

***Supporting  
Family Caregivers  
of Adults With  
Communication  
Disorders***

A Resource Guide for  
Speech-Language  
Pathologists and Audiologists

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# 2

## *The Dynamics of Family Caregiving*

Joan C. Payne

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### **Who Are Family Caregivers?**

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Family caregivers are major contributors to the quality of life and wellness of persons in their care, and essential to the success of any health-related intervention program. Within the United States, a significant number of persons are designated as family caregivers. State-by-state analyses show that there are millions of family caregivers who are providing continuous support to adults who can no longer care for themselves (National Alliance for Caregiving in collaboration with AARP, 2009).

As of 2009, 65.7 million caregivers make up 29% of the U.S. adult population providing care to someone who is ill, disabled, or aged (National Alliance for Caregiving in collaboration with AARP, 2009). An estimated 52 million caregivers provide care to adults over age 18 with a disability or illness (Coughlin, 2010). In addition, 43.5 million adult family caregivers care for someone aged 50 years and older, and 14.9 million care for someone who has Alzheimer's

disease or other dementias (Alzheimer's Association, 2011). Caregivers who help an older adult say that the main problem or illness the person they care for has is aging (15%) followed by diabetes, cancer, and heart disease. One quarter (25%) of caregivers helping an older adult report that the person they care for is suffering from Alzheimer's disease, another type of dementia, or other mental confusion, but less than one in ten (8%) say this is their care recipient's main problem or illness (Alzheimer's Association, 2011).

Previous descriptions of the impact of family caregiving on society suggest that family support is a buffer to stress and provides positive outcomes for family members (Reinhard, Given, Petlick, & Bemis, 2008). Earlier, Cantor (1991) proposed a social care model of kinship support that has relevance for present-day consideration. According to Cantor, there are three major areas of kin and non-kin assistance: socialization and self-actualization, instrumental tasks of daily living, and personal care assistance in time of illness or crises. In his view, older adults tend to rely most heavily on spouses and adult children for instrumental, task-oriented support; their friends and spouses (usually the husband) for confiding support; and their groups, organizations, and acquaintances for esteem support.

The prevailing thought is that the quality and variety of supportive relationships decrease the number of health risks that cause or exacerbate major illness. Support networks also function to sustain older adults in time of changing health status. Overall, families are the major societal mechanism for the production of positive outcomes for their members (Brown, 1990; Feinberg, 2013).

## **How Is Family Caregiving Provided?**

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Family caregivers provide unpaid assistance for 20 hours or more weekly for the physical and emotional needs of another person. Another definition is that a family caregiver is someone over the age of 18 years old who has provided unpaid care to a relative or friend over the age of 18 years old in the last 12 months

(National Alliance for Caregiving & Evercare, 2006). In order to appreciate the roles and responsibilities of family caregivers, it is necessary to clarify who in an individual's support network provides the most intense level of care. Increasingly, once a person is discharged from acute care, hands-on care, generally in a home, is provided by family and friends. The home may be that of the caregiver or the care recipient. Many family caregivers care for a loved one from a long-distance location. Family caregivers also advocate for persons in the institutional setting. Those who provide care of this type are called family caregivers (Family Caregiver Alliance, 2014). The acceptance of caregiving responsibilities has its foundation in a relationship, but the act of caregiving is an additional role that requires preparation, acceptance, support, and resources (Reinhard, Feinberg, & Choula, 2011).

### **What Is Meant by “Family”?**

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Family refers to persons who share a profound and loving relationship with one another. Hence, the designation of family includes those with whom a caregiver is related by blood, such as children, siblings, aunts, uncles, and grandparents, and also includes stepparents, in-law parents and grandparents, spouses, and domestic partners (U.S. Department of Labor, 2014). Friends and fictive kin also provide caregiving. Fictive kin are persons who are regarded as close as family, such as “Play Mother,” and who assume in many ways the roles of persons related by blood (Payne, 1992). Approximately 83% of 1,247 caregivers interviewed reported that they are caring for relatives while 17% reported caring for people outside of the family (National Alliance for Caregiving in collaboration with AARP, 2004).

