

## CAREGIVING

### What's Normal, What's Not?

Part 1 of a Series

Caregiving has fast become an expected life event, just like getting married, having children, working and retiring. Because of aging, illness and injury, many people find themselves providing care for a family member or friend. What begins as a kind gesture, often leads to more routine care. While people providing assistance to a loved one may not consider themselves as caregivers, your involvement can help others maintain independence and maximize quality of life.

The type of assistance people often need includes:

- Emotional – listening and responding to concerns, providing encouragement and moral support, maintaining contact, and simply being there for someone.
- Financial – organizing bills, writing checks, balancing the checkbook, and providing money to help cover expenses.
- Physical – assisting with daily living including personal care, household chores, meals, driving, medication, etc.
- Spiritual – helping people find meaning and purpose in life, maintaining hope, coping, and finding peace through prayer, meditation, and cultural and religious preferences.

#### Did You Know...

- 27% of American households consist of one person living alone? (Gross, 2005)
- 48% of adults ages 50 to 70 have retirement savings of less than \$50,000? (Commonwealth Fund, 2005)
- 21% of the US population, age 18 and older, serves as adult (family) caregivers? (Caregiving, 2004)
- 82% of the US population believes in the healing power of prayer? (Wallis, 1996)

If you are not already providing care or support for a family member or friend, chances are you will at some time during your life. While each situation differs, studies indicate that adult children, relatives and spouses who assume the responsibility of caregiver are not prepared. Most people lack the information, skills and confidence that they need. The best time to prepare and become familiar with the roles and responsibilities of caregiving is before there is a need to provide support.

#### What is Caregiving?

- According to National Family Caregivers Association ([www.NFCACares.org](http://www.NFCACares.org)) president Suzanne Mintz, “[Family] Caregivers are those unpaid family members, friends, and volunteers who provide care and assistance to people who are either chronically ill or disabled.”

- According to the Family Caregiver Alliance (www.Caregiver.org) “A caregiver is anyone who provides assistance to someone else that is in some degree incapacitated and needs help.”
- Medical literature tends to focus more on the physical aspects of caregiving such as providing support with activities of daily living (ADLs). As the name suggests, ADLs are those things which people engage in on a daily basis. These activities are basic to caring for one’s self and maintaining independence. There are two specific types of ADL care: personal care and independent living.
  - **Personal Care** (Activities of daily living – ADLs) involves activities such as bathing (sponge, bath or shower), getting dressed, getting in or out of bed or a chair (also called transferring), using the toilet, eating, and getting around or walking.
  - **Independent Living** (Instrumental activities of daily living – IADLs) activities have to do with preparing meals, managing money (writing checks, paying bills), shopping for groceries or personal items, maintaining a residence, performing housework (e.g. laundry, cleaning), taking medications, using a telephone, handling mail, and traveling by car or public transportation.

Regardless of the formal definition, some of the tasks or activities commonly associated with caregiving include:

- Companionship
- Helping around the house
- Providing transportation for appointments and errands
- Assisting with grocery shopping and meals
- Dispensing medications and refilling prescriptions
- Organizing mail, assisting with personal finances and bill paying
- Providing personal care - bathing, dressing, using the toilet, etc.
- Coordinating family and professional care
- Monitoring vital signs and changing bandages
- Representing another person’s interests

### Who are the Caregivers?

Caregivers may be female or male, young or old, married or single. Caregivers may also be volunteers or paid professionals.

1. **Informal Caregivers**, also referred to as Family Caregivers, are unpaid family members, friends or neighbors who provide care either on a part-time or full-time basis.
2. **Formal Caregivers**, also referred to as Professional Caregivers, are people who are paid to provide care and who may be professionally trained and certified.

People providing care often expect to be needed part-time, but for many, the need becomes full-time. The division of responsibility for providing care is rarely equal among family members. A daughter or closest living relative tends to take on most of the care responsibility.

