



GIVING AND CARING: A RESOURCE BOOKLET FOR DEMENTIA CAREGIVERS

“There are only four kinds of people in the world:
those who have been caregivers,
those who are currently caregivers,
those who will be caregivers, and
those who will need caregivers.”

- Rosalynn Carter, former First Lady of the United States



Lakeland Regional Medical Center hopes that you find the following information useful as you continue your important work as a caregiver.

Research has demonstrated that by promoting caregiver skills in problem solving, stress management, management of problem behaviors, and working with the health care system, caregivers can be made both more effective and more resilient.

(Rosalynn Carter Institute for Caregiving).

TABLE OF CONTENTS

What is a Caregiver?page 3

Who are the Family Caregivers?page 3

Family Meetingspage 4

Questions for the Family or Caregiving Teampage 4

Caregiver Stress Quizpage 5

Suggestions for Caregiverspage 5

Caregiver Dollarspage 6

Caregiver Checklistpage 7

Financial Issues and Resourcespage 8

Caregiver Resourcespage 8

Commonly Used Termspage 10

“Alone we can do so little, together we can do so much.”

- Helen Keller



WHAT IS A CAREGIVER? ¹

A caregiver is any relative, partner, friend, or neighbor who has a significant personal relationship with and provides a broad range of assistance for an older person or adult with a chronic or disabling condition. These individuals may be the sole caregiver or one of several that live with or separately from the person receiving care.

WHO ARE THE FAMILY CAREGIVERS? ²

An estimated 44 million Americans, ages 18 years and older, provide unpaid assistance and support to older people and adults who live in the community (outside of a healthcare facility). Types of caregivers vary, but research on this group reveals some themes:

- Women outnumber men (about 2:1)
- Most are middle aged (35-64 years old) and married or living with a partner
- Most (83%) are relatives of the person they are caring for, including daughters/sons, spouses, grandchildren and siblings
- About 1 in 4 (24%) caregivers live with or close to the person they are caring for; about 4 in 10 (42%) are no more than 20 minutes away from the person they are caring for
- About half of the caregivers (48%) are employed at full time jobs
- The amount of care given on a weekly basis varies widely. Nearly half provide fewer than 8 hours of caregiving, but 1 in 5 caregivers provide more than 40 hours a week of care
- Caregiving goes on for a long time- an average of 4.3 years.

Plain and simple, being a caregiver is hard work! Many caregivers describe health problems as a result of their caregiving activities. Depressive symptoms and mental health problems occur more frequently in caregivers than in non-caregiving peers. The majority of caregivers find it difficult to balance work and family responsibilities, along with managing emotional and physical stress. With this in mind, caregivers are often unaware of support services available to them. A recent study of Alzheimer's caregivers found that 75% had unmet needs; only 9% used respite services and only 11% participated in support groups. ³

When family members receive caregiver support services, including counseling, information, and ongoing support, people with moderate dementia have been able to defer nursing home placement by nearly a year. ⁴

1. Family Caregiver Alliance, a program of the National Center on Caregiving.

2. Caregiving in the United States, National Alliance for Caregivers and AARP (2004).

3. Families Care: Alzheimers Caregiving in the United States, National Alliance for Caregivers and AARP (2004).

4. Mittelman MS, Ferris SH, Shulman E, Steinberg G, Ambinder A, Mackell JA. A comprehensive Support Program: Effect on Depression in Spouse-Caregiver of Alzheimer Disease Patients. *The Gerontologist* (1995). 35: 792-802.



FAMILY MEETINGS

Communication is the key! Especially when important caregiving decisions are being made, family meetings are effective means of discussing difficult topics.

If families are unable to meet in the same location, a conference call or speaker phone call may be helpful.

Organizing a family meeting provides a structured environment for open and on-going discussions. Not all issues can be solved; compromise is often the best solution.

Recognize that asking for assistance is a healthy way to approach the task of caregiving for your loved one. Group your needs/tasks into categories, such as transportation, meals, or visitation. For example, some helpers are comfortable cooking and delivering meals, but do not want the responsibility of transportation- and vice versa.

Remember that family members may be at very different places emotionally. Some may feel overwhelmed, frightened, or not at all comfortable at the possibility of caring for an older or sick person. Some may want to be in charge and 'run the show.' Some may be already grieving the current losses or the probable losses ahead.

