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## Caregiving<sup>1</sup>

An estimated 19-22% of families across the U.S. may be caring for an adult with a cognitive impairment. Cognitive impairments include a variety of diseases and disorders such as Alzheimer's disease, Parkinson's disease, stroke, head injury or AIDS dementia. Although each disorder has its own unique features, family members and caregivers often share common problems, situations and strategies, regardless of the diagnosis.

Cognitively impaired persons typically require special care, including (often 24-hour) supervision, specialized communication techniques, management of bizarre or difficult behaviors, incontinence, and help with activities of daily living (ADLs), e.g., bathing, eating, transferring from bed to a chair or wheelchair, toileting and/or other personal care.

While each caregiving situation is different, caregivers are likely to experience enormous stress from their responsibilities in caring for a loved one. Many individuals become depressed or anxious and others report physical ailments associated with the stress of caregiving. For this reason, finding practical ways to cope and get help are especially important.

### Caring at Home

Caregivers often learn through trial and error the best ways to help an impaired relative maintain routines for eating, hygiene and other activities at home. Special training in the use of assistive equipment and managing difficult behaviors may be needed. It is also important to follow a **safety checklist**.

Be aware of potential dangers from:

- Fire hazards such as stoves, other appliances, cigarettes, lighters and matches;
- Sharp objects such as knives, razors and sewing needles;
- Poisons, medicines, hazardous house-hold products;
- Loose rugs, furniture and cluttered pathways;
- Inadequate lighting;
- Water heater temperature—adjust setting to avoid burns from hot water;
- Car keys and/or spark plugs—do not allow an impaired person to drive;
- Items outside that may cause falls, such as hoses, tools, gates.

Be sure to provide:

- Emergency exits, locks to secure house, and, if necessary, door alarms or an identification bracelet and a current photo;

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<sup>1</sup> Source: Family Caregiver Alliance in cooperation with the State of California's Caregiver Resource Centers, a statewide system of resource centers serving families and caregivers of brain-impaired adults. Funded by the California Department of Mental Health. Revised September 1999. ©All rights reserved.

- Bathroom grab bars, non-skid rugs, paper cups rather than glass;
- Supervision of food and alcohol consumption to ensure proper nutrition and to monitor intake of too much or too little food;
- Emergency phone numbers and information.

## **Managing Problem Behaviors**

Individuals with cognitive impairment may experience a range of behavioral problems including communication difficulties, perseveration (fixation on/repetition of an idea or activity), aggressive or impulsive behaviors, lack of motivation, memory problems, incontinence, poor judgment and wandering. Helpful suggestions for managing these problems include keeping language simple and asking one question at a time. Break down tasks and questions. For example, instead of asking, "would you like to come in and sit down and have a snack?", use simple commands such as, "come here," "sit down," and "here's a snack."

Wandering and poor judgment may signify the need for 24-hour supervision. Be sure to run through the home safety checklist. In addition, learn whom to contact in your community in case of an emergency. You may wish to consult with friends, family, church groups, social service agencies, senior centers and support groups. If wandering or aggressive behaviors are problems, contact with emergency police, fire and medical systems may be necessary. Further readings on behavior management strategies are included under the Recommended Readings section in this fact sheet.

## **Taking Care Of Yourself**

Some caregivers are reluctant to acknowledge the strain associated with the many tasks, responsibilities and long hours devoted to the caregiving role. Many feel overwhelmed or burned out. It is important not only to give yourself credit for the work you are doing as a caregiver, but also to arrange for some support and an occasional break from daily duties. While extended vacations may not be realistic, it is critical for everyone to schedule some relaxation time for themselves. This may be a short outing, quiet time at home, a visit with a friend, etc. In order to get time off, the caregiver may require respite care/assistance from others to stay with the patient.

Monitor your own health; stress may contribute to a variety of health problems. Balanced meals, adequate sleep, and attention to persistent ailments are essential ways to take care of yourself. They will also enhance your physical ability, coping skills and stamina to provide care. By taking care of yourself, you will be better able, both physically and emotionally, to provide care for your loved one.

