

Supporting Wisconsin's Family Caregivers



"I've felt more confident in recognizing the reasons for anger and other feelings. Evaluating first, rather than reacting instantly, has been a great help."

—*Powerful Tools* participant



Situation

Growing numbers of at-home family caregivers (44 million according to a 2004 survey by the National Alliance for Caregiving and AARP) are heralding a change in American society.

More and more people today find themselves caring for a spouse, partner, parent, family member or close friend in their home. In fact, family members and friends now account for about 80% of all long-term care in the U.S.

What is driving this trend? The high cost and shortage of trained caregivers; the desire to provide personalized care within the family; and the changing levels and demands of caregiving are a few of the reasons.

Whatever the causes, family caregiving is emerging as a major social and economic issue across the nation. As a result, more people find themselves faced with learning new skills and making adjustments in personal, family and work life. Recent research documents how the stress and worries caregivers experience often compel them to neglect their own physical and mental health. This can lead to depression, extreme fatigue, poor eating and exercise habits, and greater reliance on medications. Many caregivers believe their own downward health spiral has reduced their ability to provide care.

The physical, emotional and financial impacts caregivers experience carry over to other areas of their lives as well. The responsibilities and stresses of those who hold down jobs are increasingly affecting the workplace. About two-thirds of the caregivers of older adults are employed (64%). Nearly half of them (47%) provide up to 40 hours of unpaid care while maintaining a full-time job.

Employed family members don't always recognize their role as caregivers or seek extra support. But many find themselves lacking caregiving knowledge and skills, emotionally drained and not knowing where to turn for help.

According to a study of U.S. businesses, employers lose more than \$33.6 billion annually due to fulltime employed caregivers' absenteeism, workday interruptions, caregiver crises, unpaid leave and costs when employees have to quit.

The bottom line is that family caregivers form the backbone of today's long-term care system. A majority have had little training on how to be a caregiver and often have their own health concerns. Nine in ten report their health as fair or poor and many are depressed, especially those caring for someone with dementia.

Family caregivers need support to learn coping skills and strategies to help them maintain their own health and well-being—both at home and in the workplace. And both public and private sector organizations need more education about the role caregivers are playing in their communities.

Response

UW-Extension Family Living Programs recognized the need for support and resources for the growing ranks of family caregivers. In response, the program drew on the expertise of its specialists and educators to develop a comprehensive approach that helps meet caregivers' needs and educates the broader community about the issues that are involved in home caregiving.

Family Living Programs:

- 1) Provides professional development on caregiving-related issues for Extension colleagues and other professionals who work with caregivers and volunteers.
- 2) Develops programs for caregivers that incorporate different kinds of educational approaches.
- 3) Furnishes support for community networks and collaborations that support caregivers.
- 4) Teaches curricula and provides instruction based on the latest research in the area of caregiving for caregivers and those with whom they interact.

In partnership with AARP, Family Living Programs founded the Wisconsin Alliance for Family Caregivers with the mission of providing education, training and support to caregivers and the professionals who work with them. With Family Living leadership, Alliance members work closely with caregiving professionals to provide educational programs and resources.

For example, Family Living educators teach a six-week course titled *Powerful Tools for Caregivers* that focuses on people who have cared for a spouse for an extended time. Another course, *Elder Care and Work: Finding the Balance* is a day-long program

adapted for employees trying to maintain full-time jobs while caring for family members.

Extension staff have provided master trainings for class leaders so they can work with employers. They also work directly with employers to educate them on how their employees are affected by providing care.

Extension educators have trained class leaders on the curricula *Caregiving Relationships* and helped adapt the curriculum *Caregiving Near Life's End* to be more user friendly for trained class leaders.

Family Living Programs also supports and enhances the work of many state and community partners who deal with aging and family issues by providing expertise, training and education. Some of those partners include:

- Family caregiver coalitions, dementia networks, long-term care councils and regional consortiums
- County and tribal social workers, hospitals and health care providers
- Wisconsin Alzheimer's Network
- AARP
- Non-profits, including the Wisconsin Repite Association and inter-faith organizations
- The Wisconsin Department of Health and Family Services Bureau of Aging & Disability Resources, including local aging offices

Outcomes

By the end of 2007, the Wisconsin Alliance for Family Caregivers, supported by Family Living Programs, helped to train more than 500 leaders in four different caregiving-related curricula (numbers indicate how many leaders were trained in each): 1) *Powerful Tools for Caregivers* (194); 2) *Caregiving Relationships* (190); *Caregiving Near*

Life's End (37); and *Elder Care and Work: Finding the Balance* (93).

Class leaders trained in one of these four curricula have taught more than 7,000 family caregivers in the past six years. Leaders are now available to teach at least one curriculum in 88% (64) of Wisconsin's 72 counties.

Class leaders use the curriculum resources with caregivers in a variety of outreach methods, including support groups, one-on-one, workshops, learning sessions and exhibits.

Feedback from participants in these courses has been overwhelmingly positive. For example:

- After participating in one of the sessions, a caregiver commented, "I've felt more confident in recognizing the reasons for anger and other feelings. Evaluating first rather than reacting instantly has been a great help."
- A social worker reported that she takes course materials with her when she visits caregivers.
- Another class leader had taught the *Elder Care and Work* curriculum three times when the local paper followed up with a feature story on the issue.
- One hospice has used the *Caregiving Near Life's End* curriculum to train all its social workers.

The leadership and participation of Family Living Programs has made a positive difference by helping to address the needs of family caregivers, their families and their communities.

Contact:

Mary Brintnall-Peterson
Program specialist in aging
608-262-8083
mary.brintnall-peterson@uwex.edu

