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FAMILY RELATIONSHIPS

Elderly Caregiving

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People are living longer than ever before. It has been estimated that the average American woman will need to provide about 18 years of some type of care for her elders. Because many women are marrying and having children later, they frequently find themselves in the sandwich generation, caring for their children and elders at the same time.

Family members provide approximately 80 percent of the necessary care for the elderly. Usually there is one primary caregiver and most often this is an adult daughter or spouse.

The primary caregiver frequently must provide this care under complex circumstances. Adult daughters often have to balance the concerns of their own immediate families, their work outside the home, and their responsibilities for elderly caregiving.

If you are not currently caring for an elder, chances are that you will at some time during your life.

This guide provides information about our aging population, issues related to caregiving, ideas for taking care of yourself and resources that can help.

CHALLENGES CHOICES

The aging population

The United States has been steadily aging for many decades. In 1900, about 3.1 million persons, or roughly 4 percent of the population, were aged 65 years and older. By 1990, the number of elderly persons had reached 31.2 million or 12.6 percent of the total population. This graying is expected to continue until at least the year 2040, when the elderly portion of the total U.S. population could total 22.6 percent.

Most dramatic is the increase in the oldest segment of society, those needing the most care. While the 65 to 74 age group is expected to increase by 17 percent between 1980 and 2000, the population over age 85 will more than double during this period.

In Missouri alone, the population of residents 85 years or older increased 33 percent between 1980 and 1990. The growth among the oldest-old is one of the results of improved health care and disease prevention techniques used in the United States during the 20th century.

Many older adults develop mental or physical impairments that will eventually cause them to need some outside help. In 1994, more than 6 million older Americans received some form of daily in-home care. Currently, half of the over-85 population needs some assistance with activities of daily living, such as eating, toileting or dressing. The availability of caregivers to the elderly is a critical factor in their being able to remain in the home, rather than having to be placed in an institution.

Although a caregiver can be anyone — a spouse, child, friend or neighbor, usually it is a woman. The typical caregiver is 57 years old, female, married and employed outside the home. She can expect to spend as many years caring for a parent as for her children. There is also a good chance that she will be a caregiver to more than one person during her lifetime.

While the number of older people is increasing, the pool of available caregivers for them is shrinking. Large numbers of women continue to enter the workplace, including those middle-aged women who are most often the caregivers to the elderly.

Also, those adults moving into the elderly age group have had fewer children, so there are fewer individuals to take on the caregiver role. The divorce rate has also had an effect. There are fewer spouses to provide care, and children often must care for divorced parents living in separate locations.

In addition, many of the females who are caregivers are fast approaching old age themselves. Because women are often younger at the time of marriage and generally outlive men, the caregiver in an older couple is likely to be the wife.

Thirty-five percent of caregivers are over age 65 and ten percent are over 75 years of age. These women are often called the hidden victims of caregiving because of their advanced age and the added strain of caring for another person.

What it means to be a caregiver

Caregiving can be defined as providing unpaid assistance for the physical and emotional needs of another person, ranging from partial assistance to 24-hour care, depending on his or her condition.

Caregivers can provide a wide range of services, depending on the degree of disability, economic situation and living environment of the older person. Outside help may or may not be involved. The person being assisted is the care receiver. This person may live with the caregiver or live elsewhere.

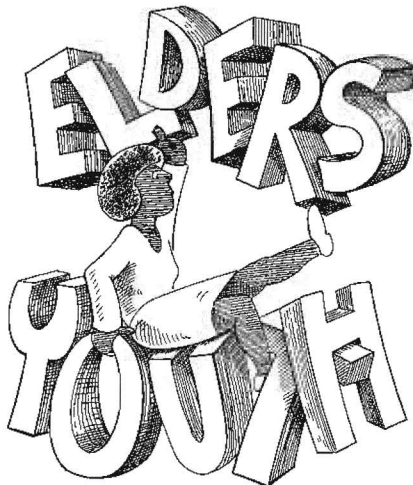
Quite often, as the disability increases, there is a progression in the amount of hands-on care that is needed, from assistance with daily living tasks to round-the-clock care. The type and amount of care will also vary with the type of disease or disability, that is, someone with Alzheimer's disease will

have different needs than someone with cancer, for example.

