs of long-term care, either in nursing homes or at home.<sup>1</sup> Medicare only helps with time-limited care in a nursing home or with the transition home after someone has been hospitalized. Moreover, Medicare specifically prohibits the type of custodial care needed by people with chronic illnesses and disabilities.<sup>2</sup>

- *Private long-term-care insurance is expensive and limited in coverage.* Most older people cannot afford private long-term-care insurance. Only about 4 percent of people 65 and older have any kind of private long-term-care insurance.<sup>3</sup> Benefits are generally limited in scope and duration. The best policies, which provide comprehensive benefits over the long term, in 1993 charged premiums that averaged \$2,137 for persons aged 65 and \$6,811 for those over the age of 79.<sup>4</sup> Most studies have found that only about 20 percent of older people can afford private

long-term-care insurance.<sup>5,6,11</sup>

Under the recently enacted federal health insurance legislation, known as the Kennedy-Kassebaum bill, long-term-care insurance premiums incurred after December 31, 1996, are now deductible as medical expenses, up to a limit that varies by age.<sup>62</sup> However, with so few older people able to purchase such private insurance, this tax break will benefit very few.

- *Out-of-pocket costs are high.* Older people and their families pay out-of-pocket for about 44 percent of the total costs of long-term care.<sup>11</sup> Out-of-pocket payments account for 51 percent of nursing home costs and 26 percent of homecare expenditures.<sup>11</sup> Nearly 40 percent of persons with chronic illness report they cannot afford the services they need.<sup>2</sup>

### How Is Long-Term Care Paid For?

Long-term care is paid for in a number of ways:

- Family and friends—mostly women—provide the overwhelming majority of long-term care for frail and disabled older people on an unpaid basis.<sup>3</sup>

- On a paid basis, an estimated \$108 billion was spent on long-term care in the United States in 1993.<sup>1</sup>

- Nearly two-thirds (64 percent) of these costs (\$69.1 billion) were paid for with public dollars, \$43.1 billion from the federal government and \$26 billion from state governments.<sup>1</sup>

- The remaining one-third (36 percent) of these costs (\$38.5 billion) were paid for by private sources, mostly as out-of-pocket spending by individuals and their families.<sup>1</sup>

- Private long-term-care insurance paid less than one percent of the total cost, estimated at about \$200 million.<sup>1</sup>

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"At first I couldn't understand why he did the things he did, such as cut up water hoses and hide and destroy so many things. Now I believe I feel more frustration. As his illness progresses, it's getting harder for me to constantly care for him and cope with all other responsibilities."

(84-year-old wife caring for her husband, who has Alzheimer's disease)

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*A bias toward institutionalization still drives long-term-care spending.* Long-term care expenditures are largely used for institutional care. Of the estimated \$108 billion spent on long-term care in 1993, 72 percent of the dollars went for nursing home care and only 28 percent went for homecare.<sup>41</sup>

While nursing homes are clearly important in the continuum of care, most people want to remain in their own homes as long as possible. The following case brings the bias in favor of institutionalization issue into focus:

*Contrary to popular belief, Medicaid, not Medicare, is the largest source of public funding for long-term care.* Medicaid is a federal/state health program for low income people of all ages and is the payer of last resort. Many families

spend down to poverty paying for care for an older relative.<sup>44</sup> About three-fifths of Medicaid long-term-care funds are for older people.<sup>45</sup>

In 1994, total Medicaid expenditures exceeded \$137 billion. Of these funds, about one-third, or \$45.8 billion, was spent on long-term care. Only \$8.5 billion of these funds was spent for home and community-based care, amounting to 18.6 percent of all Medicaid long-term-care expenditures and 6.2 percent of total Medicaid expenditures nationwide. In sharp contrast, Medicaid expenditures for nursing homes were over \$28 billion, or triple the funds for home and community-based care.<sup>46</sup>

*The cost of nursing home care is beyond the means of most people.* The cost of a year's care in a nursing home averages \$40,000<sup>47</sup> and can be higher than \$100,000.<sup>48</sup> In contrast, the median income for households headed by persons 65 and older in 1996 was \$28,983.<sup>49</sup> Only 40 percent of older persons have annual household incomes of more than \$35,000. This is less than the cost of one year of nursing home care.<sup>50,51</sup>

*Middle-class families are hit the hardest.* Impaired older people and their families who do not qualify for Medicaid, yet cannot afford to pay for home and community-based care or nursing home care, are most at risk of financial bankruptcy. These families desperately need help.

The average per capita cost of caring for a noninstitutionalized older person with one chronic condition is \$2,970. This cost climbs to \$6,018 for an older person with two or more chronic conditions. In contrast, the per capita cost for older people with acute health problems only is \$1,652.<sup>52</sup>

Out-of-pocket expenses for home care were estimated to average \$242 a month in 1993. People age 65 and older spent an average of \$348 a month, while expenditures for those under 65 years of age averaged \$134 a month for home care.<sup>53</sup>

*Studies document the economic burden on families.* The total annual cost of home and community-based care for a disabled older person is estimated to be \$9,600 (in 1993 dollars) for both informal care and formal services. Up to 80 percent of these costs are borne by families.<sup>54</sup>

