

# Are You A Caregiver?

**Are you providing unpaid assistance to a spouse, relative, or friend who is ill, disabled, or needs help with basic activities of daily living?** Do you help with rides to the doctor, shopping, meals, bill paying, bathing, grooming, dressing, walking or transferring to a wheelchair, housekeeping, managing medications, or arranging services to be provided by others? If you provide services like these, whether or not you live with the person you are helping, you are a caregiver.

You are not alone. A study by the National Alliance for Caregiving and AARP found that 22.4 million households, or about one in four households in the U.S., is involved in providing care to someone fifty or over. More than half of all caregivers are employed full or part-time, and some are caring for children at the same time. Many of us will be caregivers several times during our lifetimes.

Caregiving provides opportunities to demonstrate love and commitment, to share special moments, to resolve relationships, and to live in integrity with spiritual and cultural beliefs. These meaningful experiences may be coupled with exhaustion, inadequate resources, and failure to take care of oneself while caregiving.

We have learned that the earlier help is accepted by a caregiver, the longer that person can continue caregiving, with less risk to the caregiver's physical and mental health. If not freely offered, help may be requested from extended family, friends, neighbors, and place of worship. This is called informal support, and every caregiver needs this type of help. Assistance may also come from formal programs for seniors and caregivers.

This *Caregiver Handbook* has been written to let you, a caregiver for someone sixty or over in Pinellas County, Florida, know about resources that may provide you with knowledge, support, and relief. Among these resources are books, videos, Internet web sites, support groups, and formal services available in Pinellas County. Some of these are also available throughout Florida or nationwide for long-distance caregivers. Also included in this handbook are descriptions of various stages of caregiving and step-by-step suggestions for preparing for each stage so as to have the most positive experience possible. We hope you enjoy this *Caregiver Handbook* and find it useful.

# How To Use This Handbook

One of the hardest things about being a caregiver is isolation, the sense of being alone with a difficult job to do. The *Caregiver Handbook* was written to let you know that you are not alone and that there are resources to help you. We hope this book will make it easier for you to identify your needs, make educated decisions, and find relief and joy throughout your caregiving experience.

The *Caregiver Handbook* is divided into sections separated by tabs for quick reference. Using a three-ring binder with tabs was the printing style most requested by caregivers and professionals who reviewed the draft *Caregiver Handbook*. A three-ring binder allows for future additions and deletions and for a section with personal caregiving information. Listed below are the different parts of the Handbook.

**For information about the services or programs described in this Handbook, call the Senior Helpline at 800-96-ELDER (800-963-5337) in Pinellas or 727-217-8111 in other areas of Florida.**

## Introduction and Glossaries

This section includes “Are You a Caregiver” and “How to Use This Handbook”. We hope you will take time to read these three pages, since they provide an introduction to the *Caregiver Handbook* and how to make best use of it. A “Glossary of Terms” and “Glossary of Acronyms” follow. You may want to start reading other sections of the Handbook and come back to these glossaries as needed.

## The Four Stages of Caregiving

The **Four Stages of Caregiving** covers caregiving from beginning to heavy home care to nursing home and end-of-life care. Each stage opens with a short overview about what to expect followed by caregiving topics appropriate for that stage. You may see yourself in one of these stages, and planning ahead may make it easier to face the next stage with confidence. Caregiving issues are explained, and Pinellas County resources of many types are described. Some state and national resources are mentioned, also.

The **Four Stages of Caregiving** can be read like a step-by-step instruction manual, one stage after another, or you may want to read the overviews and then skip around, choosing a topic that interests you and saving the rest for another time. Each of the four stages, separated by tabs in the *Caregiver Handbook*, is listed below with a short description of what is covered. See the Table of Contents for all topics.

## Stage One: Getting Started

Recognize the impact of caregiving on your life and family, learn how to be a caregiver, and find out more about the older person who needs care.

## **Stage Two: Finding Help**

Accept help from family, friends, place of worship, support groups, and formal services. Learn about help for working caregivers.

## **Stage Three: Heavy Care**

Prevent caregiver burnout and injury while providing heavy care, protect your care receiver's health and safety, and consider facility care.

## **Stage Four: Letting Go**

Resolve relationships, complete end-of-life decisions, use hospice care, let yourself grieve, care for yourself, and have a plan for your life after caregiving has ended.