The isolation often felt while caring for an impaired loved one at home can be devastating in itself. For many, this is eased by attending support group meetings with other persons in similar situations. Support groups provide emotional support and caregiving tips, as well as information on community resources from others who have learned from experience. Online support groups on the Internet can be very helpful. Therapeutic counseling may also be beneficial for further problem solving. A professional counselor can help you cope

with feelings of anger, frustration, guilt, loss, or competing personal, work and family demands.

## **Defining Needs and Planning for the Future**

Financial and legal planning are important to consider. Issues such as financing long-term care, protecting your assets, obtaining the authority for surrogate decision-making, and other matters often need attention. Make an appointment with an attorney knowledgeable in estate planning, probate, and, if possible, public benefits planning.

Other areas often requiring planning include coordination between community services and other involved friends and family members. Decisions about placement in a nursing home or other care options can often be facilitated by a professional familiar with brain impairments, caregiving and community resources.

It is a good idea to take some time to evaluate, in writing, both short and long-term needs. This can be done by first listing the things you may need help with, now or in the future. Next, list all your informal supports (e.g., family, friends, neighbors) and decide how each person might help meet the needs. List any advantages and disadvantages which might be involved in asking these people to help. Write down ideas for overcoming the disadvantages. Repeat the list for formal supports (e.g., community services, home care workers, day programs). It is important to set a time frame for any action or activities planned.

## **Does Your Home Meet Your Needs? A Checklist<sup>2</sup>**

According to a recent AARP housing survey, 83 percent of older Americans want to stay in their current homes for the rest of their lives. They find their homes comfortable and convenient and feel secure and independent there. However, as people age, the design of their homes plays an increasingly important role in how they manage their daily activities. Homes that were perfectly convenient at age 55 can cause problems in later years, as diminishing physical abilities make daily routines more difficult without some design modifications.

### What You Should Know **Take a good look at your home**

Simple alterations can prevent one-third of all home accidents. These changes not only increase your safety, but enhance your comfort and increase the likelihood of your remaining independent in your home and community. So it is important to look at your home with a critical eye. Use the checklist that follows to identify problem areas in every part of your house. On a separate sheet of paper, note any ideas you have for improvement. This example may give you an idea of how to chart your ideas:

<b>Area of the House</b>	<b>Yes</b>	<b>No</b>	<b>Ideas for Improvement</b>
<b>Kitchen</b> Are faucets easy to use?		x	Replace with lever handles.

Then make a list of your daily activities and what you like to do most. Your home should not be a roadblock to your goals. Review your checklist, compare it with your goals, and draw up a plan for modifying your home that will make your everyday living easier, safer, and more fulfilling.

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<sup>2</sup> Source: AARP Universal Design Homepage. For further assistance concerning home modifications, please refer to <http://www.aarp.org/universalhome/home.html>

**Look at your home as if for the first time...**

Answer the following questions for each room/area of the house. Write down any problems you find and your ideas for improvement.

Area of the House	Yes	No	Ideas for Improvement
<b>Windows/ Doors</b>			
Are windows/doors easy to open/close?			
Are locks sturdy/easy to operate?			
Are doors wide enough for a walker/wheelchair?			
Are door thresholds raised too high?			
Is there space to maneuver while opening/closing doors?			
Does the front door have a view panel?			
If so, is it at a proper height for you?			
<b>Floor Surfaces</b>			
Is the surface safe? Non-slip?			
Are there scatter rugs or door mats that may be dangerous?			
Are there changes in levels?			
If so, are they obvious or marked in some way?			
<b>Steps/ Stairways/ Walkways</b>			
Are they in good repair?			
Smooth/safe surfaces?			
Are there handrails on both sides of stairway?			
Is there grasping space for both knuckles and fingers on railings?			
Are the stair treads deep enough for your whole foot?			
Are there any hazardous open risers on stairs?			
Would a ramp be feasible in any of these areas if it became necessary?			