Two-fifths of all caregivers report that they have incurred additional expenses as a result of caregiving. Twenty-six percent of caregivers spend up to 10 percent of their monthly income on caregiving. Nearly one-third (31 percent) of caregivers have incurred bills for travel, 24 percent for medical diets for the person in need, and 25 percent for telephone and utility charges.<sup>55</sup>

Nearly 80 percent of older people and their families who buy home-accessibility equipment (e.g., grab bars, wheelchair ramps) pay with their own money.<sup>56</sup>

*The financial burden on families of people with dementing illnesses is particularly severe.* These families, who may provide care for 10 years or longer, bear the burden of informal care. They also pay a large share of the formal care cost:

• In one study, average care costs for a person with dementia over a three-month period amounted to \$4,564,

or over \$18,000 a year. Cash expenditures by caregivers for formal services or equipment averaged only 29 percent of the total care costs, with *unpaid labor* accounting for 71 percent of the family care costs.<sup>57</sup>

• In another study, the annual cost of care for people with Alzheimer's disease living in the community (in 1990 dollars) was valued at \$47,083. Almost three-fourths of that cost—or \$34,517—is borne by informal and family caregivers. The impaired person received an average of 286 hours of unpaid care per month—or about 10 hours a day of care from family and informal caregivers.<sup>58</sup>

• About 75 percent of caregivers for people with dementia reported that they did not use paid formal services because they could not afford them.<sup>59</sup>

*Employers—in both the public and private sectors—also pay for the cost of care.* Availability of home and community-based services is critical to employers because these services relieve workers of their caregiving duties. Studies of the prevalence of personal caregiving among employees caring for older relatives range from 2 percent to 12 percent.<sup>60</sup> Depending on the prevalence estimate used, employer costs—such as costs of absenteeism, replacing a worker who quits, or workday interruptions—can run from \$5.5 million to as high as \$33 million per year.<sup>61,62</sup>

### Talking Points

• Long-term care is an economic burden for most families. Middle-class families are hit the hardest.

• Medicare does not cover long-term care, private insurance is expensive and limited in coverage, and out-of-pocket costs are high.

• Long-term care is largely provided by family and friends on an *unpaid* basis.

• Total spending on long-term care in the United States was about \$108 billion in 1993. About 64 percent of the costs were paid with public dollars (mostly Medicaid), and about 36 percent were paid for by private sources, mostly out-of-pocket spending. Less than one percent of the cost was paid by private long-term-care insurance.

• A bias in favor of institutionalization still drives long-term-care spending. Of the estimated \$108 billion spent on long-term care (1993 dollars), 72 percent went for nursing home care and only 28 percent went for home care.

• The cost of nursing home care—averaging about \$40,000 a year—is beyond the means of most people.

• The costs to employers—in both the public and private sectors—is also high: One study estimates that employer costs can run from \$5.5 million to as high as \$33 million per year.

• Older people and their families who do not qualify for Medicaid yet cannot afford to pay for long-term care are most at risk of financial bankruptcy.

• Despite older peoples' strong preferences for home and community-based services, there are few service options: Long-term-care dollars are overwhelmingly spent on nursing home care.

\* To reduce the costs of caring, states and the federal government must establish public policy to support and strengthen families in their caregiving role and shift the focus and incentives in long-term care from institutional care to home and community-based services.

### FAMILY CAREGIVER SUPPORT PROGRAMS: THE STATE OF THE ART

Policy makers are beginning to recognize the critical role of families in the provision of long-term care as a way to help control rising costs of care. Four main public policy approaches are promoted to support caregiving families: (1) direct services; (2) financial incentives and compensation, including direct payments and tax incentives; (3) the cash-and-counseling model; and (4) employer-based mechanisms.

#### Direct Services to Support Family Caregivers

Home and community-based services can help care for the caregiver by directly assisting families in their day-to-day caregiving responsibilities. Caregiver-specific services have the potential for reducing caregiver distress and improving coping skills so that families can continue to provide care. Direct services complement and assist families without supplanting their caregiving roles.

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"When I compare past with present it makes me very sad and depressed. I try to think positive most of the time. [I feel fearful] only when his condition worsens. Many nights I am up with him at least two or three times per night."

*(54-year-old wife caring for her husband, who suffers from Alzheimer's disease)*

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Support services needed by family caregivers may include a range of information and emotional and financial supports. Most caregiver support programs are provided through voluntary agencies (e.g., the Alzheimer's Association or the American Cancer Society) or through limited state programs funded under Title III of the Older Americans Act, Medicaid waivers, or state general funds. Eligibility for these programs is often restricted by age, diagnostic group, or income. (See page 00 for examples of state programs.) Moreover, many states have gaps in available services or have no caregiver support programs at all.<sup>14</sup>

Recent research on caregiver support services has shown very promising results. In a study investigating patterns of service use for one type of respite service (adult daycare) for caregivers of persons with dementia, researchers found that the sustained use of adult day services by caregivers of persons with dementia can substantially reduce their levels of caregiving-related stress and improve their mental health.<sup>15</sup> In a longitudinal study of family caregivers of people with Alzheimer's disease, researchers found that

caregivers who used ongoing education, attended six sessions of counseling, and participated in a support group were 35 percent less likely to place their spouse in a nursing home than those in the control group. Spouse caregivers who received this combination of caregiver support services deferred institutionalization of their spouse by an average of 329 days.<sup>16</sup>

Information and assistance are the number-one need of family caregivers.<sup>17</sup> More often than not, the average family is unaware of services available in the community and the means of gaining access to them. Information is needed on how and where to get help, implications of a diagnosis, costs of care, and how to plan for future care needs. Increasingly, families are using the Internet to access information on caregiving and available services.

