

Family Caregiving

Sometimes it arrives as a midnight crisis; for others, caring for an ailing loved one has become part of the family fabric over time.

From mowing a lawn and balancing a checkbook to managing medications or monitoring nursing home care, family caregiving means providing regular assistance to someone who is frail or chronically ill. These loved ones may be aging parents, ill spouses, disabled children, or lonely neighbors. But they all have one thing in common: They need the help of family and community to remain functional.

In the last decade, the number of Americans who care for elderly, disabled, or chronically ill friends or relatives has doubled to 54 million. This trend will only skyrocket as the number of people over the age 65 doubles in the next 30 years. The fastest-growing elder population is now people over 85 – those most in need of the kind of personal assistance that family members provide, usually at home.

According to the U.S. Department of Labor, the typical caregiver is a 46 year-old working woman who spends an additional 18 hours a week caring for her 77 year-old mother who lives nearby. The stakes are even higher for loved ones with a dementing disease: The Alzheimer's Association estimates that many caregivers spend 70 hours a week in addition to career and family responsibilities.

Yet long-term care needs are not something most families are aware of or trained to handle. With chronic illness on the rise, however, conditions like heart disease, diabetes, incontinence, and arthritis threaten to overwhelm families because personal care is rarely covered by most health insurance plans, including Medicare, which focus instead on acute illnesses.

Family caregiving is a modern phenomenon: With people living longer, with more women in the workforce, and with more families fragmented geographically and emotionally, there isn't always someone at home to care for an aging relative. Along with an upheaval in lifestyles and relationships, emotions and expectations, caregiving can be financially catastrophic: A 1999 MetLife study found that caregivers may spend more than \$659,000 over a lifetime, including lost wages and promotions.

A more recent MetLife Study of Employed Caregivers, conducted by the National Alliance for Caregiving and LifePlans, Inc., found that employees caring for elderly or sick relatives who have long-term care insurance are almost twice as likely to stay in the workforce as those caring for relatives without the coverage. Employees with long-term care insurance also reported more quality time and companionship and less stress with hands-on assistance.

Despite best intentions, caregiving can be stressful. How do you know what your loved one needs most? When do you step in, and how do you plan for the future?

The best approach to caregiving is to keep things simple. First, determine if your loved one's needs are primarily medical, social/behavioral, functional, legal/financial, housing, or cognitive/mental. This can be done through a geriatric medical assessment. Then the family should designate a primary caregiver, get educated about community and Internet resources, and design a flexible care plan – with or without professional assistance – for the long term.

Many adult children fall into the trap of thinking they can – and must – do everything for their parents alone. This belief leads to anger, resentment, guilt,

and burnout, especially when they realize they can no longer continue providing around-the-clock home care. However, there are effective planning tools available, such as long-term care insurance. Coverage under many of these policies allows caregivers to shift between professional and family care, giving them a needed respite break while assuring the best continuity of care for their parents at home.

Gerontologist Vickie Schmall suggests further tips:

- Before making decisions, understand your motives and feelings. Involve your relative in all choices, and recognize his/her right to make decisions.
- Avoid preconceived ideas about what is “best.”
- Hold a family meeting with a professional facilitator if necessary.
- Remember there are no perfect answers.
- Take care of yourself along with your loved one.

“Making sound, compassionate decisions is a skill that requires preparation, cooperation, and practice,” says Schmall. “What is important in caregiving is not just to survive, but to thrive.”

For more information and free brochures on long-term care planning, contact the California Department of Health Services, California Partnership for Long-Term Care at (800) CARE445.

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