Be patient with one another. To keep everyone informed and to meet changing care needs as they occur, family meetings need to occur on a regular basis. 'Thank you' is always appreciated by the caregiver.

QUESTIONS FOR THE FAMILY OR CAREGIVING TEAM

Some questions that families may want to consider, ensuring that all care needs are met

Who will be the primary caregiver? How much involvement will other members have? How do caregivers share information? (phone calls, emails, face-to-face meetings)

Which responsibilities will other family members have? Which responsibilities can be shared? (medical appointments, shopping and errands, daycare, phone calls to insurance companies, medication administration, and meals)

If secondary caregivers live far away, can money be sent to provide respite for primary caregiver?

Can caregivers plan a calendar for visits- both for benefit of patient and to allow for respite for primary caregiver?

Does everyone have access to important legal and financial papers? (wills, insurance policies, retirement and banking accounts)

Does everyone know the patient's end-of-life concerns or wishes? (advance directives, DNR orders, funeral and burial plans)



CAREGIVER STRESS CHECK

Source: Alzheimer's Association, 2009

You may be so concerned about caring for someone else that you do not realize you could be putting your own health at risk. The following check list may offer new insights.

- Do you feel like you have to do it all yourself- and that you should be doing more?
- Do you feel withdrawn from family, friends and activities that you used to enjoy?
- Do you worry that the person you care for is safe?
- Do you feel anxious about money and healthcare decisions?
- Do you deny the impact of the disease and its effects on your family?
- Do you feel grief or sadness that your relationship with the patient isn't what it used to be?
- Do you get frustrated and angry when the patient continually repeats things and does not seem to listen?
- Do you have health problems that are taking a toll on you?

There are things you can do to stay healthy, making you a more effective caregiver. It is suggested that you make time for yourself, by consulting your own doctor and contacting various community agencies for a full range of support services. Find the complete 'Caregiver Stress Check,' with helpful resources, at <http://www.alz.org/stress-check/>.

SUGGESTIONS FOR CAREGIVERS

Caring for the caregiver

1. Self-care is important: maintaining good nutrition and plenty of rest, planning proper exercise, taking a real respite, and recognizing your own strengths and limitations.
2. Know what community resources are available (see page 8).
3. Ask others for help- family, friends, and community resources. No one can do it all by themselves. When people offer to help- say yes! Keep a list of specific things others can provide (yard work, running errands, making phone call, cooking, cleaning, transportation, buying groceries, helping with children).
4. Attend a support group- you will gain understanding and support from others facing similar issues, and learn about many caregiving training and educational offerings
5. Health care for yourself is vital- have an annual physical, get a flu vaccination and keep your own medical and dental appointments.



6. Include positive ways to renew your soul: such as spiritual or faith-based services, inspirational music or poetry. Most hospitals, hospices and healthcare facilities have non-denominational chaplains, if you do not already have existing spiritual support.
7. Keep a journal: writing out your feelings and emotions helps put them in perspective and can be a stress reliever.
8. Take time to enjoy special things: continue with hobbies, spend time with friends and remember to laugh and celebrate small joys in your day.
9. Have a clear back-up plan in case you are temporarily or permanently unable to be the caregiver.
10. Do express your feelings to those you care about.

CAREGIVING DOLLARS

Items and services that might meet your caregiving needs

- An Adult Day Program allows the caregiver the ability to get rest or stay employed.
- Durable Medical Equipment – bath benches, raised toilet seats or safety bars
- An ID or medical alert bracelet, especially for those with dementia or chronic medical conditions
- A personal emergency response system to summon help, if needed
- Home delivered meals
- A personal care attendant
- Weekly housekeeping services; chore services for lawn and household repairs
- A personal wandering alarm OR home and door alarms to support safety of a loved one
- Legal services to assist with questions, prepare legal papers, get personal affairs in order
- In-house or group respite services to allow for personal needs of caregiver

(Source: Kris Maxham, staff author for Today's Caregiver Magazine/Caregiver.com)



CAREGIVER CHECKLIST

Your best defense against a caregiving crisis! Give to other family members; keep list in a visible place in the home

List of Doctors

Names, addresses, and phone numbers; identify specialties, such as dentist, podiatrist, audiologist, vision care, and primary care.