Long-term-care planning and care management help assess the needs of families and the impaired person, explore courses of action and care options, and arrange any necessary support services in the community. Helping the family respond to crises and adjust to new daily routines is essential to help families cope over the long-term.

Support groups emphasize coping strategies and peer support to help caregivers.<sup>18</sup> Support groups are offered by organizations representing nearly every form of chronic illness (e.g., Alzheimer's disease, stroke, cancer) and are very popular.<sup>19</sup>

Counseling assists families in solving problems and in resolution of psychosocial issues related to caring for the impaired person.<sup>20</sup> Psychoeducational (group) models are also effective and are intended both to provide information and to help caregivers develop a specific set of coping skills.<sup>21</sup>

Respite care addresses one of the most pressing needs identified by families, namely, temporary relief to reduce the strain that caregivers experience on a day-to-day basis.<sup>22</sup> Respite care can allow time to go to the doctor or the grocery store, participate in a support group, or attend a class to learn caregiving skills.<sup>23</sup> A unique feature of respite care is the help it offers to both the caregiver and the care recipient. Respite care can be provided at home (in-home care), or in a group or institutional setting (out-of-home services). Out-of-home services include adult day centers, foster homes, nursing homes, hospitals, respite camps, and other facilities. Researchers have suggested that respite care can relieve the burden of the caregiving situation and allow families to continue to care for loved ones who would otherwise have been placed in a nursing home.<sup>24,25</sup> Families who have used respite programs overwhelmingly value the service and report high levels of consumer satisfaction.<sup>26,27</sup>

Home modification programs help caregivers adapt their homes to make it possible to provide care. Very limited resources are available for home repairs. There is generally no reimbursement for consumable supplies (e.g., incontinence products) purchased by family caregivers at home.

Legal and financial planning are key services to help families plan for the costs of future long-term care and to make arrangements for medical decisions and advance

directives. Cognitive impairment, in particular, creates complex legal and financial problems for impaired persons and their families, who may need advice on property rights, contracts, estate planning methods, durable powers of attorney, conservatorships, and other matters.

*Education and training programs* can effectively help families with practical advice regarding day-to-day concerns. Research has shown that these programs can produce positive outcomes for the caregiver<sup>44,45</sup> and delay nursing home placement.<sup>46</sup>

#### Financial Incentives and Compensation

Financial incentives and compensation can take several forms:

*Direct payments to families* take many forms and embody the emerging trend in consumer-directed care. Generally, programs provide family caregivers with cash grants or vouchers to purchase services for the care of their older relative. The justifications for family payments arise out of commitments to support family care, the lack of other resources, and the desire to minimize long-term-care costs.<sup>46</sup> At present, thirty-five states have programs that pay family caregivers for the provision of homemaker, chore, or personal care services.<sup>47</sup> Of these, thirteen states use Medicaid waivers to pay family members to provide care to a functionally impaired relative; the rest use state funds as the source of funding for family compensation.<sup>48,49</sup>

There are several disadvantages to direct payments to families as they now exist. Nine out of the thirty-five states (about 25 percent) require caregivers to give up outside employment if they are receiving caregiver compensation. This strategy provides little relief to caregivers to replace lost income. Other program restrictions include kinship criteria (e.g., excluding adult children, or grandparents caring for grandchildren), living arrangements (e.g., excluding caregivers who do not share a household with the care recipient), and type of services covered.<sup>48,49</sup>

*Tax incentives* have gained more political appeal among some policymakers recently because they are relatively easy to administer and have a cost-sharing component. Tax incentives generally include deductions or credits.

The two main types of tax deductions are adjustments to gross income or itemized deductions from taxable income. Tax deductions tend to favor higher-income people, giving them more subsidy per dollar deducted than taxpayers in lower-income brackets.<sup>50</sup> Beginning in 1997, out-of-pocket expenses for long-term care, including custodial care and long-term-care insurance premiums, are deductible as medical expenses. The expenses must be for care for a "chronically ill individual" who needs help with at least two ADLs or requires "substantial supervision to protect against threats to health and safety due to severe cognitive impairment."<sup>51</sup>

The other major tax strategy is the use of tax credits. Unlike tax deductions, tax credits generally benefit low-income taxpayers. Tax credits usually require the caregiv-

er to live with the care recipient and be employed outside the home. These requirements tend to limit the use of this tax strategy, particularly when one family member—usually the female spouse—has the full-time job of caregiving.<sup>52</sup>

#### Cash-and-Counseling Model

A promising consumer-directed strategy is the cash-and-counseling model. This model combines elements of financial support with direct services, such as information and counseling, to help consumers make informed choices about long-term care. At least ninety-four countries have governmental programs that provide cash allowances to disabled individuals who require supervision or assistance with activities of daily living or household tasks. Not only is this option appealing to people with disabilities and to their families, but it could prove successful to the federal government and to states as a cost-effective use of limited long-term care resources.<sup>53</sup>

The national cash-and-counseling demonstration project for Medicaid recipients of long-term care is now underway in four states (Arkansas, Florida, New York, and New Jersey), funded by The Robert Wood Johnson Foundation and the Office of the Assistant Secretary for

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"My health has suffered and my blood pressure went up. I cry often; it's not a bowl of cherries. I hope I'll have enough money to live on."

