



The National Alliance for Caregiving

and

MetLife Foundation

present the

2008

NATIONAL FAMILY CAREGIVING AWARDS

PROFILES OF AWARDEES

JULY 22, 2008

*Supported by a grant from
MetLife Foundation*

**Acknowledgments**

The National Alliance for Caregiving is grateful to MetLife Foundation for its generous support of the 2008 National Family Caregiving Awards. MetLife Foundation's commitment to family caregivers has made it possible to identify outstanding programs around the country that offer support to and educate the legions of family caregivers who provide the backbone of long-term care services in the United States.

The National Alliance for Caregiving is also grateful to the many service providers throughout the United States who participated in this competition. The Alliance commends all applicants for their tremendous efforts in responding to the needs of caregivers in their communities through innovative and effective caregiving programs.

Background

Non-profit organizations, agencies, and universities applied for the awards in the categories of caregiver support and caregiver education, either as a small community (with a population of 100,000 or fewer) or a large community (100,001 or more). Their detailed applications were judged in the following categories: innovation, effectiveness or impact, basis in research, diversity, and potential for replication or adaptability. Many outstanding applications were received and many innovative and effective programs were identified.

A total of six programs—three caregiver support programs and three caregiver education programs—were chosen to receive the National Family Caregiving Awards. Each award winning program is honored with \$25,000 to be used to further their caregiver support or educational efforts.

A growing number of older adults are responsible for the care of their physically, mentally, or developmentally disabled adult child. As these parents age, they require more support as they are less able to provide direct care for their adult children. Further, many parents have not prepared for the day when they are no longer able to provide assistance to their adult child with a disability. To meet this growing caregiving need, the MetLife Foundation and the National Alliance for Caregiving also accepted proposals for a \$5,000 seed grant for a non-profit organization to create a program to meet the needs of older persons caring for their adult children with disabilities.

This booklet provides a description for each of the award winning programs. In addition, detailed information about these programs is posted on the National Alliance for Caregiving's web site at www.caregiving.org.



**The National Alliance
for Caregiving
and
MetLife Foundation
2008 Family
Caregiving Awards**

CAREGIVER SUPPORT AWARDS

MINORITY SPECIAL RECOGNITION AWARD
ACC Drop-In Respite and Caregiver Cooperative
Asian Community Center
Sacramento, California

Time Out Respite Program
Center for Intergenerational Learning
Temple University
Philadelphia, Pennsylvania

ALZHEIMER'S SPECIAL RECOGNITION AWARD
Memory Mobile
Alzheimer's Association – Gulf Coast Chapter
Pinellas Park, Florida

CAREGIVER EDUCATION AWARDS

Caregivers' Guide for Bone Marrow/Stem Cell Transplant
National Bone Marrow Transplant Link
Southfield, Michigan

Online Caregiver Support Groups
CancerCare
New York, New York

Old Order Amish Caregiver Program
Mid-Illinois Senior Services, Inc.
Sullivan, Illinois

HONORABLE MENTION AWARDS

Healing Hearts Center for Grieving Children and Families
Regional Hospice of Western Connecticut
Danbury, Connecticut

Future Care Planning Services
Lifespan
Rochester, New York

SEED GRANT AWARD RECIPIENT

Future is Now!
The Rehabilitation Research and Training Center on
Aging with Developmental Disabilities
University of Illinois at Chicago
Chicago, Illinois



IN THE CATEGORY OF
CAREGIVER SUPPORT
(LARGE COMMUNITY)

**Asian Community Center
Sacramento, California**

*ACC Drop-In Respite and
Caregiver Cooperative*

In the Asian Community Center's Drop-In Respite and Caregiver Cooperative Program, caregiver-volunteers "earn and buy" respite time with other Co-op members, sharing their caregiving methods and engaging in self-learning, while building a community resource.

The Asian Community Center's (ACC) mission is to promote the general welfare and enhance the quality of life for the community by identifying, developing, and providing culturally-sensitive health and social services for older adults. ACC Drop-In Respite and Caregiver Cooperative serves elders with cognitive and/or physical impairments. Services are open to everyone, with special outreach to Asian American families, who often face language and cultural barriers and may be unwilling or unable to seek help from mainstream social and health agencies.

Initially a one-day program where family caregivers could drop off their elderly care recipient or stay and participate, when caregivers requested another session, lack of funding prompted them form a cooperative where they exchange volunteering for their care recipient's attendance. Caregivers collaborate with staff to plan and implement program activities. In addition to the Cooperative, the Caregiver Council, comprising caregivers, staff, and volunteers, addresses program issues together, empowering caregivers to make decisions affecting themselves, their elder, and the respite program. In coordination with ACC's Lifelong Learning and Wellness classes, ACC Rides Transportation, and other agencies, the program provides a array of caregiver supports. ACC Drop-In Respite and Caregiver Cooperative doubled availability while keeping sessions affordable. Nationally, it is one of only a handful of respite programs specifically targeting Asian American populations, with Asian languages spoken and some Asian programming, although many of the participants are also Caucasian, Latino, and African American. ACC is the only adult respite cooperative in the country.