## **More Resources and Tips**

More Resources and Tips includes resource lists and caregiver tips. See this section for more information about the Caregiver's REST Project, which produced the *Caregiver Handbook* and a caregiver web site.

## **Recommended Books, Videos, and Web Sites**

Recommended Books and Videos includes reviews of some of our favorites. Recommended Web Sites is alphabetized under national, state, and local categories as requested by caregivers who reviewed the draft Handbook. Commercial as well as government web sites are listed with a short review of each site.

## **Personal Planner**

Use this section to expand the *Caregiver Handbook* into a Caregiver Notebook with personal information to help you with caregiving. Suggested additions are caregiver workshop notes, a calendar, doctor's instructions, medical history, forms and caregiver tips printed from web sites, medications chart, important family information or at least emergency contacts, care receiver likes and dislikes, and other information that may be helpful to you and to substitute caregivers. We hope you will take time to fill this section of the *Caregiver Handbook*, which was left empty for this purpose.

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**Note:** Throughout the *Caregiver Handbook*, we will include web sites that may be helpful. Often, we will refer to another section of the *Caregiver Handbook*, the Senior Helpline's *Senior Resource Directory*, the Senior Helpline, and toll-free information lines as other ways to find similar information.

# Glossary of Terms

This glossary covers many terms used in the fields of caregiving and aging. Some of these terms appear in the *Caregiver Handbook*, and you may hear others when trying to find services. This is not a complete list of terms, and this list is not meant as an endorsement. See your legal, medical, or financial advisor if you have questions. A Glossary of Acronyms follows. **You may want to start reading the Four Stages of Caregiving and return to this section as needed for reference.**

**Access Services:** Those services and activities designed to enhance and facilitate the awareness of and participation in programs available to elders. Examples are information and referral, outreach, and transportation (see definitions below).

**Activities of Daily Living (ADLs):** These activities include assistance with eating, feeding, transferring, dressing, bathing, walking, toileting and self-administration of medications. Widely used as a basis for assessing functional status.

**Administration on Aging (AoA):** The official federal agency dedicated to implement programs that provide supportive home and community-based services to older persons and their caregivers. Each year the Department receives millions of dollars in federal funds from AoA to contract with the regional area agencies on aging.

**Administrator:** A person licensed to run a nursing home; one who has received training in fiscal, legal, social and medical aspects of running an institution.

**Adult Family Care Home:** A full-time, family-type living arrangement, licensed by the Agency for Health Care Administration in which a person or persons provide room, board, and one or more personal services, as appropriate for the level of functional impairment for three or fewer non-relatives who are elders or disabled adults placed in the home by the Florida Department of Children and Families.

**Advisory Council:** A voluntary group of citizens who provide information, guidance, advice, and support to the Area Agencies on Aging to develop, coordinate, and administer services to elders. The Department of Elder Affairs also has an advisory Council, as do some service providers.

**Aging Network:** The agencies and organizations at the local, state, and national level involved in serving and/ or representing the needs of elders. Participants may be involved in service systems development, advocacy, planning, research, coordination, policy development, training and education, administration, and direct service provision.

**Alzheimer's Disease:** A progressive, irreversible form of dementia. It is the most common form of dementia that affects 5% of those over 65 and 20% of those over 80. The cause of the disease is unknown at this time. Symptoms begin with loss of memory and rational thinking and usually progresses to total disability over a number of years. Its effects are mainly on the mind, not the physical body.

**Ancillary Services:** Those services needed by a nursing home resident, but not provided by the nursing home, such as podiatry and dental services. Ancillary services may not be included in the basic rate of the facility.

**Area Agency on Aging (AAA):** A quasi-governmental entity mandated by the Older Americans Act. A public or nonprofit private agency or office designated by the Department of Elder Affairs to coordinate and administer the Department's programs and to provide, through contracting agencies, service within a planning and service area (PSA). The area agencies on aging are used as the state network at the district level.

**Area Plan:** Document submitted by the Area Agency on Aging to the state unit on aging which identifies and prioritizes needs and specifies how needs will be met through service provision and other activities for the period of the plan.

**Assessment:** A written evaluation of needs completed by a social worker, nurse, or other professional and used to determine eligibility and priority for some services and to help with developing a care plan.

**Assisted Living Facility (ALF):** A residential facility which provides food service and one or more personal services for four or more adults who require such services or provides extended congregate care, limited nursing services, or limited mental health services when specifically licensed to do so by Agency for Health Care Administration.