Appliances/ Kitchen/ Bath				
Is arrangement convenient and safe?				
Can oven/refrigerator be opened easily?				
Are stove controls easy to use?				
Are they clearly marked?				
Is counter height/depth good for you?				
Can you sit while working?				
Are door cabinet knobs easy to use?				
Are faucets easy to use?				
Do you have convenience items such as a garbage disposal?				
A trash compactor?				
A hand-held shower head?				
Can you get in and out of tub/shower with ease?				
Do you have bath/shower seat?				
Are there grab bars where needed?				
Is hot water heater regulated to prevent scalding/burning?				
Storage				
Is storage located conveniently?				
Is storage adequate and usable?				
Can you easily reach closet items?				
Have you maximized your storage space with innovative products?				
Electrical Outlets/ Switches/ Alarms				
Are outlets/switches easy to turn on/off?				
Are outlets properly grounded to prevent electrical shock?				
Are extension cords in good condition?				
Are they needed?				
Do you have smoke detectors in all necessary areas?				
Do you have an alarm system?				
Is the telephone readily available				

for emergencies?			
Is the telephone equipped for hearing enhancement if necessary?			
Can you hear the doorbell in every part of the house?			
<b>Lighting/Ventilation</b>			
Is lighting sufficient for purpose of area?			
Is lighting bright enough for safety?			
Do you have night lights where needed?			
Is area well-ventilated?			
<b>Driveway/Garage</b>			
Is parking space available?			
Is it convenient to entrance way?			
Does garage door have an automatic opener?			

**FYI: Ideas for improvement that can enhance your comfort, safety, and independence**

- Lever door handles and faucet handles that operate easily with a push
- Adjustable closet rods
- A night light in bedroom
- No scatter rugs
- Handrails on both sides of staircases and outside steps
- Brighter staircase lighting
- Large rocker light switches that turn on/off with a push
- Electric outlets 27 inches above floor
- Peephole or view panel in front door
- Walk-in shower with grab bars and portable or adjustable shower seat
- Hand-held adjustable shower head
- Non-skid surface for bathtub and shower floor
- Grab bars by the toilet and tub
- Tilting or full length mirror in bathroom
- Bathroom telephone that is reachable if you should fall
- Adjustable countertops or lower counter for work space in kitchen
- Rounded kitchen counter tops
- Sliding shelves in cupboards, lazy susan in corner cabinet

## **FAMILY CAREGIVERS SELF-CARE TIPS**

### **Twelve Tips for Caregivers<sup>3</sup>**

Many people find caregiving emotionally exhausting. Even for the caregivers who are doing a great job (and most are), the feelings of burnout are prevalent. The day after day routine can be draining and not very fulfilling. Caregivers use their internal resources and abilities with the goal of keeping the care receiver comfortable at home if possible. This is sometimes done with superhuman effort, and the caregivers become ill because they have neglected their own health. It is ironic that many moves to a nursing home occur not because of the *care receiver's* condition, but because of the caregiver's condition.

Studies show that caregiver exhaustion, illness, and death are the most common reasons for nursing home moves. Keeping caregivers healthy both physically and emotionally is important. Caregivers need to be convinced to be selfish and take time for themselves. This is a necessity, not a luxury.

If you are feeling a bit worn down, try some of these suggestions:

1. Feeling healthy is always a good place to start. Treat yourself to consistent eating, sleeping, and exercising habits.
2. Organize your time, set priorities, and don't waste time and energy on small, unimportant problems.
3. Find a creative outlet in which you can use your hands and see some progress. Too often in caregiving, you can feel like you're getting no where. With a hobby, like gardening, you can see your efforts come to fruition.
4. Expect to succeed in whatever you do and celebrate your successes and efforts. Buy some flowers as a reward.
5. Practice relaxation techniques such as deep breathing and stretching tense muscles.
6. Surround yourself with things pleasing to your senses.
7. Focus your attention on someone besides the care receiver. Do something nice for a stranger, friend, or yourself.
8. Arrange for time away and spend it with people who boost your spirits.
9. Have people with whom you share your burdens and joys.

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<sup>3</sup> [www.caregivermn.org](http://www.caregivermn.org)

10. Involve yourself with others experiencing similar situations. Try a caregiver support group.

11. Don't be shy. Ask for assistance because caregiving can be a partnership where you share responsibilities with others.