Although caregiving is often described as loving and rewarding, there is consensus that caregiving can be stressful for both the caregiver and the care recipient. Fear of the unknown, fear that resources are not adequate, anxiety about health problems, and grief for the inevitable changes caused by diseases and disorders can affect quality of life for the entire support network as well as for the patient. Density and quality of friend and family

supports can serve to decrease the level of anxiety in persons who are receiving care.

## **Responsibilities of Family Caregivers**

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Caregiving lasts an average of 4.6 years (National Alliance for Caregiving in collaboration with AARP, 2009). Family caregivers provide care, ranging from partial assistance to 24-hour care, depending on the severity of the disease, disorder, or condition. Most family caregivers report that they provide unpaid care to chronically ill or disabled older persons for 20 hours a week or more and donate physical, instrumental (help with daily living tasks), emotional, psychological, and often financial assistance to those who are in their care.

Assistance in activities of daily living (ADLs) means that the caregiver provides those services that maintain the individual's health and well-being at the most rudimentary and critical levels, such as assisting limited or nonambulatory care recipients with transference, toileting, bathing, and other personal hygiene needs, feeding (if needed), and ensuring that medicine is taken. Help with instrumental activities of daily living (IADLs) includes providing assistance in such activities as food preparation, shopping, running errands, paying bills, providing transportation, and meeting with medical and rehabilitative personnel on behalf of the care recipient (National Alliance for Caregiving in collaboration with AARP, 2009).

Results of the Home Alone study (AARP with United Health Hospital Fund, 2012) clearly show how challenging caregiver tasks are when there is a need to provide complex chronic care. Nearly half of the caregivers surveyed (46% or 777) performed medical and nursing tasks. More than 96% (747) also provided ADL supports (e.g., personal hygiene, dressing/undressing, or getting in and out of bed) or IADL support (e.g., taking prescribed medications, shopping for groceries, transportation, or using technology) or both. Of these caregivers nearly two-thirds (501) reported that they did all three types of tasks. Of the nonmedical family caregivers, two-thirds (605) provided IADL

assistance only (AARP with United Health Hospital Fund, 2012; Reinhard, Levine, & Samis, 2012).

Family caregivers also provide more intangible types of care such as psychological, spiritual, and emotional support. The close relationship between the caregiver and care recipient is a shared relationship with involved emotions, experiences, and memories (Alzheimer's Association, 2011). This type of support bolsters self-confidence, helps the care recipient to adjust to restrictions brought on by disabling conditions, facilitates acceptance of new physical realities and self-image, and/or prepares the care recipient for the end of life.

## Caregiver Roles

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Caregivers tend to function in primary or secondary roles (Keith, 1995). Primary caregivers are those who bear the heaviest responsibility for daily care, while secondary care providers, often other relatives and friends who function as partners or within teams, provide more limited support. Although men are increasingly functioning as primary family caregivers, the typical primary family caregiver is a mature (average age is 48 years), working woman who is providing 20 hours or more of unpaid care for an aging parent, usually her mother. Hence, the term, "sandwich generation" speaks to the difficulties often experienced by women caregivers who find themselves caring for an ill family member, sometimes from a long distance, while still working and often parenting children or young adults.

Children and young adults between 8 and 18 years of age participate actively in family caregiving as well, although most are not the sole providers. There are an estimated 1.3 to 1.4 million child caregivers nationally. Child caregivers tend to live in households with lower incomes than do noncaregivers. Most are caring for a parent or a grandparent and are less likely to live in two-parent households. Alzheimer's disease is the most common care recipient's condition (National Alliance for Caregiving & the United Hospital Fund, 2005).

Psychological and emotional support are also part of the secondary caregiver's role. Secondary caregivers, often other