**Benefit Period:** A way of measuring the claimant's use of services under Medicare's Hospital Insurance. The claimant's first Benefit Period starts the first time he/she enters a hospital after his hospital insurance begins. When the claimant has been out of a hospital (or other facility primarily providing skilled nursing or rehabilitation services) for 60 days in a row, a new benefit period starts the next time he enters the hospital. There is no limit to the number of benefit periods a person can have.

**Care Manager/Case Manager:** A social worker, nurse, or other professional who assesses needs and helps families plan and arrange informal and formal services.

**Care Plan:** A plan made by a care manager to help a family plan and arrange informal and formal services after an assessment is completed.

**Charge Nurse:** A Licensed Practical Nurse (LPN) or Registered Nurse (RN) who is responsible for supervising the aides of a given unit, dispensing medication, providing patient care, etc.

**Coinsurance:** The amount, usually 20% of Medicare allowed charges, that are not reimbursed by the Medicare program.

**Community Focal Point:** A central place in a community which is designated by the AAA for bringing together a full range of services for elders.

**Continent:** Ability to control the passage of urine and feces. The opposite is incontinent or unable to control the passage of urine or feces.

**Custodial Care:** Care that attempts to maintain a person at an existing level and that does not involve any skilled rehabilitation or nursing services. See also Personal Care.

**Director of Nursing:** A Registered Nurse (RN) who oversees the nursing department, including nursing supervisors, Licensed Practical Nurses, nurses aides and orderlies. The Director of Nursing writes job descriptions, hires and fires the nursing staff and writes and executes procedures and policies for nursing practice.

**Do Not Resuscitate Order (DNR):** A code or order usually appearing in a patient's medical record indicating that in the event the heart and/or breathing stops, no intervention be undertaken by staff. Death occurs undisturbed. This does not mean that the individual does not receive care. Continuing care is provided as it would to any individual (medications for pain, antibiotics, etc.) except as stated above.

**Durable Medical Equipment (DME):** As defined by Medicare, DME is equipment that 1) can withstand repeated use, 2) is primarily and customarily used to serve a medical purpose, 3) is generally not useful to a person in the absence of an illness or injury, and 4) is appropriate for use in the home. Examples include oxygen and wheelchairs.

**Durable Power of Attorney:** A Power of Attorney not affected by subsequent disability of the individual.

**General Revenue (GR):** The fund which consists of all moneys received by the State from every source. The State's General Revenue Fund accounts for all the assets and resources used for the general administration of the State and in the provision of services to people of the State.

**Greatest Economic Need:** An income level at or below the poverty level established by the Bureau of the Census.

**Greatest Social Need:** Non-economic factors which include physical and mental disabilities, language barriers, cultural or social isolation, including that caused by racial or ethnic status which restrict an individual's ability to perform normal daily tasks or which threaten his/her capacity to live independently.

**Health Care Financing Administration (HCFA):** An executive department of the Department of Health and Human Services that has ultimate authority over Medicare and Medicaid.

**Health Maintenance Organization (HMO):** An organization that, for a prepaid fee, provides a comprehensive range of health maintenance and treatment services (including hospitalization, preventive care, diagnosis and nursing). HMOs are sponsored by large employers, labor unions, medical schools, hospitals, medical clinics and insurance companies.

**Home Health Agency (HHA):** A public or private agency certified by Medicare that specializes in providing skilled nurses, homemakers, home health aides and therapeutic services, such as physical therapy or occupational therapy in an individual's home.

**Home Health Care:** Health services provided in the homes of the elderly, disabled, sick or convalescent. Services provided include nursing care, social services, home health aide and homemaking services, and various rehabilitation

**Homemaker or Home Health Aid:** A person who is paid to help in the home with agencies make a distinction between homemaking (or housekeeping) services and personal care services.

**Hospice Care:** Care that addresses the physical, spiritual, emotional, psychological, social, financial and legal needs of the dying patient and his/her family. A concept that refers to enhancing the dying person's quality of life. Hospice care can be given in the home, a special hospice facility or a combination of both.

**Incapacitated Adult:** A legally incapacitated person is someone who is impaired by sickness, accident, injury, mental illness, mental disability, chronic use of drugs, chronic intoxication or any other causes, to the extent that the person does not have sufficient understanding or ability to make or communicate responsible decisions concerning his/her day-to-day care.

