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Coping with Caregiving

Take Care of Yourself While Caring for Others



It can be a labor of love, and sometimes a job of necessity. A total of about 43 million U.S. adults provide unpaid care for someone with a serious health condition each year. These often-unsung heroes provide hours of assistance to others. Yet the stress and strain of caregiving can take a toll on their own health. NIH-funded researchers are working to understand the risks these caregivers face. And scientists are seeking better ways to protect caregivers' health.

Many of us will end up becoming a caregiver at some point in our lives. Chances are we'll be helping out older family members who can't fully care for themselves. Such caregiving can include everyday tasks, such as helping with meals, schedules, and bathing and dressing. It can also include managing medicines, doctor visits, health insurance, and money. Caregivers often give emotional support as well.

People who provide unpaid care for an elderly, ill, or disabled family member or friend in the home are called informal caregivers. Most are middle-aged. Roughly two-thirds are women. Nearly half of informal caregivers assist someone who's age 75 or older. As the elderly population continues to grow nationwide, so will the need for informal caregivers.

Studies have shown that some people can thrive when caring for others. Caregiving may help to strengthen connections to a loved one. Some find joy or fulfillment in looking after others. But for many, the strain of caregiving can become overwhelming. Friends and family often take on the caregiving role without any training. They're expected to meet many complex demands without much help. Most care-givers hold down a full-time job in addition to the hours of unpaid help they give to someone else.

"With all of its rewards, there is a substantial cost to caregiving—financially, physically, and emotionally," says Dr. Richard J. Hodes, director of NIH's National Institute on Aging. "One important insight from our research is that because of the stress and time demands placed on caregivers, they are less likely to find time to address their own health problems."

Informal caregivers, for example, may be less likely to fill a needed prescription for themselves or get a screening test for breast cancer. "Caregivers also tend to report lower levels of physical activity, poorer nutrition, and poorer sleep or sleep disturbance," says Dr. Erin Kent, an NIH expert on cancer caregiving.

Studies have linked informal caregiving to a variety of long-term health problems. Caregivers are more likely to have heart disease, cancer, diabetes, arthritis, and excess weight. Caregivers are also at risk for depression or anxiety. And they're more likely to have problems with memory and paying attention.

"Caregivers may even suffer from physical health problems related to caregiving tasks, such as back or muscle injuries from lifting patients," Kent adds.

Caregivers may face different challenges and risks depending on the health of the person they're caring for. Taking care of loved ones with cancer or dementia can be especially demanding. Research suggests that these caregivers bear greater levels of physical and mental burdens than caregivers of the frail elderly or people with diabetes.

"Cancer caregivers often spend more hours per day providing more intensive care over a shorter period of time," Kent says. "The health of cancer patients can deteriorate quickly, which can cause heightened stress for caregivers. And aggressive cancer treatments can leave patients greatly weakened. They may need extra care, and their medications may need to be monitored more often."

Cancer survivorship, too, can bring intense levels of uncertainty and anxiety. "A hallmark of cancer is that it may return months or even years later," Kent says. "Both cancer survivors and their caregivers may struggle to live with ongoing fear and stress of a cancer recurrence."

Dementia can also create unique challenges to caregivers. The health care costs alone can take an enormous toll. One recent study found that out-of-pocket spending for families of dementia patients during the last 5 years of life averaged \$61,522, which was 81% higher than for older people who died from other causes.

Research has found that caregivers for people with dementia have particularly high levels of potentially harmful stress hormones. Caregivers and care recipients often struggle with the problems related to dementia, such as agitation, aggression, trouble sleeping, wandering, and confusion. These caregivers spend more days sick with an infectious disease, have a weaker immune response to the flu vaccine, and have slower wound healing.

One major successful and expanding effort to help ease caregiver stress is known as REACH (Resources for Enhancing Alzheimer's Caregiver Health). Nearly a decade ago, NIH-funded researchers showed that a supportive, educational program for dementia caregivers could greatly improve their quality of life and reduce rates of clinical depression. As part of the program, trained staff connected with caregivers over 6 months by making several home visits, telephone calls, and structured telephone support sessions.

"REACH showed that what caregivers need is support. They need to know that there are people out there and resources available to help them," says Dr. John Haaga, who oversees NIH's behavioral and social research related to aging.

The REACH program is now being more widely employed. It's been adapted for use in free community-based programs, such as in local Area Agencies on Aging. It's also being used by the U.S. Department of Veterans Affairs and by the Indian Health Service, in collaboration with the Administration for Community Living.

"We know how to support families caring for an older adult. But that knowledge is not easily accessible to the families who need it," says Dr. Laura Gitlin, a coauthor of the REACH study and an expert on caregiving and aging at Johns Hopkins University. "Caregivers need to know it's not only acceptable, but recommended, that they find time to care for themselves. They should consider joining a caregiver's support group, taking breaks each day, and keeping up with their own hobbies and interests."

To learn more about aging-related caregiver resources, contact NIH's National Institute on Aging at 1-800-222-2225 or niaic@nia.nih.gov. To learn about cancer-related caregiver resources, contact NIH's National Cancer Institute at 1-800-422-6237. See the Web Links box to find a variety of online caregiving resources.