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IN THE CATEGORY OF
CAREGIVER SUPPORT
(LARGE COMMUNITY)

**Center for
Intergenerational Learning
Temple University
Philadelphia, Pennsylvania**

*Time Out
Respite Program*

The Time Out Respite Program mobilizes college students to provide in-home respite services to caregiving families throughout the Philadelphia area.

The Time Out Respite Program is an innovative, low-cost resource for personalized respite care for families caring for elderly relatives living in Philadelphia. Time Out recruits, trains, and matches college students with the frail elderly to provide companionship, mental stimulation, and assistance with activities of daily living. Families pay students directly at a rate less than half of home health care agencies. For the past twenty-two years, this program has succeeded in enhancing the quality of life for caregivers and their frail older loved ones. Each year, approximately 125 families receive over 10,000 respite hours from student respite workers who are carefully screened, trained, and supervised.

Sponsored by the Temple University Center for Intergenerational Learning, Time Out fosters the development of unique relationships between care recipients and students. Since one student is paired with a family for at least a semester, a close bond usually develops. Time Out requires only a two-hour minimum per visit, thus allowing caregivers with limited resources an opportunity to schedule regular, short respite breaks.

Participating families consistently report reduced stress from caregiving responsibilities and more time for themselves. Elderly care recipients feel less isolated and love the opportunity to interact with students. Students gain a better understanding of their own families, a heightened respect for older adults, and overall personal and professional growth.

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IN THE CATEGORY OF
CAREGIVER SUPPORT
(SMALL COMMUNITY)

**Alzheimer's Association
Gulf Coast Chapter
Pinellas Park, Florida**

Memory Mobile

The Memory Mobile is the only mobile Alzheimer's outreach, support, and education service delivery vehicle in the country.

Within the culturally and geographically diverse 17 county service region of the Alzheimer's Association—Florida Gulf Coast Chapter, an estimated 187,000 people are living with Alzheimer's disease. If the Florida Gulf Coast Chapter were a state, it would be 8th in the country in incidence of Alzheimer's disease. Compounding the outreach and service delivery issues associated with such a high incidence of cases, the Chapter's service population is very culturally diverse and consists of both rural and urban populations.

While the ability to reach and provide services to people living with Alzheimer's disease and their caregivers throughout the service region was a priority to the Chapter, it was neither fiscally nor service effective to create enough physical offices to reach and support the Chapter's rural services regions while maintaining sufficient services to meet the demand in the Chapter's more densely populated, metropolitan areas. In 2001, the Chapter addressed this challenge by documenting the need for and then obtaining private donations and public funding through the State of Florida to create and implement what is now known as the Memory Mobile.

The Memory Mobile provides outreach, care consultations, memory screenings and caregiver education targeting isolated families dealing with, or at risk for Alzheimer's disease residing in rural communities. By utilizing the Memory Mobile, the Chapter has been able to assist the program's target population to overcome many of the barriers that have historically prevented them from being aware of and able to access Alzheimer's education and support services.

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IN THE CATEGORY OF
CAREGIVER EDUCATION
(LARGE COMMUNITY)

**The National Bone Marrow
Transplant Link
Southfield, Michigan**

*Caregivers' Guide for
Bone Marrow/Stem Cell
Transplant: Practical
Perspectives*

The Caregivers' Guide for Bone Marrow/Stem Cell Transplant was developed to educate loved ones about their vital role through the experiences and perspectives of fellow caregivers.

Established in 1992, the mission of the National Bone Marrow Transplant Link (nbmtLINK) is “to provide help and hope to bone marrow/stem cell transplant patients, their caregivers and families, enabling them to better cope with the emotional challenges of transplant from diagnosis through survivorship, by offering vital information and personalized support services.” As with many serious medical conditions, caregiving for a BMT patient is an all-consuming activity over a prolonged period of time, threatening to dismantle relationships, upsetting family and work roles, and shaking financial security. Caregivers are often unprepared for the role they are about to fill, which can last for months, even years.

To meet these challenges, the nbmtLINK worked with BMT caregivers, survivors, a social worker, a nurse, and a caregiver advocate to help them write their own narratives and offer practical advice to today's caregivers as to how they can best fill the role, while making sure to take care of themselves in the process. The result was an easy-to-read sixty-page booklet that provides many different supportive perspectives on caregiving. Staff also compiled a resource listing included in the booklet and convened a panel of reviewers from the field to help edit the manuscript.