12. Live for today.

## Medicare: What Caregivers Need to Know<sup>4</sup>

Medicare is the main health insurance program for the elderly and for permanently disabled younger Americans. Established by Congress in 1965 and changed many times, the program is not free healthcare. Instead, it is health *insurance* with important enrollment and benefit rules and many out-of-pocket costs for recipients. Even with its limitations and expenses, however, Medicare protects most elderly and persons with permanent disabilities from the high costs that can result from illness or failing health.

About 40 million Americans are enrolled in Medicare. It is managed by The Centers for Medicare & Medicaid. The program is funded through deductions from workers' paychecks, federal revenues, and premiums paid by Medicare enrollees. Healthcare and other service providers approved by Medicare are paid when their claims are submitted to claims processors. Enrollees, also called beneficiaries or recipients, receive payment summaries and are billed for any costs that are not paid by Medicare.

### Why Caregivers Need to Know about Medicare

Medicare is a vast program with complicated rules. Whether an individual or family becomes a caregiver because of a sudden, acute illness or as a result of a gradually worsening illness, knowledge of Medicare is important. If the beneficiary becomes incapacitated and unable to handle his or her own affairs, the caregiver will likely have to monitor claims, keep up supplemental coverage, pay out-of-pocket costs and, when necessary, appeal decisions about care or benefits.

This fact sheet summarizes basic information about Medicare for families and caregivers. The sections on Additional Reading and Resources provide more in-depth information.

Caregivers and care receivers need to understand what Medicare is *not* and what it does *not* do:

- Medicare is NOT "free" healthcare.
- Medicare does NOT cover prescription medicines outside a hospital except in very limited cases.
- Medicare does NOT cover extended, long-term care at home or in a nursing home beyond certain specified periods or purposes.
- Medicare does NOT cover services deemed to be medically unnecessary (that is, so-called "custodial care") if they are the only services needed. (Examples: bathing, dressing, eating, shopping, cleaning and 24-hour supervision at home.)

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<sup>4</sup> Prepared by the National Center on Caregiving at Family Caregiver Alliance. Reviewed by Marisa A. Scala, Executive Director, Center for Medicare Education. Funded by the Archstone Foundation. Printed June 2003. ©2003 Family Caregiver Alliance. All Rights Reserved.

- Medicare does NOT cover all preventive care; it excludes routine annual physical exams, and routine dental, foot and eye care.
- Medicare does NOT pay for most healthcare while traveling outside the U.S.

## **Eligibility and Enrollment**

Medicare offers two plans, *Original Medicare* and *Medicare + Choice*. All Americans who are qualified to receive Social Security or Railroad Retirement benefits, and their spouses, can enroll in Original Medicare (Parts A and B). For those already receiving Social Security, enrollment in Original Medicare is automatic on the first day of the month they turn 65. Otherwise, individuals can apply for Medicare when they apply for Social Security at age 65.

A permanently disabled younger person is automatically enrolled in Medicare two years after Social Security Disability benefits begin. Persons with End-Stage Renal Disease or Amyotrophic Lateral Sclerosis (ALS)—regardless of age—are also eligible for Medicare. At the time they are first enrolled, new Medicare recipients receive instructions for selecting a program under the Medicare + Choice plan option. (See plan descriptions below under Medicare Benefits.)

Individuals who are ineligible for Social Security, such as retired government workers who paid into Medicare-only plans, can also enroll in Medicare during the initial enrollment period. Certain people, including those who did not work enough quarters to earn Social Security benefits, may apply for Medicare but must pay an additional monthly premium.

**Opting out of Part B (Medical Insurance):** A person may decline to participate in Part B (“opt out”) for various reasons: he or she may still be employed and covered by a plan at work, or may be retired and covered by a retiree plan and feel that Part B coverage is not needed. Those who opt out of Part B can enroll at a later date but, depending on the reason for declining Part B in the first place, may face penalties and higher premiums. It is important to discuss all options with Medicare and employee-benefits counselors before turning 65 or becoming eligible for Medicare.