List of prescription medications

Include prescribing physician, strength and dosage of medication, purpose, special instructions and dispensing pharmacy (include phone number)

List of over-the-counter medications

Include minor pain relievers, vitamins, supplements and herbal medications

Medical information

Include diagnosis and other related conditions, previous surgeries, chronic conditions, alcohol use, smoking history, all allergies (food, medication, latex, etc)

Legal and financial information

Names and contact information of lawyers, bank and safe deposit information, documentation of prepaid funeral arrangements, veteran status, advance directives (health care surrogate, durable power of attorney, living will, estate will)

Insurance

Names and contact information for medical, life, long-term care, auto, property insurances

Local contacts

Names and contact information for clergy, relatives, neighbors, friends, care manager

Local services

Hospital preference, adult day care, assisted living facilities, nursing homes, home health agencies, companion services, meals-on-wheels, restaurants that deliver

Personal information of patient

Birthplace, previous occupation, favorite foods and activities, daily routine, hobbies, musical preference, religion, previous military service, things that upset them/calm them. Include name and contact information for any pet care (veterinarian and groomer).

(adapted from the University of South Florida's Eric Pfeiffer Suncoast Alzheimer's Center; updated February 2009)



FINANCIAL ISSUES AND RESOURCES

Available for your benefit

Benefits Check-up: www.benefitscheckup.org provided by National Council on Aging; helps people over age 55 to find federal, state and local programs (public and private) that may pay for some of their medical care and/or prescription costs.

Insurance Consumer Hotline: 1-800-342-2762

Long-term Care / SHINE (Serving Health Insurance Needs for Elders): 1-800-963-5337 (1-800-96-ELDER); www.floridashine.org/longtermcare.html

Medicaid Recipient Services: 1-800-392-2161

Medicare: 1-800-633-4227; www.medicare.gov

Partnership for Prescription Assistance: www.helpingpatients.org/ has all the information related to discount and free programs offered by various pharmaceutical companies.

Social Security: 1-800-772-1213; www.socialsecurity.gov

Veterans Benefits: Polk County office 863-534-5225 or 863-534-5220

CAREGIVER RESOURCES

Internet and local resources

AARP: Countless information on caregiving, plus the latest books, news and tips, located on the AARP website. www.aarp.org/family/caregiving/

Alzheimer's Association: Extensive resources; including the four-part HBO series The Alzheimer's Project. 1-800-272-3900 www.alz.org

Caregiver Media Group: Produces Today's Caregiver, (one year magazine subscription is \$18.00 for 6 issues), as well as other books. www.caregiver.com

Caregiver Support Services: Features the Family Caregiving Training program (seven information-packed topics through the American Red Cross). Topics such as: Positioning and Helping Your Loved One Move; Assisting with Personal Care; and Home Safety. Each topic is \$25.00. 1-402-502-1764 www.caregiversupportservices.org

Caregiving.com: Insights, information and inspirations. www.caregiving.com



- CareGuide@Home:** Has multiple on-line resource guides, such as: Health and Well Being, Mind and Memory, Care at Home, Living Alternatives. www.eldercare.com
- Eldercare:** The Eldercare Locator, which locates state and local agencies by zipcode. 1-800-677-1116 www.eldercare.gov
- Family Caregiver Alliance:** First community-based nonprofit organization in the country to address the needs of families and friends providing long-term care at home; offers programs at national, state and local levels to support caregivers. www.caregiver.org
- National Alliance for Caregiving:** Provides information and education, such as the Family Caregiving 101: an online resource dealing with the challenges of caregiving. www.caregiving.org
- National Association of Professional Geriatric Care Managers:** 1-520-881-8008 www.caremanager.org
- National Family Caregivers Association (NFCA):** Has multiple on-line brochures, such as Improving Doctor Caregiver Communication. 1-800-896-3650 www.thefamilycaregiver.org
- Polk County Elderly Services:** 1-863-534-5320
- Polk County Family Caregivers, Inc.:** Personal/family membership \$15.00/year. www.polkcaregivers.org
- Rosalynn Carter Institute for Caregiving:** Supports individuals and caregivers coping with chronic illness and disability across the lifespan. www.rosalynncarter.org
- The Savvy Senior:** A national information service devoted to older Americans, provides nationally syndicated newspaper column, senior newswire service, resource books, weekly radio program and television features on NBC, CNBC, CNN and Retirement Living TV. www.eldercare.gov
- The Well Spouse Foundation:** A membership organization (\$25 per year), the foundation advocates for and addresses the needs of individuals caring for a chronically ill and/or disabled spouse/partner. Offers a newsletter and support groups. www.wellspouse.org
- US Administration on Aging:** Helps the elderly maintain their dignity and independence through comprehensive, coordinated, and cost effective systems of long-term care, and livable communities. 1-202-619-0724 www.aoa.gov