The original version was published in 2003; the booklet was significantly revised for the second edition, released in 2007. Over the past several months, the nbmtLINK has distributed over 3,000 booklets to caregivers and health professionals. Combined with the first edition, the nbmtLINK estimates that over 20,000 Caregivers' Guides have been distributed nationwide.

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IN THE CATEGORY OF
CAREGIVER EDUCATION
(LARGE COMMUNITY)

**Cancer Care
New York, New York**

*Online Caregiver
Support Groups*

Online Caregiver Support Groups provide virtual 24/7 access to support and information for people across the country caring for a loved one with cancer.

For more than a decade, CancerCare's online groups have provided settings through which caregivers of people with cancer can access peer support, treatment advice, coping strategies, and other information.

These groups utilize an internet-based message board format, accessible only by password to registered members who are each assessed for potential referral to other CancerCare services, such as individual counseling, educational workshops and publications, and financial assistance. The message boards are moderated by master's level oncology social workers, and are accessible to members 24 hours a day, seven days a week to provide them with a forum for sharing information and providing each other emotional support.

The online format enables caregivers to reach out to one another from any part of the country to obtain help from experienced oncology social workers, and to connect with other caregivers to share experiences and lend emotional support. Last year, more than 1,700 people from all 50 states and the District of Columbia participated in one or more of CancerCare's Online Caregiver Support Groups. Participants find that they are able to improve their ability to manage their loved ones' cancer diagnosis, treatment, post-treatment issues or their loss of a loved one, while sharing valuable resources and strategies for their own self care. Online support groups are an especially important source of support for caregivers living in rural areas and for working people who are unable to schedule or to take the time to participate in traditional face-to-face support programs.

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IN THE CATEGORY OF
CAREGIVER EDUCATION
(SMALL COMMUNITY)

**Mid-Illinois Senior Services
Sullivan, Illinois**

*Old Order Amish
Caregiver Program*

The Old Order Amish Caregiver Program is successfully providing support, counseling and training—with intense emphasis on cultural sensitivity to the Amish beliefs and ways—while overcoming obstacles that have historically kept the Amish from seeking help outside their faith.

In 2004, the Mid-Illinois Senior Services Caregiver Program began serving the Old Order Amish community. The region boasts the largest Old Order Amish population in the State of Illinois. The agency currently serves an Amish community of 26 church districts with each district having 100+ families for a total of approximately 3000 people. The Old Order Amish are a patriarchal, pre-industrial society who have not joined the world of consumer consumption. They shun electricity, travel by horse and buggy and believe in simplicity and self-denial over comfort and convenience.

The program's success can be directly attributed to strict emphasis on being culturally sensitive to the Amish beliefs and ways. This remains the highest priority. The program was designed to overcome the four major barriers for the Amish: isolation/lack of transportation, the need for confidentiality outside the Amish community, lack of knowledge/access to outside resources, and the strong belief in self-denial over comfort.

The program is providing for the needs expressed to program staff by the Amish, including these key areas: a confidential support group with transportation provided for all who are unable to come by buggy; in-home counseling for all caregivers and their extended families; trainings offered on a one-to-one basis or group setting; and in-home mental health counseling. This program, referred to by the Amish as a “blessing sent to us in our time of need,” has successfully integrated into a culture developed on principles that traditionally denounce the beliefs of modern society.

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HONORABLE MENTION

**Regional Hospice of
Western Connecticut
Danbury, Connecticut**

*Healing Hearts Center
for Grieving Children
and Families*

The Healing Hearts Center for Grieving Children & Families is committed to providing exceptional bereavement care specifically designed to help adults and children with their grief and to support them as they rebuild their lives, not only during the course of active care, but also after a patient dies.

Regional Hospice of Western Connecticut provides care, comfort and compassion through hospice and homecare programs and The Healing Hearts Center for Grieving Children & Families. In order to improve the quality of life of patients and their caregivers, Regional Hospice offers expert services reaching beyond traditional hospice care. The Healing Hearts Center is committed to providing exceptional bereavement care aimed at preventing long-term negative affects associated with complicated bereavement by educating caregivers and families about what to expect after losing a loved one, including the unique process of mourning a loved one and ways to cope with a major loss. The focus at Healing Hearts is on improved outcomes of care for participants. Staff recognize the importance of bereavement support services in considering quality of care and actively embrace caregivers of hospice patients as well as the bereaved within the community, bringing support to those who need it. Bereavement services include individual support, local community support groups, bereavement volunteers, and support for children.

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HONORABLE MENTION

**Lifespan
Rochester, New York**

*Future Care
Planning Services*

Future Care Planning Services (FCPS) provides comprehensive life care planning services that assure peace of mind and a legacy of love for the caregiver while providing choices and autonomy for the person with a disability.