**Informal Support:** Help from families, friends, faith communities/place of worship, and others who are not part of government-funded or private-pay formal support services.

**Institutionalization:** Admission of an individual to an institution, such as a nursing home, where he or she will reside for an extended period of time or indefinitely.

**Lead Agency:** An agency designated at least once every three years by an area agency on aging as a result of a request for proposal process. The lead agency coordinates some or all of the services, either directly or through subcontracts, for functionally impaired elderly persons.

**Living Will:** A document stating that describes a person's wishes with respect to the use of heroic life support measures to maintain one's life.

**Local Services Program (LSP):** A program that provided continued funding for various community-based services originally provided through Title XX. The areas receiving services are designated by legislative proviso or specific appropriations.

**Long-Term Care:** Term used to represent a range of services that address the health, social, and personal care needs of individuals delivered over a long period of time to persons who have never developed or have lost some capacity for self care.

**Managed Care:** Used as a description for an entire array of programs. Generally, managed care implies that there is some form of influence in the delivery of health

care by persons other than the caregiver and patient. It includes quality assurance, aggressive care management, coordination of care, control to manage costs, and peer review and data gathering and dissemination to providers. A primary care physician or other gatekeeper opens the door to the various specialists.

**Medicaid:** A state-administered medical assistance program that serves low-income families, those 65 and older, people who are blind, and people who are disabled. One must apply and qualify before one is eligible for Medicaid coverage. The Department of Children and Family Services' Medicaid Economic Services office determines financial eligibility for Medicaid services. Financial requirements for Medicaid eligibility are based on assets and income. The requirements are not universal for all Medicaid services; therefore, individuals may qualify for some Medicaid services but not others. There are additional medical eligibility requirements for Medicaid coverage of nursing home care. The Department of Elder Affairs' Comprehensive Assessment and Review for Long-Term Care Services (CARES) office determines medical eligibility for nursing home placement under the Medicaid program.

**Medicaid Waivers:** Programs for which the federal Omnibus Budget Reconciliation Act of 1981 authorized the Secretary of Health and Human Services (HHS) to waive federal requirements to allow states to provide home and community-based services to individuals who would require institutionalization without these services. Florida Medicaid has 13 waivers, four of which the Department of Elder Affairs coordinates.

**Medicare:** A federal health insurance program that serves people 65 and older and those with certain disabilities, regardless of income. Medicare has two parts, Part A (Hospital insurance) and Part B (Medical insurance). Qualified individuals are automatically enrolled in Medicare Part A, but must apply to become eligible for Part B coverage. Medicare generally pays for the first twenty days in a nursing home following a hospital stay of at least three days. Medicare generally pays a portion of the nursing home bill (after the first 20 days) for up to 100 days per year.

**Medigap Insurance:** These policies are sold by private insurance companies. They are specifically designed to help pay health care expenses either not covered or not fully covered by Medicare.

**Multi-purpose Senior Center:** A community facility which provides a wide range of supportive services including health, nutrition, social, and education; and is a facility for recreation and group activities for elders. AAAs are urged by the Older Americans Act to designate them as community focal points.

**Needs Assessment:** Collecting, analyzing, and interpreting data about the problems of elders which could be solved by provision of supportive services and which is used in planning, policy formulation, program planning, service development and advocacy activities.

**Nursing Home (NH)** – a facility that provides custodial and personal and/or nursing care for persons who are unable to care for themselves.

**Older Americans Act:** Law enacted in 1965 (PL 89-73) that gives elderly citizens more opportunity to participate in and receive the benefits of modern society. For example, adequate housing, income, employment, nutrition and health care.

**Ombudsman:** A "citizen's representative" in a nursing home who protects a person's rights through advocacy, providing information and encouraging institutions to respect citizens' rights.

**Optional State Supplementation (OSS)** – OSS is a cash assistance program administered by the Department of Children and Families. Its purpose is to supplement a person's income to help pay for costs in a special living arrangement. It is not a Medicaid program. This Program has been re-designed to provide the state funds for the federal Medicaid match to create Assistive Care Services.

**Personal Care:** Care that involves help with eating, dressing, walking and other personal needs but very little or no nursing supervision. The terms "custodial care," "domiciliary care" and "residential care" are often used interchangeably with personal care, although personal care strictly defined may imply a somewhat higher level of service.

