

Information for People Who Provide Care for Elders

Caregiver

FACT SHEET

Bulletin #4203

Caregiving: What is it? Who does it?

Each year, close to two million Americans celebrate their 65th birthday. Many will live another 15, 20 or more years as independent and active older adults. However, living longer can bring challenges. Illness or disability may prevent people from caring for themselves; many may need ongoing care and help.

When older people are no longer able to manage on their own, they often turn to their families and friends for help. These helpful people become caregivers.

Caring for a spouse is the most common form of caregiving for an older person.

You may be a caregiver. You may be a spouse, son, daughter or other relative. You may be young or old. You may be providing care out of love or a sense of obligation. More often than not, you feel both love

and obligation. You may find caregiving to be satisfying and rewarding, or you may find it to be frustrating.

You may be providing support alone or arranging the work of others who give direct care. Several people may be involved in caregiving, decision-making and financial responsibilities. However, you may have the major responsibility for the older person's well-being.

Are You a Caregiver?

You are a caregiver if you provide care in the home for an older, chronically ill or disabled family member or friend. The time you spend

Facts on Caregivers

- 22.4 million U.S. households provide caregiving.
- 20% share a household with the person being cared for.
- 72.5% are female.
- family and friends are the sole assistance for nearly 75% of impaired older adults.
- Most caregiving falls to one person.

Facts on Those Who Need or Receive Care

- 22.9% of people 65 and over are functionally disabled or need long term care.
- 22% of care recipients suffer from dementia.
- a person 65 years old can expect to be functionally impaired for five years or more of their remaining life.

Caregiver Roles

- Caregiving responsibilities take an average of 18 hours per week.
- 18.6% of caregivers are providing care for 40 or more hours per week.
- 75-80% of caregivers provide assistance with transportation, grocery shopping and housework.
- In 1997 the estimated economic value of informal care provided by caregivers totaled \$196 billion.

may vary from a few hours a day to many days. Tasks may include:

- Bathing and dressing your loved one
- Cooking
- Cleaning
- Laundry
- Handling finances
- Giving shots and other medications
- Changing dressings and intravenous tubes
- Running errands to stores and businesses
- Appointments with the doctor, dentist, etc.
- Providing information to a loved one and to other friends and family members

Long distance Caregivers:

People with relatives living far away have hard questions and issues to address. Talk with the relative to learn as much as possible about the situation. When you visit, you'll want to assess the relative's well-being. Note eating habits, contact with others, handling of finances, safety practices and any unusual behavior.

It is not possible to provide personal care from a distance, so you'll need to set up other sources of support, such as clergy, neighbors, friends and local social service agencies.

Employed Caregivers: When the caregiver is employed outside the home, various problems can develop. The work place may not be responsive to your situation.

This can create problems with office hours, vacation, sick leave, personal leave and other benefits.

As a caregiver you will have to manage your time very carefully. You may be unavailable on short notice, and have trouble finding or setting up services.

No matter what kind of caregiving they provide, caregivers need to learn new skills. Your family may have to learn some new ways of doing things also.

Employed caregivers tend to be younger and are responsible for three or four generations. It may take time to adjust work and family duties. Barriers in the community (office hours, poor accessibility for people with disabilities) can also create problems.

Caring for a Spouse: Caring for a spouse is the most common form of caregiving for an older person. This situation is often sudden, after an accident or illness, with little time for planning. Pressure from society and family or promises made to a spouse often make choices more difficult.

If a spouse is limited in their abilities, your responsibilities for household tasks may

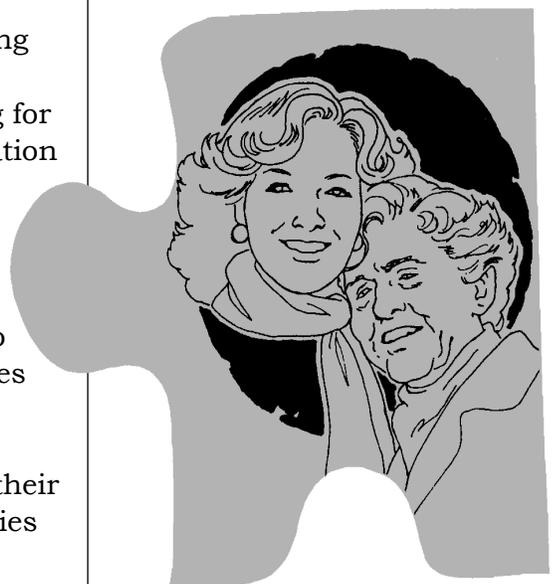
change. Caregivers may have to do things they have never done before. Learning new tasks, coping with fear and a lack of experience, plus additional work can be frustrating for all concerned.

Sandwich Generation

Caregivers: When caregivers become "sandwiched" between two generations, they are often unprepared to juggle everyone's needs. Caring for a family member may occur at the same time as other life transitions, such as children entering adolescence or leaving home.

People who care for others during middle age often care for more than one person (spouse, parent, parent-in-law, etc.). Many women spend as much or more time caring for an older person as they do caring for their children.

There is also what we might call a double-decker (or double-whammy) sandwich generation. For example, a 70-year-old person may be caring



for his or her 90-year-old parents, plus an ailing spouse, as well as adult children who are going through divorces or having financial problems. There may also be worries over the grandchildren.

Why do People Provide Care in the Home?

There are a variety of reasons for providing care in the home:

- Love for the older family member or friend.
- Desire to provide care in familiar surroundings.
- A sense of obligation.
- Fear that no one else can provide quality care.
- As a last resort, if outside care is unavailable or too costly.

Are Most Family Caregivers Trained for the Job They Do?

No. Most family caregivers find themselves in a caregiving situation suddenly and unexpectedly. They do the best they can, relying on experience, intuition and advice. Caregivers can learn how to handle their responsibilities with help from professionals, other caregivers, community classes, group meetings and resource materials.

No matter what kind of caregiving they provide, caregivers need to learn new skills. Your family may have to learn some new ways of doing things also.

Is the Role of a Caregiver Easy?

Few situations in life are as tense and stressful as having to provide care for an aged loved one who may be in poor health or dying. It is hard to see someone we're close to become dependent, disabled and disoriented. Nothing we can do will make everything all right. The elder may be in such poor health that he or she does not even know us and cannot thank us for our efforts.

When the caregiving load is

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heavy, you might be frightened by feelings, such as rage, anger at the elder for being a burden or irritation with them for needing care. These feelings can give rise to guilt: we feel there must be something wrong with us if we have such negative feelings. However, these feelings are completely normal and acceptable. They do not mean that you don't love the person or that you are bad or unworthy. They show you are normal and human. Feelings of anger, guilt and frustration can actually help you determine your next steps.

Caregivers may also be dealing with their own aging process. For some, this process might involve the recognition of their own mortality. You may

become concerned about the time you have left to live. This can be a time to rethink who you are, what you want from life, what you value and what your roles are. This involves some personal restructuring and adapting to changing situations.

Caregiving can be very stressful. However, it can also be rewarding. Other fact sheets in this series will give you ideas on balancing work, family and caregiving, as well as suggestions on how to take care of yourself as a caregiver.

For more information on caregiving, contact your county Extension office.

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References *Family Caregiving in an Aging Society* by Sharon Tennstedt, Ph.D., National Institute on Aging grant no. AG07182 and AG11171, March 1999.

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