Caregivers can also be considered primary or secondary. The person who has the main responsibility for the individual is the primary caregiver. Secondary caregivers offer support to the primary caregiver. If the primary caregiver is a daughter, the secondary caregivers tend to be the son-in-law and the grandchildren. While secondary caregivers are usually family members, they can also be friends or non-relatives. Secondary caregivers tend to be less involved in personal care of the elder, but help with transportation, shopping and home repairs.

Caregiving is an act of love — with consequences

Women have historically been presumed to be responsible for the well-being of their family members. In the past, the unmarried daughter was expected to provide care for an aging parent. Today, caregivers are overwhelmingly spouses and daughters. Women have at times been victim to what has been called the compassion trap. Their nurturing skills and sensitivity to others have made them more willing to take on difficult and often unrewarding personal duties.



Approximately two million women are part of the sandwich generation, caring for children and parents simultaneously. Working women have found that they must become skilled jugglers to meet all of the demands on their time.

The working woman who is also an elderly caregiver doubles up on her responsibilities and cuts back on her personal leisure time to fit everything in. Approximately 12 percent of women reported they needed to quit their jobs to fulfill their caregiving demands. Though most individuals take on the caregiving role willingly, Sommers and Shields in *Women Take Care* state that “caregiving is an act of love — with consequences.”

Feelings experienced by a caregiver

Caregivers experience a wide range of feelings. Though most of them willingly choose to play a primary role in the care of their loved one, this role often carries with it conflicting emotions that must be dealt with. Among them:

■ **Sadness and grief.** Knowing that a person is in declining health and seeing it happen before your eyes can be difficult. Realizing that a loved one is suffering is often traumatic. Knowing that your husband, mother, sister, aunt or grandmother has a short time to live may cause you to begin grieving even before they die.

■ **Fear and worry.** Those of you who are taking care of someone in declining health may be plagued by fears. What will the future hold? How long will my loved one live? What if mother needs more care than I can give her? What if something happens to me, and I can't take care of her at all? How do I get extra help? Will we be able to afford this? Will I be able to hold on to my job or will they let me

go? Will I have to quit? What if dad needs to be put in a nursing home — will I be able to do that?

■ **Anger.** Dealing with a loved one who is ill can be frustrating. Illness can affect people differently and some elderly persons may lash out at their loved ones out of their own fear, frustration, and growing dependency. The ill person might seem like a stranger. The caregiver needs to deal with her own anger; anger at the care receiver, at having to be the caregiver, at family members who may not be helping out, or at the doctors.

■ **Guilt.** The caregiver may feel guilty about many things, including guilt for not doing enough to change the situation or make the person happier, guilt for becoming angry with the ill person, for neglecting one's own spouse, children and other responsibilities. You may even feel guilty for enjoying time away from the loved one.

■ **Fatigue.** Being stretched in several directions can lead to fatigue. Caring for two households, caring for a person in ill health, dealing with the night-time wandering of an Alzheimer's patient and coping with incontinence are examples of things you may experience. In addition, having your own sleep interrupted regularly can lead to serious exhaustion. All of these things can last several months or even years.

■ **Isolation.** If you are the person primarily responsible for another's care, you may feel tied down and isolated. The person you're caring for might need to have someone nearby at all times, or simply not want to be left alone. Studies have indicated that caregivers experience a significant reduction in the amount of free time they have. You may feel that no one understands your situation or how you're feeling. It is important that you recognize these feelings of isolation and realize that they are normal.

A Caregiver's Bill of Rights

I have the right:

- ✓ **To take care of myself:** This is not an act of selfishness. It will give me the capability of taking better care of my relative.
- ✓ **To seek help from others** even though my relative may object. I recognize the limits of my own endurance and strength.
- ✓ **To take pride in what I am accomplishing** and to applaud the courage it has sometimes taken to meet the needs of my relative.
- ✓ **To protect my individuality** and my right to make a life for myself that will sustain me in the time when my relative no longer needs my full-time help.

Excerpted from "A Caregiver's Bill of Rights," *Caregiving: Helping An Aging Loved One*, by Jo Horne, AARP Books, 1985

You can add your own ideas to this list. Review it often!