(83-year-old husband caring for his wife, who had a stroke nine years ago)

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Planning and Evaluation, U.S. Department of Health and Human Services. Under this demonstration project, older and younger people with disabilities will choose between traditional case-managed personal assistance services and cash grants along with information services. The cash component provides monthly cash allowances, and the counseling component provides people with consumer information, advice, and assistance to help them direct their own care. Possible uses of the cash include purchasing services from a homecare agency, paying a relative or friend to provide personal care, or purchasing respite care. Proponents of this model cite several potential benefits including the following: (1) empowerment of consumers, (2) support for families and other informal caregivers, (3) a unified model for serving persons of all ages with disabilities, (4) lower unit costs of care and lower total costs to governments, and (5) encouragement of consumer-directed chronic care systems.<sup>54</sup> Use of the cash-and-counseling approach, however, raises quality assurance concerns that must be addressed at both the national and state levels.

California's statewide system of Caregiver Resource Centers (CRCs) for families and caregivers of cognitively

impaired adults offers a similar option to caregivers through the use of respite vouchers along with ongoing support services. Research has shown that this consumer-directed "direct pay" program (wherein caregivers

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"My most stressful moments have occurred when I had a job in the shop which was on a tight schedule and it seemed that mother was calling me into the house every five minutes. I now wear a stop watch while working so that I can keep track of exactly how much time I do spend on a job. I punch it off when she calls me into the house and punch it back on when I'm working again."

*(40-year-old daughter caring for her mother, who has a brain tumor)*

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are given vouchers to hire and manage their own respite workers) is both preferred by caregivers and more cost-effective than the agency-based program (wherein caregivers are given vouchers to purchase service hours from homecare agencies under subcontract with the CRC).<sup>30</sup>

#### Employer-Based Mechanisms

Increasingly, both public and private employers are using either unpaid leave for caregiving or dependent care assistance plans to provide indirect financial assistance to caregivers. Enactment of the Family and Medical Leave Act (FMLA) of 1993 was an important first step by the federal government in helping protect the jobs and work benefits of employees who also have family care responsibilities. The law permits full-time employees to take up to 12 weeks of unpaid leave per year for a birth or adoption or to care for an ill child, spouse, or parent. While providing an important measure of basic job security for workers who have caregiving responsibility, the law contains a number of restrictions that dilute its usefulness. Principally, the law provides *unpaid* leave, thus, for family caregivers who cannot afford lost income, the time off may not meet their real needs. Additionally, the law covers only about 11 percent of American worksites and 60 percent of American workers;<sup>31</sup> those who work in small businesses are not covered by the federal law. Workers caring for an aunt or uncle, a sibling, a grandparent, or an unmarried partner also are not covered.

As of July 1992, some thirty-one states had passed some type of family and medical leave legislation.<sup>32</sup> There is a great deal of variation in the provisions in each of these laws, with some states offering more generous benefits than others. State experience with leave legislation has shown that most of the beneficiaries use leaves for the birth or adoption of a child rather than for care of an ill child, spouse, or parent. Whether more caregivers will use this benefit as it becomes more known remains to be seen.<sup>33</sup>

A dependent care assistance plan (DCAP) is another mechanism used by some employers. Under the federal

tax code, the federal government allows employers to provide employees with up to \$5,000 in dependent care assistance annually. A number of restrictions regarding eligibility, allowable expenses, and definition of "dependent" limit the DCAPs utility for care of older people.<sup>34</sup> Typically, DCAPs have been for childcare rather than eldercare expenses.<sup>35</sup>

#### Direct Services vs. Financial Support Strategies: Is One Preferable to the Other?

A number of studies have examined caregiver preferences for dollars versus services. Caregivers generally prefer services which provide relief from daily caregiving and increase coping skills over financial supports.<sup>32,33</sup> In one study, over 80 percent of families chose a support service rather than financial support.<sup>34</sup>

It is crucial to advocate for policies that enable families to continue to provide care. Public policies are needed to provide both direct services and financial support strategies. Moreover, policymakers need to recognize and address the real need of older people and their families: To ensure access to quality, affordable long-term care, in the least restrictive setting for the person needing care, that best meets family needs.<sup>34</sup> What public policy can and must do is guarantee a national program that protects families from the emotional and financial bankruptcy that are often the result of providing long-term care.

#### Talking Points

- Four main policy strategies currently support caregiving families: (1) direct services (e.g., respite care); (2) financial incentives and compensation, including direct payments and tax incentives; (3) the cash-and-counseling model; and (4) employer-based mechanisms. All are limited in scope.

- Cash and counseling is a promising consumer-directed model that combines the elements of financial support with direct services to help consumers make informed choices about long-term care.

- Research has shown that most caregivers prefer services to dollars.

- Public policy must guarantee a national program that protects families from the emotional and financial bankruptcy that can be the result of long-term care.

#### EMERGING TRENDS

The emerging trends, highlighted below, are expected to continue into the twenty-first century. Advocates can help shape these trends to strengthen caregiving families.