**Medicare + Choice, (M+C)** is provided through private companies or other sources as a managed care or private fee-for-service plan. M+C requires a participant to enroll separately in the M+C plan, although they still pay Medicare Parts A and B premiums when applicable. A recipient may enroll in M+C at any time, according to the provider’s rules and enrollment periods. In fact, Medicare beneficiaries may switch back and forth between Original Medicare and Medicare + Choice at any time, so long as the M+C plan is accepting new members. But beneficiaries should seek advice from Medicare and the plan provider before making such decisions.

## **Medicare Benefits**

**Original Medicare:** Also called “Fee-for-Service Medicare,” Original Medicare consists of Part A (Hospital Insurance) and Part B (Medical Insurance).

Under Part A, those who receive Social Security and Railroad Retirement benefits pay no monthly premium. Others who do not have enough quarters of Medicare-covered employment may be charged a monthly premium that ranges in 2003 from \$174 to \$316. All recipients will have additional (“out-of-pocket”) expenses for some services.

Part A covers:

- **Stays in a hospital, “critical access hospitals” and mental health facilities.** Medicare pays for medically necessary services and supplies during the stay (e.g., surgery, intensive care, diagnostic tests, *inpatient* prescription drugs but *not outpatient* drugs, meals, and inpatient rehabilitation). The recipient pays a *deductible* (\$840 in 2003) for each *benefit period*. (A benefit period begins the day someone starts receiving care in a hospital or nursing facility and ends when that person has been out of the hospital or nursing facility for 60 days.) Recipients begin paying *coinsurance* on day 61 (\$210 per day in 2003, increasing to \$420 per day after 90 days). There are no limits to the number of times one can be hospitalized—but each new stay starts a *benefit period* during which continuing treatment or care must occur, and another deductible must be paid.
- **Stays in a skilled nursing facility (SNF) up to 100 days** if they occur within 30 days of a minimum three-day stay in a hospital and are related to the reason for the hospital stay. (Most people receive much less though.) The care must be certified by a physician as *medically necessary* and includes the need for either *daily skilled nursing care* or *rehabilitation services*. Beneficiaries begin paying *coinsurance* on the 21<sup>st</sup> day (\$105 per day in 2003.)
- **Home health care**, if a person meets the following conditions:
  - is homebound (it is very difficult to leave home alone without assistance)
  - needs skilled nursing care (care given or supervised by a registered nurse) or skilled therapy services
  - is certified by a physician as needing skilled home health care.

Medicare pays for part-time (up to 35 hours per week) skilled nursing care, assistance from a home health aide if it supports the skilled care, physical, occupational and speech therapy, medical social services, and medical supplies. Durable medical equipment such as hospital beds, wheelchairs, oxygen or walkers are covered but the recipient must pay 20 percent of the cost.

- **Hospice care**, including pain relief, physician and nursing services, home and health aide and homemaker services, supportive medical and social services, physical therapy, medical equipment and symptom management, is provided free under Medicare to those terminally ill persons with life expectancies of six months or less or who waive standard Medicare benefits for treatment. A 5 percent (up to

\$5) coinsurance is charged for drugs. Inpatient care will be provided with a 5 percent copayment if the family caregiver needs respite.

**Part B (Medical Insurance)** covers approximately 80 percent of the approved cost of outpatient medical care if it is *medically necessary* or an *approved preventive benefit*. Recipients pay a *monthly premium* (\$58.70 in 2003), which is usually deducted from their Social Security or other government retirement check, and an *annual deductible* of \$100. Recipients pay *coinsurance* for many services, usually 20 percent of the Medicare-approved costs with some exceptions, including mental health care for which the coinsurance is 50 percent. Some services have additional copayment requirements.

Part B covers medical and related services, including visits to physicians and surgeons, outpatient medical and surgical services and supplies, diagnostic tests, ambulance services, durable medical equipment, outpatient mental healthcare, limited home health care, and physical, occupational and speech rehabilitation services not covered under Part A. The services provided must be covered by Medicare, and practitioners must accept Medicare patients if a doctor "*accepts assignment*," which means he or she cannot charge more than Medicare-approved amount for a service.