Even though caring for an elderly person can be a stressful experience, it can also be a rewarding one for the caregiver. On the positive side, it can strengthen your relationships with your elders and give you a chance to get to know them better.

Providing assistance for your elders can give you the opportunity to express love and appreciation for the support that they have given to you. You can take great pride in the contributions that you are able to make at this time in their lives. Several studies have reported that when there is a strong bond established between the caregiver and the care recipient, caregivers feel less stress. Most older persons desire to have individuals in their family provide assistance to them and family members desire this as well.

Taking care of yourself

An important part of being a successful caregiver is remembering to take care of yourself. To provide effective care, you need to maintain your own health.

Neglecting yourself can have long-term consequences, not only for you, but for the person who needs your

care. Adequate sleep and exercise, plus nutritious meals, are essential to your own well-being. Remember that the better care you take of your own health and emotions, the more you will be able to come through for the elderly person who needs you.

Taking time for yourself is also essential to your well-being. Helping an elderly person should not mean giving up all of your activities and relationships with other people. Give yourself a break from your caregiving activities by getting outside help.

Hire someone to stay with your elderly relative so that you can go out for lunch, go shopping or see a movie. Extended breaks, so that you can take a vacation or simply get some rest and relaxation, should be planned for as well. Perhaps a friend or another family member can take over for a while. Too frequently, caregivers are unwilling to ask for help because they think it may be a sign of inadequacy.

You may need to set limits on what you will do, difficult as this may seem. You cannot be expected to do it all. Other family members, even if they don't live nearby, can make a contribution. Community resources are available to help with many aspects of caregiving. Contact your local Division

of Aging Office (DOA) and ask about local services. Or you can call the Missouri Information and Referral Hotline at 1-800-235-5503.

Many caregivers have found that organized support groups are helpful in dealing with the stress of caregiving. Attending an eldercare support group can give you a chance to share openly with other caregivers and to gain new ideas to help you manage your situation.

It's very important to have someone you can confide in and with whom you can share your true feelings. You can get information about local support groups by contacting a local hospital, home health agency or the Area Agency on Aging. Information on caregiving support groups is also available from Children of Aging Parents (CAPS) at 215-345-5104.

It's a family matter

The need to provide care for an elder can happen suddenly or it can develop slowly. Your previously independent mother can fall and break her hip, or your father's diminishing eyesight can make it dangerous for him to continue to drive his car. If you are the oldest daughter or the child who lives closest to your parents, chances are

you'll be the first to take action. Very soon, other family members may need to be contacted and become involved.

A major step toward family problem solving is for everyone to recognize that the caregiving responsibilities belong to all family members. Each person can do something, even if he or she lives at a distance.

The caregiving decisions that are made should focus on your elder's needs, perceptions and preferences. Usually, he or she will want to remain independent and in his or her own home as long as possible. Here are some of the services that might be available to your elders.

Potential services for the elderly

■ **Household chores.** High schools and colleges often keep lists of students who will do these chores for a small fee. Boy Scouts or 4-H groups may shovel snow or rake leaves as a service project for their organization.

■ **Nutrition sites.** Noon-time meals on weekdays are served in a central location such as a senior center or community center.

■ **Home-delivered meals.** This service is frequently called Meals on Wheels, and it provides a hot meal delivered to the home at noon, usually on weekdays.

■ **Emergency response systems.** Medic Alert and Lifeline are examples of commercial programs that provide different types of emergency service on a 24-hour basis.

■ **Telephone reassurance.** An individual calls an elderly person at a pre-determined time each day.