##### Shift in Long-Term Care from Federal to State Level

Federal cutbacks in Medicaid and limited national health reform have shifted the focus in long-term care from the federal to the state level. Recently, states have been exploring strategies to expand home and community-based services systems. This expansion has slowed, and in some cases reversed, the growth of nursing homes

in some states (i.e., Oregon and Washington).<sup>53</sup> States have found that home and community-based services cost less per person, on average, than caring for a person in a nursing home.<sup>54</sup> Nationally, the number of nursing home residents was up only 4 percent between 1985 and 1995, despite an 18 percent increase in the population 65 and older.<sup>55</sup> Additionally, with the focus on providing a continuum of care, states are increasingly looking at infrastructure issues, particularly consolidating long-term-care programs within one state agency, and seeking Medicaid waivers to provide an array of home and community-based services, including family support.

#### Consumer-Directed Care

A trend in the delivery of quality and cost-effective home and community-based long-term care is the movement toward consumer-directed services. The concept of consumer direction implies that consumers prefer to make decisions about their service needs and are able to take a more active role in managing their own services. This growing interest in consumer-directed care is an outgrowth of the independent living movement, which was started in the 1970s primarily by younger adults with disabilities<sup>56</sup> and has now led to a number of new initiatives bridging the aging and disability communities.<sup>57</sup> The issue of allowing people to manage their own care is controversial at the state level because many states view their traditional care management process as a means for maintaining both quality of services and control over expenditures.<sup>58</sup>

One such consumer-directed initiative known as cash and counseling was described previously. Another new initiative is Independent Choices: Enhancing Consumer Direction for People with Disabilities. This \$3-million grants program is supported by The Robert Wood Johnson Foundation. In June 1997, some thirteen demonstration and research projects were awarded grants to explore various aspects of consumer direction and choice in home and community-based services.<sup>59</sup> Some disability advocates anticipate consumer choice to be the next civil rights issue.<sup>60</sup>

#### Managed Care and Consumer Protections

For the foreseeable future, managed care is here to stay. Future emphasis on cost control and coordination will give rise to managed long-term-care plans in Medicare as well as Medicaid.<sup>61</sup> In the present debate, interest at the state level has largely focused on how managed care can contain costs. However, from the consumers perspective, how well managed care coordinates and delivers services and responds to individual and family needs is as important as its ability to contain costs.<sup>62</sup> Policy issues to be addressed include the following: (1) consumer protections in marketing and enrollment and disenrollment policies; (2) assuring ready access to affordable, appropriate, and quality care; (3) consumer choice of qualified providers in the least restrictive, most appropriate setting that recognizes family needs; and (4) a

full range of health and long-term-care services, including access to specialists for individuals whose chronic conditions require such care.

#### Use of Technology in Delivering Information and Services

Today, with a computer and modem, global choices for obtaining caregiving tips and long-term-care advice are available with a few keystrokes. The recent explosion of technology is transforming the way we gain access to and deliver services. According to Find/SVP Emerging Technologies Research, an estimated 40 to 45 million people in the United States were using the Internet in 1997; that number is projected to more than triple to 150 million Americans by the year 2000. Discussion groups, support groups, counseling, online health information, and caregiving resources are now readily available using computer technology. The proliferation of Web sites in health and long-term care reflects a need for information to help people make more informed choices about their own care and the care of their families. Issues of quality and timely information, as well as concerns about confidentiality, will probably be debated in the coming years.

#### MODEL STATE PROGRAMS TO SUPPORT FAMILY CAREGIVERS

There is no comprehensive listing of state-funded caregiver support programs because there is no uniform definition of family or informal caregivers. Caregiver support programs are extremely diverse and dependent upon individual state priorities and resources. Existing programs are administered by a range of state agencies, including departments of aging, mental health, health services, human services, and social services. Some programs are caregiver-specific; others are part of larger home and community-based long-term-care programs. Respite care is the service most typically funded by state governments.

Ideas of the defined client, eligibility, mode of delivery, and funding are varied and inconsistent.

In some caregiver support programs, the impaired person is the defined client; in others, the family caregiver is considered the client and the legitimate recipient of services.

Eligibility criteria vary along a number of dimensions, generally based on such factors as age, type of impairment, or income. Some programs target caregivers of older persons, while others serve caregivers regardless of the age of the care recipient. Most state-funded programs serve three general caregiver populations: those caring for the functionally impaired, the cognitively impaired (particularly with Alzheimer's disease or related dementias), and the developmentally disabled. Some programs target low-income families through Medicaid waivers. Other programs target low-middle-income families—those just above the eligibility limit for other public benefits but with limited resources to purchase needed services.



The mode of delivery varies among states. Some programs provide direct services in the form of information and referral, care management, and the like, while others provide financial support through either cash allowances or vouchers to purchase needed services. Still others offer a combination of direct services and financial compensation.