Routine annual exams are not covered but several preventive benefits, such as colorectal cancer screening, mammograms, and flu or pneumonia shots, are covered.

**Medicare + Choice:** A recent option under Medicare, called "Medicare plus Choice," offers several advantages and disadvantages. A person can choose a program from a company or provider that is under contract with Medicare for a *Medicare Managed Care Plan*, such as a health maintenance organization (HMO), or *Medicare Private Fee-for-Service Plan*. Under "Medicare + Choice," Medicare pays a set amount to the plan provider each month and the provider must offer the standard Medicare benefits.

A major reason for selecting M+C is that some providers also offer additional services such as prescription drugs or more preventive and wellness care. Beneficiaries continue to pay the Part B monthly premium, and may pay an additional premium to the M+C provider, as well as any other deductibles or copayments that the plan requires.

Other advantages of M+C include receiving all care in one location or through one group of professionals, less paperwork, and lower costs than some other Medicare plans. Drawbacks may include being required to see only doctors within the plan and limits on the number of enrollees. A growing problem is that some M+C providers are reducing services or leaving the Medicare system. Because M+C providers sign one-year contracts with Medicare, such changes can occur frequently. If a provider leaves Medicare, enrollees return to Original Medicare or can select another provider, if one is available in their area. One should seek advice from Medicare immediately either through (800) MEDICARE or a state health insurance counseling program (SHIP).

## Medicare Costs

The Henry J. Kaiser Family Foundation reports that Medicare pays just 56 percent of beneficiaries' total healthcare costs with the balance paid out of the individual's own pocket or by other insurers.<sup>[1]</sup> These costs increase annually and include the premiums, deductibles and other out-of-pocket costs detailed above under descriptions for Part A and Part B. In fact, Medicare Part B works much like traditional health insurance by requiring deductibles and coinsurance. Several programs attempt to help beneficiaries pay for these out-of-pocket expenses.

## Paying for Unfunded Costs

**Insurance:** Private insurance companies and other public programs continue to play a role in healthcare for seniors and younger persons with disabilities. Options for funding enrollees' out-of-pocket expenses include:

- **Medigap and Other Supplemental Insurance** – Ten standardized insurance plans (called "Medigap") have been approved by Congress to supplement Medicare. They are offered by private insurance companies or organizations, although not all companies provide all ten plans. Purchasers of Medigap policies must pay a monthly premium *in addition to* the premiums paid for Medicare Part B. Lower cost Medicare SELECT policies are offered but may require use of specific hospitals or doctors. Medicare + Choice participants cannot purchase Medigap policies. All Medigap plans are designed to pay for various Part A and Part B expenses, such as the \$100 annual deductible under Part B, additional hospital days, a portion of doctors' services not paid by Medicare, and so on. A few of the plans provide additional home health or limited prescription drug coverage. See "Resources" for programs that can help with Medigap policy selection. Medicare beneficiaries under age 65 are currently able to purchase Medigap insurance only in those states that require coverage of the younger age group.
- **Employer or Union Insurance:** Many Medicare recipients receive some form of health insurance from their employer or union even after retirement. Before making any decisions about coverage, recipients should talk to a Medicare or employee benefits counselor to learn the limitations of employer-sponsored insurance and the rules for enrolling in Medicare Part B. For more information, consult The Medicare Rights Center's brochure, "Medicare and Employer Insurance: How They Work Together" (see Resources).
- **Long-Term Care and Other Specialized Insurance:** Little is standardized in long-term care insurance policies. Caregivers can refer to several publications available from AARP or *Consumer Reports* or request a copy of "Understanding Long Term Care Insurance" from the American Healthcare Association and National Center for Assisted Living at (800) 321-0343 or [www.ahcabookstore.org](http://www.ahcabookstore.org). Other

specialized private insurance policies are available including disability, home health or cancer-only plans.

**Veterans and Military Service:** Eligible veterans and military retirees can receive health benefits through the Veterans' Administration and TRICARE for Life, respectively.