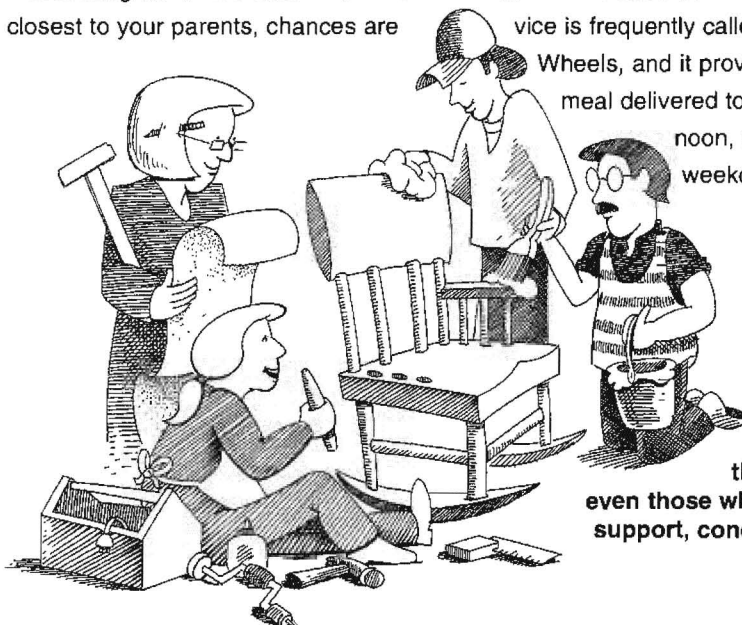
■ **Home health care.** A variety of medical or personal care services can be brought into the home. Depending on the nature of the service, some may be covered by Medicare or other insurance plans.

■ **Homeshare.** A program through local family service agencies in which a group of older adults share a house or an apartment.

■ **Adult day care.** Supervised care, planned activities and health services are provided in a community facility for elderly citizens who would otherwise be at home, alone, during the day.

■ **Group living facilities.** Senior housing is frequently available that offers independent living along with central dining and various other support activities.

■ **Long-distance care.** Professional geriatric care managers can investigate options, provide guidance and supervision of an elderly person's care, if a family member does not live nearby.



The responsibility for caregiving belongs to the whole family. One person doesn't have to shoulder the burden alone. Every family member can help — even those who live far away can help by providing emotional support, concern and advice.

Family communications

Getting all family members together for face-to-face communications is the best approach for decision-making. This meeting gives everyone the opportunity to discuss caregiving concerns, identify potential problems and solutions, and negotiate the sharing of the tasks.

It allows each family member the chance to clarify expectations and minimize any misunderstandings. Whenever possible, the elderly person who needs the additional care should be involved in the discussion. He or she has a right to participate in the decisions that affect him or her.

Family members may overestimate the older person's needs or they can make permanent decisions too quickly. While it's important to deal with the immediate problem, the family should take the time to explore various alternatives. Better solutions can be reached if there has been adequate time given to the decision making process and all family members have been involved.

Ideally, it would be better to plan ahead, before the crisis occurs. While it's difficult to talk about, find out what kind of care your elders might choose before they become ill or incapacitated.

This will give family members more time to look into the services available and what they will cost. With frequent changes in financial support through governmental programs, family members need to familiarize themselves with the latest policies.

Good advance planning can help bring peace of mind to you and your loved ones as you face this milestone in your lives together.

Key questions to ask service providers

- Is the agency licensed by the state?
- Are there other family caregivers who are willing to serve as references for the care facility?
- What is the range of services that is provided?
- When can family members visit and observe procedures in the care facility?
- What do the services cost?
- Will Medicare or other health insurance pay for the services?
- When and where are the services provided?
- What are the qualifications of the agency's employees?
- How are family members kept informed?

Resources

American Association of Retired Persons (AARP), 1909 K Street, NW, Washington, D.C. 20049 (202-872-4700). Request this free publication: *Caregivers Resource Kit* (D15267)

Children of Aging Parents, 2761 Trenton Road, Levittown, PA 19056 (215-945-6900)

Eldercare Locator Service (1-800-677-1116)

National Family Caregivers Association, 9621 E. Bexhil Drive, Kensington, MD 20895 (1-800-986-3650)

National Council on the Aging, 600 Maryland Avenue, SW, West Wing 100, Suite 208, Washington, D.C. 20024 (202-479-1200)

Resource Manual: Information for Caregivers of the Elderly by Share Bane and Burton Halpert, Center on Aging Studies, University of Missouri at Kansas City (816-235-1747)

Sandwich Generation, P.O. Box 132, Wickatunk, NJ 07765-0132 (908-536-6215) quarterly magazine
Adult Day Care, MU Extension Publication (GH 6748)

Fit for Life, MU Extension Publication (GH 6655)

The Challenge of Balance, MU Extension Publication (GH 6651)

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