BOOKS IN PRINT

Available in Amazon.com and similar sites as of July 2009

Barbara J Bridges; *Therapeutic Caregiving: a Practical Guide for Caregivers of Persons with Alzheimer's and Other Dementia Causing Diseases.*

Beth Witrogen McLeod; *Caregiving: The Spiritual Journey of Love, Loss and Renewal.*

James R. Dowling; *Keeping Busy: A Handbook of Activities for Persons with Dementia.*

Jitka M. Zgola; *Care That Works: A Relationship Approach to Persons with Dementia.*

Lynda A. Markut and Anatole Crane; *Dementia Caregivers Share Their Stories: A Support Group in a Book.*

Starr Calo-oy and Bob Calo-oy; *Caregiving Tips A-Z: Alzheimers and Other Dementias.*

COMMONLY USED TERMS

Activities of Daily Living (ADLs)- everyday tasks such as dressing, eating, bathing, grooming, taking medication, and other personal care activities. The need for assistance or the inability to perform ADLs is used to determine eligibility for many government services, including Medicaid.

Advance Directives- statements made by an adult who has the capacity to make known their preferences for future medical treatment, also known as a Living Will. It's About How You LIVE is a national campaign encouraging individuals to make informed decisions about end-of-life care (www.caringinfo.org). The campaign encourages people to:

- Learn about options for end-of-life services and care
- Implement plans to ensure wishes are honored
- Voice decisions to family, friends and healthcare providers
- Engage in personal or community efforts to improve end-of-life care

Alzheimer's Disease- most common form of dementia. This incurable, degenerative, and terminal disease was first described by German psychiatrist and neuropathologist Alois Alzheimer in 1906 and was named after him.

Assisted Living Facility (ALF)- used for people that cannot continue to live independently. These provide housing, personalized support services and health care. Residents cannot be bedridden, cannot have stage 3 or 4 pressure ulcers and cannot require 24 hour nursing services. An ALF is not required to have a licensed nurse on staff.



Dementia- means “deprived of mind,” and refers to the progressive decline in mental function due to damage or disease in the body beyond what might be expected from normal aging. Causes multiple changes: memory loss, inability to communicate, and inability with activities of daily living.

Do Not Resuscitate Order (DNRO)- a physician’s order for the withholding of futile life-sustaining treatment; generally used when a patient has a terminal illness, a persistent vegetative state or an end-stage condition. It is very helpful for loved ones to discuss this prior to any decline in health or functional status. Detailed information available at Florida Department of Health: www.doh.state.fl.us/demo/trauma/dnro.html

Durable Power of Attorney- a choice made by an adult who has the capacity to make decisions; a trustee is appointed to make legal and/or financial decisions on his/her behalf when that person is unable to make those decisions.

Durable Power of Attorney for Healthcare- also known as a healthcare surrogate or medical power of attorney; a choice made by an adult who has the capacity to make decisions; a trustee is appointed to make healthcare decisions on his/her behalf when that person is unable to make those decisions.

Geriatric Care Managers- healthcare professionals, most often social workers, who help families in dealing with the problems and challenges associated with caring for the elderly.

Hospice- short-term, supportive care for the terminally ill (life expectancy of 6 months or less) that focuses on pain and symptom management. Care focuses on physical, emotional and spiritual support for the patient and family.

Living Will- also known as an Advance Directive; a document (often pre-printed) that indicates a person’s written instructions for medical treatment (or withholding/withdrawing of medical treatment) and is used only when the person is unable to express their wishes. Information available via Lakeland Regional Medical Center (www.lrmc.com): choose the Patients & Visitors tab, click in the sidebar entitled Advance Directives/Living Wills.

Palliative Care- active holistic care of patients with a life-limiting illness; manages pain and symptoms, along with psychological and spiritual support and advance care planning. The goal is quality of life for both patients and their families.

Respite- care that is temporarily provided by someone else so that the everyday caregiver can tend to errands, personal health needs, or physical and emotional renewal.

Skilled Nursing Facility (SNF)/Long-Term Care Facility (LTC)- used for individuals requiring skilled nursing care beyond the acute-care hospital setting, perhaps for rehabilitation or for long-term “nursing home” level of care.