In New York, one adult daughter, Ms. H, pleaded her case all the way up to the governor's office. Two 84-year-old twin sisters with Alzheimer's disease were being cared for by an increasingly frail 86-year-old sister, with some help from Ms. H. Medicaid paid for daytime care at home. However, no such care is allowed at night since nighttime care does not meet the Medicaid reimbursement criterion for active hands-on care. Yes, the two women with Alzheimer's disease wandered at night, tripped and fell, and need active supervision. Ms. H. estimated that hiring a nighttime attendant for all three sisters would cost about \$25,000 a year. The state refused to pay. Instead, the state was willing to spend \$45,000 a year for each of the three sisters to move into a nursing home.<sup>42</sup>

Funding for programs come largely from state sources, with Federal or local matching funds in only a limited number of cases. Nonetheless, it is clear that a number of states have made efforts to address the needs of family caregivers. This section highlights the model programs in California and Pennsylvania, the two most comprehensive state-funded caregiver programs, and briefly describes efforts in several other states.

#### California's Caregiver Resource Centers

Begun in 1985, California's Caregiver Resource Centers (CRCs) constitute the first statewide, state-funded program to address the needs of family caregivers, and are administered by the California Department of Mental Health (under Chapter 1658, Statutes of 1984, as amended). The service model replicates the pilot project developed by the San Francisco-based Family Caregiver Alliance (FCA), formerly Family Survival Project, in the early 1980s. The law established both statewide and regional services. At the state level, Family Caregiver Alliance serves as the statewide resources consultant to the Department of Mental Health and carries out policy and program development, develops education programs, provides training and technical assistance to the CRC sites, conducts applied research, and maintains a statewide information clearinghouse on caregiving and adult-onset (age 18-plus) brain impairments. At the regional level, eleven nonprofit CRCs serve as a point of entry to a broad range of services for caregiving families.

The CRCs serve low-middle-income families and caregivers of persons with adult-onset chronic, disabling

brain diseases and disorders (e.g., Alzheimer's and Parkinson's diseases, stroke, traumatic brain injury). Caregivers receiving subsidized respite assistance must live with the care recipient and be ineligible for California's In-Home Supportive Services (IHSS) program or other public benefits. High priority is given to families caring for cognitively impaired adults who exhibit severe behavioral problems and for whom few respite resources exist.

In fiscal year 1997-98, the state appropriation for the eleven CRCs and the statewide resources consultant is \$5.047 million. All CRCs provide a core package of caregiver support services including: specialized information and referral; caregiver assessment in the home; family consultation and care planning; individual, group and family counseling; support groups; education and training, including psychoeducational classes; vouchered legal consultations with attorneys; and vouchered respite assistance (including homecare, adult day services, overnight stays in a facility, weekend camps, and other respite options).

CRCs serve over 9,000 family caregivers a year. Six in ten caregivers completing an initial intake phone call go on to receive additional services. Nearly 800 families receive an average of seven hours of respite per week. The average monthly respite cost per family caregiver is \$222, including an average copayment of \$18. More than 3,000 California families are on a respite wait list.

#### Pennsylvania's Family Caregiver Support Program

The Pennsylvania Family Caregiving Support Program (FCSP), begun in 1987, is administered by the Division of Managed Care, Pennsylvania Department of Aging, under Title 6, Chapter 20, Pennsylvania Code, as amended. The FCSP provides a combination of services,

"This help has been a lifeline. You have given me the support I needed to continue caring for my wife in our home. This is where she wants to be."

*(69-year-old husband caring for his wife, who has multiple sclerosis)*

financial assistance, and care management to about 7,000 caregivers a year. The statewide program is managed locally through the state's fifty-two Area Agencies on Aging. Clients are families and other caregivers who care for an older, functionally dependent relative at home. Eligible caregivers must live with the care recipient and cannot have incomes which exceed 380 percent of the poverty level.

The state appropriation for the FCSP is \$9.862 million in fiscal year 1997-98. The funds cover a range of support services including the following: assessment of needs of the caregiver, care recipient, and caregiving environment; counseling in coping skills; benefits counseling and assistance in completing insurance and benefits forms; training and education; financial assistance with ongoing

caregiving expenses and assistive devices; respite care and home chore services; and one-time grants for home modifications.

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"Respite saved my life mentally, physically, and economically."

*(65-year-old wife caring for her husband, who has Alzheimer's disease)*

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Financial assistance is in the form of reimbursement, on a cost-sharing basis, for the out-of-pocket purchase of supplies and services of up to \$200 per month. To receive the maximum benefit, eligible families incomes may not exceed 380 percent of the poverty level. A percentage of reimbursement is covered for higher-income families. There is a \$2,000 lifetime cap on financial assistance for home modifications and assistive devices.

#### New Jersey's Respite Program

The New Jersey program, offered statewide since 1988, is administered by the New Jersey Department of Health and Senior Services. The state appropriation is \$4 million, and nearly 2,000 persons are served per year. The program provides respite services for elderly and functionally impaired people age 18 and over to relieve their unpaid caregivers from the stress of providing daily care. Eligible people must have an income of less than \$1,450 per month and less than \$40,000 in liquid resources. Respite services include companions, homemaker/home health aides, medical or social adult daycare, temporary care in a facility, overnight care in a camp setting, and private nurses.

#### Washington's State Respite Care Program

The Washington program started as a pilot project in 1988 and went statewide in 1989. The program is administered by the state Department of Social and Health Services, Aging and Adult Services Administration, and is operated through the state's thirteen local Area Agencies on Aging. In 1997, the respite program is funded through a state appropriation of \$2.47 million; however, federal funding from the Older Americans Act may be used to provide additional respite to eligible older adults. About 2,000 caregivers receive services annually. Eligible people are unpaid caregivers who have the primary responsibility for care or supervision of a functionally impaired adult who is at risk of being institutionalized. Services include the following: assessment and care planning, supervision, respite, personal care, and nursing care. No direct payments are given to families. Caregivers pay for available respite in the community based on a sliding fee scale.