**Planning and Service Area (PSA):** A geographical area in the state that is designated for the purposes of planning, development, delivery and overall administration of services under an area plan, under the jurisdiction of an Area Agency on Aging.

**Power of Attorney:** The simplest and least expensive legal device for authorizing a person to manage the affairs of another. In essence, it is a written agreement, usually with a close relative, an attorney, business associate or financial advisor, authorizing that person to sign documents and conduct transactions on the individual's behalf. The individual can delegate as much or as little power as desired and end the arrangement at any time.

**Representative Payee:** An individual who has been chosen by the Social Security Administration (SSA) and who agrees to receive a Social Security or SSI recipient's check and to handle the funds in the best interest of the recipient.

**Resident Rights:** Those rights prescribed by federal law for residents of nursing facilities and other types of institutions that participate in Medicare and Medicaid.

**Respite:** The in-home care of a chronically ill beneficiary intended to give the caregiver a rest. Can also be provided by a hospice or a nursing facility.

**Request for Proposals (RFP):** Method used by AAA's to seek competitive bids from persons/ groups wishing to provide services. Specifies the requirements.

**Senior Center:** A community facility for the elderly. Senior centers provide a variety of activities for their members including any combination of recreational, educational, cultural or social events.

**Service Provider:** Any entity which is awarded a grant or contract to provide services.

**Skilled Care:** Institutional care that is less intensive than hospital care in its nursing and medical service, but which includes procedures whose administration requires the training and skills of an RN. Both Medicare and Medicaid reimburse for care at the skilled level.

**Social Security:** A national insurance program that provides income to workers when they retire or are disabled and to dependent survivors when a worker dies. Retirement payments are based on worker's earning during employment

**Social Security Administration (SSA):** The federal governmental agency that administers programs throughout the US by means of geographically defined regional offices and geographically defined district offices.

**Spend Down:** Under the Medicaid program, a method by which an individual establishes Medicaid eligibility by reducing gross income through incurring medical expenses until net income (after medical expenses) meets Medicaid financial requirements. A resident spends down when he/she is no longer sufficiently covered by a third-party payer (usually Medicare) and has exhausted all personal assets. The resident then becomes eligible for Medicaid coverage.

**State Plan on Aging:** Includes specific programmatic and fiscal commitments which the State Unit on Aging will administer over a multi-year period.

**State Unit on Aging (SUA):** An agency of state government (in Florida, the Department of Elder Affairs), which serves as the state focal point for all matters affecting elders; monitors Area Agencies on Aging.

**Targeting:** The direction of services and programs to a particular group of people, e.g., those in greatest economic or social need, with particular attention to low-income minority persons.

**Transfer of Assets:** Transfer of a potential Medicaid recipient's money or possessions to a third party, which may be interpreted under state and federal Medicaid law as an attempt to qualify the person for Medicaid when he/she would not otherwise be eligible. Medicaid regulations govern time frames and conditions which individuals may transfer assets to others without jeopardizing Medicaid eligibility.

# Glossary of Acronyms

<b>AAA</b>	Area Agency on Aging, also referred to as Area Agency.
<b>ALF</b>	Assisted Living Facility.
<b>ADI</b>	Alzheimer's Disease Initiative
<b>AOA</b>	Administration on Aging within the U.S. Department of Health and Human Services.
<b>CARES</b>	Comprehensive Assessment and Review of Long-term Care Services, (Medicaid nursing home pre-admission screening program).
<b>CCE</b>	Community Care for the Elderly Program.
<b>DCF</b>	Florida Department of Children and Families.
<b>DOEA</b>	Florida Department of Elder Affairs, also referred to as the Department.
<b>EHEAEP</b>	Emergency Home Energy Assistance for the Elderly Program.
<b>HCE</b>	Home Care for the Elderly Program.
<b>HHS</b>	United States Department of Health and Human Services.
<b>ICP</b>	Institutional Care Program.
<b>OAA</b>	Older Americans Act.
<b>OSS</b>	Optional State Supplementation Program.
<b>PSA</b>	Planning and Service Area.
<b>RFP</b>	Request for Proposals.
<b>SSI</b>	Supplemental Security Income Program.
<b>SUA</b>	State Unit on Aging.
<b>USDA</b>	United States Department of Agriculture