For someone to consider him or herself a family caregiver requires the person to acknowledge that a loved one faces functional limitations and requires care – something many people would rather deny.

The average amount of time a family caregiver spends per week providing care is about 20 hours. An estimated 50% of all caregivers reportedly provide eight hours or less of care a week. Approximately 20% of caregivers provide 40+ hours of care a week.

Caregiving can be short-term while someone is recuperating or rehabilitating. It can also be a long-term commitment as a result of a person's deteriorating health. Caregivers provide support for an average of 4.5 years.

Family caregivers often struggle with juggling the demands of work, personal life, and caregiving responsibilities. Likewise, it can be challenging to deal with the uncertainty that comes with each day. In addition to adjusting their schedules, caregivers often find themselves re-evaluating their values, goals and behaviors.

Although most people have good intentions, the care process can be challenging and good intentions are not always recognized. Remember that it is usually easier for people to give than to receive. Many older adults have been self-sufficient all their lives and find it hard to accept support. Receiving requires acceptance of one's limitations and that help may be needed. Also, many older people may be concerned about being a burden to others or becoming vulnerable.

### **Who are the Care Recipients?**

Care recipients tend to be immediate or extended family members (85%), more often than friends or neighbors (15%). In addition to the unpaid time caregivers give of themselves, over 50% contribute financially to another person's care.

Over 66% of care recipients have a chronic or long-term health condition, and approximately 10% have short-term care needs. A 2003 study conducted by the National Alliance for Caregiving and the AARP indicates 80% of care recipients are age 50 or older.

### **Recommendations for Caregivers**

1. **Don't Overlook the Relationship** – Caregivers want to help and tend to feel the need to be doing something. Oftentimes a loved one may simply want you to be there so he or she is not alone.
2. **Take Care of You** – Caregivers often face depression, anxiety and personal health problems. Be careful not to overlook your own health and well-being by giving too much of yourself.
3. **Seek Information and Support** – Caregivers are often unprepared to deal with the many challenges and decisions they face. Take time to get information, skills training and support.

### **Common Ways Caregivers Help:**

26% of caregivers assist with three or more personal care activities.

- “36% help care recipients get in and out of bed and chairs,
- 29% help with dressing,
- 26% help with bathing,
- 23% help with toileting,
- 18% help with feeding, and
- 16% help with incontinence care.”

80% of caregivers help with independent living activities

- “82% provide transportation,
- 75% shop for groceries,
- 69% do housework,
- 64% manage finances,
- 59% prepare meals,
- 41% disperse medications, and
- 30% arrange services.”

(Giorgianni, 2005)

4. **Deal with Your Emotions** – Caregivers often struggle as loved ones face physical and cognitive (mental) limitations. As you experience a wide range of emotions, be careful not to deny your feelings. Talking with others may help you accept and cope with loss.
5. **Be Prepared for Conflict** – Caregivers often experience conflict as they try to balance family, work and community responsibilities. Also, family may not agree on the care that is needed, and the individual roles and responsibilities. Be open, honest and kind when talking with others.

While Andy Rooney of the CBS television program 60 Minutes is not an expert on aging, long-term care or caregiving, people taking on the role of family caregiver may find the following words of wisdom to be helpful. *I've learned that...*

- Being kind is more important than being right.
- Sometimes all a person needs is a hand to hold, and a heart to understand.
- Life is like a roll of toilet paper - the closer it gets to the end, the faster it goes.
- Under everyone's hard shell is someone who wants to be appreciated and loved.
- I can always pray for someone when I don't have the strength to help him in some other way.
- The Lord didn't do it all in one day - what makes me think that I can?
- To ignore the facts does not change the facts.
- One should keep his words both soft and tender, because tomorrow, he may have to eat them.
- I cannot choose how I feel, but I can choose what I do about it.

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The Center for Aging with Dignity offers Your Care Advocate literature as a community service. We are committed to helping people understand and address life-changing health and care concerns. (C1-07.05-CAD)

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