Future Care Planning Services (FCPS) was established in May 2002 as a legal joint partnership among three highly regarded agencies in the aging and disabilities fields. The staff of FCPS works with each family to explore all legal and financial planning options with the primary goal of insuring the security and safety of their loved one. Staff recognizes from vast experience that providing manuals and classes do not meet the needs of the unique target population of caregivers. Caregivers of adults with disabilities experience multiple barriers to planning including fear of their own mortality, lack of confidence in other's abilities to care for their loved one, and the stress of daily caregiving. Lifespan serves families regardless of the disability or connection to the delivery service system. The bulk of work is done with individual families but there are also comprehensive community and professional seminars. FCPS provides a place where everything can be tied together: legal concerns, financial issues, and information about available home health care resources. FCPS serves as a road map for caregivers and provides a positive planning process to allow caregivers of adults with disabilities to see beyond today.

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SEED GRANT AWARD

**Department of Disability
and Human Development
University of Illinois
at Chicago
Chicago, Illinois**

The Future Is Now!

This innovative future planning training program will use a “train-the-trainer” approach to implement the empirically tested “The Future Is Now” curriculum developed for adults with intellectual/ developmental disabilities and their families.

“The Future is Now” program is a peer support psycho-educational intervention developed to support aging caregivers and adults with developmental disabilities in planning for the future. The intervention consists of a legal/financial training session followed by five additional small-group workshops. The five workshops cover the following topics: 1) Taking the big step, 2) Building relationships and skills, 3) Housing, 4) work, retirement and leisure, and 5) Who will be the keeper of the dream?

Families and individuals with intellectual/ developmental disabilities help to co-facilitate the workshops and support each other in discussions about the future and in sharing information. Each workshop lasts approximately two hours and is typically spaced two to four weeks apart. The goals of the “The Future is Now” training are to: increase concrete future planning activities taken by families; impact subjective appraisals of caregivers (decrease feelings of burden and increase feelings of satisfaction and self-efficacy); and increase choice-making opportunities and inclusion of individuals with developmental disabilities in the future planning. More specifically these five sessions aim to: decrease cognitive, emotional and behavioral barriers to planning; explore alternatives in the community for housing, work, and leisure; increase participation in planning by parents, siblings and people with intellectual/ developmental disabilities; empower individuals to have choice and control in their future plans; and get families to begin planning.

This project will take eight weeks to recruit, plan, and publicize two trainings. Follow-up will occur at six months after the train-the-trainer sessions to assess follow-up outcomes of the training.

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**National Project
Advisory Committee**

The National Alliance for Caregiving is very appreciative of our Advisory Committee members and reviewers. Their task was enormous, and they served the project well, with commitment, tenacity, and wisdom.

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**National Alliance
for Caregiving
Member Organizations**

AARP
ALS Association
Alzheimer's Association
Alzheimer's Foundation of America
American Academy of Home Care Physicians
American Association of Homes and Services
for the Aging
American Geriatrics Society: Foundation
for Health in Aging
American Occupational Therapy Association
American Psychological Association
American Red Cross
American Society on Aging
CareOptionsOnLine (NavGate Technologies)
Center for the Advancement of Health
Children of Aging Parents
Easter Seals
Evercare
Family Support Center
GlaxoSmithKline
Genworth Financial
Hamacher Resource Group, LLC
Healthcare Leadership Council
Home Instead Senior Care
Johnson & Johnson
LifeCare, Inc.
Lighthouse International
Lupus Foundation of America, Inc.
Mather LifeWays
MetLife Mature Market Institute
N4A
Nat'l Association of Chain Drug Stores Foundation
Nat'l Association of Professional Geriatric Care Managers
National Association of Social Workers
National Center on Caregiving/
Family Caregiving Alliance
National Council on Aging
National Hospice and Palliative Care Organization
National Multiple Sclerosis Society
Paraprofessional Healthcare Institute, Inc.
Parkinson's Disease Foundation
Pfizer Inc.
U.S. Department of Veterans Affairs (DVA)
Verizon
Well Spouse Association
Women's Institute for a Secure Retirement (WISER)



Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations that focuses on issues of family caregiving across the life span. The Alliance was created to conduct research, do policy analysis, develop national programs, and increase public awareness of family caregiving issues. Recognizing that family caregivers make important societal and financial contributions toward maintaining the well-being of those for whom they care, the Alliance's mission is to be the objective national resource on family caregiving with the goal of improving the quality of life for families and care recipients.

MetLife Foundation

MetLife Foundation was established in 1976 by MetLife to carry on its long-standing tradition of corporate contributions and community involvement. The Foundation has been involved in a variety of aging-related initiatives addressing issues of caregiving, intergenerational activities, mental fitness, health and wellness programs and civic involvement. More information about the Foundation is available at www.metlife.org.

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