#### Wisconsin's Alzheimer's Family Caregiver Support Program

The Wisconsin program, begun in 1986, is administered by the Wisconsin Department of Health and Family Services, Bureau on Aging and Long-Term Care Resources. The \$1.87 million state appropriation provides respite to nearly 1,000 families annually; another 4,600 receive other assistance (e.g., support groups, educational materials). To be eligible, one must be either the person with dementia or the family caregiver. Respite is delivered in a variety of ways. Counties have autonomy to use respite funds to do the following: (1) give funds to families to purchase services, (2) make payments directly to providers, or (3) use specific contract providers to deliver respite care.

#### New York's Caregivers Resource Centers

New York's resource centers, begun in 1989, are administered at the state level by the New York State Office for the Aging, and are located at the state's seventeen Area Agencies on Aging. In fiscal year 1997-98, the state is appropriating a total of about \$360,000 for these seventeen centers to provide outreach, information, training, support groups, resource libraries, and advocacy.

#### Minnesota's Caregiver Support and Respite Care Projects

The Minnesota projects were begun in 1992 and are administered by the state Department of Human Services, Aging and Adult Services Division. The twenty-four project sites, located in various community agencies, receive state funding up to \$20,000 each. The total state appropriation in fiscal year 1997-98 is \$480,000. The primary support services include respite care using trained volunteers, caregiver support groups, and community education. Some sites provide limited paid respite assistance.

#### Talking Points

- No comprehensive list of state-funded caregiver programs exists due to the fragmentation of services, and variations in eligibility, mode of delivery, and scope of services.
- Funding is very limited, with most states using state general revenue funds to support family and informal caregivers.
- Respite care is the service most typically funded by state governments.
- Two successful programs stand out in terms of scope, service package, and funding; these can be replicated by other states: California's Caregiver Resource Centers and Pennsylvania's Family Caregiver Support Program.

## FAMILY CAREGIVER SUPPORT POLICY: A CALL TO ACTION

States and consumer advocates have a role to play.

### The Role of States in Developing Family Caregiver Support Policies

The concept of caregiver support for an aging population is a growing issue in states across the country. Federal cutbacks in health and human services are having a profound effect on the ability of states to develop long-term-care systems that are responsive to consumer needs. States are now faced with assuming greater responsibility for shaping the financing, eligibility, coverage, and delivery systems that provide long-term care to people with disabilities.

The motivation required to bring about change is present in every state, driven by economics, values, and, of course, politics. Policymakers have a strong interest in maintaining the strength and durability of family and informal caregiver networks as the primary providers of long-term care. Therefore, it is essential that home and community-based services include support services for caregiving families. States have two main incentives for expanding home and community-based care options and providing caregiver support as part of a system of long-term care:

The first is a matter of humane public policy, a desire to help frail and disabled older persons remain at home with their families and in their communities as long as possible.

The second is driven by the bottom line to control rising costs, particularly for institutional care.<sup>15,16</sup>

### Strategies for State Action

- Utilize findings from other states. Speak with state leaders about their programs and obtain copies of existing state statutes as model language for a legislative proposal. Invite program administrators to present information on program development, implementation, and evaluation.

- Hold policy hearings on family caregiving. Give specific attention to the health and economic impacts of caregiving and appropriate programs and services to respond to identified caregiver needs.

- Use findings gleaned from a hearing or state-sponsored report to establish long-term objectives (for example, through a resolution or governor's proclamation) to develop a family caregiver support policy that integrates assistance to family caregivers as part of long-term care.

- Ensure that any state-level task force, advisory committee, or planning group that is established to develop long-term-care systems includes participation by family caregivers.

- Pursue and build public-private partnerships. For example, the Washington Aging and Adult Services Administration works with an alliance of community groups to conduct an annual caregiver conference. In

Maryland, the Office on Aging works with large employers to promote an employee assistance program for working caregivers.

- Develop consumer-oriented fact sheets on specific caregiving issues. Develop a consistent dissemination strategy in coordination with all stakeholders in the state.

- Support the development of community-based projects. Provide seed money to municipalities to create local resources (e.g., a volunteer respite program).

- Implement caregiver-friendly policies for state employees who have caregiving duties.

- Keep federal policymakers informed. Caregiving clearly is a matter of national policy.

### What Consumer Advocates Can Do to Make the Case for Supporting Caregiving Families

Advocates play an important role in educating policymakers about issues in family caregiving. Family caregivers can be effective advocates for themselves and others by providing personal stories about what it is like to care for a chronically ill older relative. Personal experiences of around-the-clock caregiving duties, inadequate resources, emotional strain, and financial hardships are compelling testimonies of need. By personalizing the issues, you may find that some legislators, or their staff, will have experienced caregiving firsthand.

