



The Duke Family Support Program: An Acclaimed Resource for AD Caregivers

By George L. Maddox, PhD

Translating research into practice, and professional advice into patient and caregiver behavior, are major challenges of contemporary health care.

The Duke Center for the Study of Aging and Human Development was designed to be an all-university, multidisciplinary center for conducting research that would be translated into training, education, and service for an aging population. In 1972 the Older Americans Resources and Services (OARS) Program and its Geriatric Evaluation and Treatment (GET) Clinic began to demonstrate how multidisciplinary patient evaluation and team care in the community could effectively serve older adult patients in an era of increasingly specialized medical and hospital care. Finding new ways to facilitate aging at home became a challenge.

The start of a statewide network

In 1978 the Duke Center illustrated its interest in community-based care with the initiation of a Family Support Program, created to assist families caring

at home for members with Alzheimer's disease (AD). At that time, the diagnosis and prognosis of AD were uncertain and insurance coverage problematic. With the prevention or cure of AD not possible, the Family Support Program was literally a bootstrap operation under the leadership of Lisa Gwyther, MSW, who joined the Center hoping to pursue a career in gerontology. What could be done "in the meantime" while people with AD and their families waited for prevention or cure?

Then Center director, I announced a meeting at Duke for families managing a person with AD at home. Fifteen people attended that first meeting—mostly from families served by the GET Clinic or participating in the research of Albert Heyman, MD, a noted Duke AD specialist. The response of the initial participants was both enthusiastic and grateful; they wanted to continue meeting and to encourage others to attend.

Attendance did increase steadily, and families came from great distances to participate. Responding to community interest around the state, Gwyther and I developed a popular presentation to discuss the characteristic challenges of helping a family member with AD at home and the value of community-based social support groups.

Gwyther proved to be an energetic, skillful community organizer. By 1982, Duke-initiated Family Support Programs were operating in 23 communities across North Carolina—from Manteo on the Atlantic coast to Murphy in the far west mountains. With Gwyther's stamina and initial support from North Carolina foundations such as Babcock and Reynolds, the Duke Hospital Auxiliary, and the emerging Alzheimer's Association, the new Aging Center program flourished and achieved state, regional, and national attention.

Requests for information about the Family Support Program have been numerous and continuing. Its publication, *The Caregiver*, which began in 1980 to report

useful news about AD management and new scientific developments, currently has more than 10,000 subscribers in all 50 states and nine foreign countries.

A wealth of valuable resources

And the following publications, which describe the development of effective, sustainable family support groups for AD patients and special issues related to their



Lisa Gwyther, MSW



care, continue to be in demand and are available from the Duke Aging Center:

- *Steps to Success*—Identifies the key decisions AD caregivers must make in providing care at home (Lisa Gwyther, Edna Ballard, and Juliessa Pavon)
- *Mobilizing Networks of Mutual Support*—Illustrates how the North Carolina network of AD Support Groups was created, maintained, and expanded (Lisa Gwyther and Beverly Brooks)
- *You Are One of Us*—Written for church members and clergy to illustrate how they can make successful connections with AD families, this best-seller is now in its 30th printing and is also available from the NIA Alzheimer's Information Center (Lisa Gwyther)
- *Pressure Points*—Addresses the management of anger in AD family relationships (Edna Ballard, Lisa Gwyther, and Patrick Toal)

The Duke Family Support Program's contributions to the understanding of why social support networks promote well-being in late adulthood have been well-established by gerontological research. The social bonding among people in networks—whose members perceive a shared fate and affirm mutual responsibilities for one another in solving problems of living—are the recognized basis of effective support groups that have been widely used to manage a broad range of health problems. Kinship groups are, in fact, the prototypic mutual support networks that provide timely and appropriate informa-

tion, practical services, and emotional support.

Social support groups demonstrably can be effective. The challenge is to create sustainable kinship-like groups that provide timely, useful information, practical help, support in mastering problems of everyday living, models of emotional mastery in responding to traumatic circumstances, and models of successful coping. The Duke Family Support Program has demonstrated and documented effective ways to help families care for members at home.

The Duke Program translated this good idea into community-based support networks with notable success, anticipating by two decades the national recognition that support of family caregivers is an important resource for health care in later life. The U.S. Administration on Aging established the National Caregiver Support Program in 2000.

Gwyther's leadership has ensured the recognition of the Aging Center's Family Support Program as a major contribution to caregiving. Nationally, she was one of 30 founding members of the Alzheimer's Association. In 1998, she was recognized in the 20th-anniversary issue of *Contemporary Long-Term Care* as one of the 20 people who had made the greatest contributions in improving the long-term care of older adults in the previous two decades.

At the Duke Medical Center, as Director of Education at the Bryan Alzheimer's Disease Research Center since 1985, she founded and continues to direct

the now prestigious annual conference that reviews for both professional and lay audiences current developments in research and practice of caring for older adults with AD. In 1983 she was the first recipient of a Heinz Congressional Fellowship in Aging and Health that enabled her to work on the health staff in the office of Senate Majority Leader George Mitchell. In 2007 she was elected President of the Gerontological Society of America in recognition of a distinguished career melding scholarship and service that translated into service the sound research idea of social support for families caring for older adults with dementia at home.

The Duke Family Support Program has earned its national reputation for translating research into services for older adults with AD and for the families that care about and for them.

For more information, call 919-660-7510 or visit www.DukeFamilySupport.org. ■

The Duke Family Support Program
Telephone Hotline
919-660-7510 (Local) and
800-646-2028 (Toll-free)