Be prepared to address two underlying assumptions influencing both public perceptions and policy:

(1) The myth of abandonment. The pervasive myth that families abandon their older relatives when they need long-term care is untrue. In reality, families provide at least 80 percent of the care to older people, even those most severely impaired with dementing illnesses. Research clearly shows that more paid help does not lead families to abandon their involvement in the care of older relatives.<sup>17,18</sup>

(2) The myth of "woodworking effect." This myth suggests that because of increased demand, there is a potential for increased expense, particularly if caregivers quit providing care or substitute formal care for unpaid care. Research has shown that few families "come out of the woodwork" to receive services.<sup>19,20,21,22</sup> Rather, most caregivers are quite reluctant to use services, generally provide care with very little support, and use formal services only as a last resort when a crisis occurs.<sup>17,23,24,25</sup>

### Strategies for Advocates

- Do your homework. Stay informed and keep up-to-date.

- Arm yourself with the facts. Use this report. A key point is that supporting caregiving families is cost-effective, as well as compassionate. If caregiver support services help families deter institutionalization of a family member, states realize enormous savings. Moreover, support for family caregivers is a critical and growing policy direction, even if cost savings from formal home and community-based services are not immediately evident.

- Form (or join) a coalition, with other advocates of government help on family-related issues to campaign for caregivers. Partner with women's rights groups, disease-specific voluntary organizations (e.g., regional chapters of the National Multiple Sclerosis Society), businesses, and aging and disability groups. Broadening your base often helps to influence policymakers. Organize and participate in briefings for legislative staff and targeted telephone and letter writing campaigns.

- Write a letter to the editor or an op-ed piece in your local newspaper. This is an excellent sounding board for educating the public (and local elected officials) about a cause. You can write about a current legislative proposal, or simply express the need to help family caregivers with practical assistance, and emotional and financial support.

- Visit your state legislator (or legislative aide) in the district office. Be sure to bring a family caregiver with you on the legislative visit to share his or her experiences as a caregiver and what types of help are needed. Plan your briefing carefully and keep it short. Use facts from this report to strengthen your case. Ask for specific support. Follow-up with a thank-you letter.

- Write a letter to your state legislator. Legislators depend on input from their constituents to learn about issues. Keep your letter brief and to the point. If you are writing about a specific bill, include the bill number. Explain why you support or oppose the bill and urge the legislator to vote accordingly. Be sure to ask the legislator to let you know what action he or she will take.

- Pay attention to which legislators serve on key aging and long-term-care committees and mobilize family caregivers in their districts.

- Testify at a public hearing. This is a way of sharing your expertise as a caregiver with key policymakers. Personal testimony can make a powerful impact.

- Keep federal policymakers apprised of your activities. Caregiving is clearly a matter of national policy.

## CONCLUSION

As we approach the twenty-first century, the aging of America and changing patterns of family life are greatly increasing the demands on family and other informal caregivers who provide long-term care for older relatives and friends. At every age, people are likely to have more older people in their families today than in the past. These profound changes will affect nearly every American family in the future.

Today, almost 100 million Americans have one or more chronic conditions. Over the next twenty-five years, this number is expected to increase to 134 million Americans. The greatest growth will be for those aged 85-plus, the most rapidly growing elderly age group and the one most in need of long-term care. In 1996 those 85-plus numbered 3.8 million, or 11 percent of the older population. By 2040, there will be almost four times as many people over 85 as there are today. Over the next twenty-five years, public and private expenditures for

long-term care, now estimated at more than \$108 billion, are projected to more than double.

Caregiving is not just an aging issue; it is a family issue and a policy issue. As public policy in long-term care shifts from the federal to the state level, support for family and informal caregiving is becoming a priority issue for many state governments because of the high costs of not taking any action. States have two main incentives for providing caregiver support and expanding home and community-based care options as part of a long-term care system: The first is a matter of values, the strong consumer preference of older people to remain at home with their families and in their communities for as long as possible, the second is driven by economics, to control the rising costs of long-term-care expenditures, particularly for nursing homes.

Policymakers are beginning to recognize the critical role of families in the provision of long-term care. Contrary to popular belief, families, not institutions, are the major providers of long-term care, providing some 80 percent of care on an unpaid basis. Research has shown that the "myth of abandonment" is unfounded; more paid help does not lead families to abandon their involvement in caring for older relatives. Research has also shown that families do not "come out of the woodwork" if there is public funding for support services: most caregivers are reluctant to use formal help, provide care with very little support, experience adverse affects to their own physical and mental health, and use formal services only as a last resort when a crisis occurs.

A range of cost-effective options has been outlined in this paper to support the informal care system to help control rising costs of long-term care. While strengthening the role of families in long-term care can produce cost savings for states and is generally the preferred option expressed by individuals, it can also place severe strain on family caregivers. Therefore, it is crucial in any long-term-care strategy to provide support services to caregiving families. Several states, particularly California and Pennsylvania, have taken steps through a combination of direct services and financial supports to sustain family caregivers. Existing programs can serve as models for other states.

Caregiving will remain an intrinsic part of the experience of American families well into the twenty-first century. Therefore, it is vitally important for consumer advocates to seize the policy agenda and focus attention: on the two major actions addressed in this paper:

- (1) Recognizing and strengthening the central role of families in the provision of long-term care; and

- (2) Shifting the focus and incentives in long-term care away from institutional care to home and community-based care.

The time to make the case is now: Strengthening the role of families and other informal caregivers is cost-effective and compassionate public policy. We can no longer afford not to act—our own future and that of our parents, grandparents, and children depend on it.

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