**Low-Income Assistance:** The incomes of one-half of Medicare beneficiaries fall below \$25,000 per year, and income levels fall lower for older population groups.<sup>[2]</sup> To help low-income participants, other publicly-funded assistance is available, including Medicaid, qualified assistance programs offered to Medicare beneficiaries, Medicare Savings Programs for those with limited income or savings, and state assistance programs. The Program for All-Inclusive Care for the Elderly (PACE) is also an option in some communities for people who would otherwise require nursing home placement.

**Prescription Drugs:** Spending in the U.S. on prescription medications increased more than 17 percent in 2001, the fourth year in a row that costs increased.<sup>[3]</sup> But Medicare does not pay for outpatient prescription drugs except in specific instances. Few Medigap supplemental insurance policies cover prescriptions; and those have deductibles and other costs. Medicare recipients who have other health coverage, such as employer sponsored insurance, or even the managed care plans of Medicare + Choice, often must pay part of their prescription expenses. Several programs aim to assist with drug costs, including State Pharmacy Assistance Programs in many states; mail order and internet-based pharmacies, discount pharmacies in the community, membership programs (e.g., AARP), and discount cards; and discount programs directly from pharmaceutical companies. Information about discount programs can be found through Needy Meds ([www.needymeds.com](http://www.needymeds.com)) and The Medicine Program ([www.themedicineprogram.com](http://www.themedicineprogram.com)), as well as several Resources listed below.

## **Medicare's Limitations**

Limits on what Medicare does and does not cover cause confusion and frustration for beneficiaries and their caregivers. In addition to the costs of healthcare, the major problems include lack of long-term care coverage, benefit periods, requirements for approved rates, and "acceptance of assignment."

There may be service limitations within geographic areas as well, especially in rural areas.

**Long-Term Care and Rehabilitation:** According to a survey by CareQuest National Work & Family LTC Solutions, 63 percent of those aged 65 and over do not know or have incorrect information about Medicare coverage for long-term care.<sup>[4]</sup> Two-thirds of all Medicare beneficiaries live with multiple chronic health conditions, and nearly one-fourth have cognitive limitations, (that is, problems with mental processes) according to the Henry J. Kaiser Family Foundation.<sup>[5]</sup> Yet the services needed by these individuals are largely not covered by Medicare because *Medicare does not cover long-term care.*

The U. S. Senate Committee on Aging defines “long-term care” as healthcare that does not have as a goal the cure of an illness but “to allow an individual to attain and maintain an optimal level of functioning. Long-term care encompasses a wide array of...services needed by individuals who have lost some capacity for self-care because of a chronic illness or disabling condition.”<sup>[6]</sup>

In a **skilled nursing facility**, Medicare will cover care only if it occurs within 30 days of a minimum three days’ stay in a hospital. The care required must be for the same condition for which one was hospitalized. Example: a Medicare beneficiary falls and breaks her hip. After receiving care for the fracture in a hospital, she is sent to a skilled nursing or inpatient rehabilitation center for further healing and therapy. While in the skilled facility she can receive skilled nursing services, aide services that support the skilled care, and physical or occupational therapy for the hip fracture. Medicare coverage will end if her doctor and care team decide that her hip has improved as much as possible while in the facility and she is sent home.

**In-home care** is also limited to authorized skilled care and services that support the skilled care. The care must be certified as medically necessary by a physician. Again, Medicare coverage may end when professional assessments determine that no further improvement will occur for the condition being treated.

*Medicare does not cover other types of care and services needed by a person who is homebound or unable to handle his or her own daily activities such as bathing, dressing, meal preparation and eating, shopping, house cleaning and so on, if that is the only help that that person needs. Medicare also does not pay for 24-hour care. The hospice benefit is more comprehensive but requires that a person have a terminal diagnosis.*

**Other obstacles:** Medicare recipients may run into other obstacles in obtaining healthcare services. They can: reach coverage limits for different services (such as skilled nursing facility stays or home health care); have to find service providers that are approved by Medicare and accept Medicare-approved payment rates; be asked to sign a “private contract” to pay higher rates; or experience service cut-backs because of changes in Medicare programs or policies.

## **Rights and Appeals**

All Medicare recipients have rights and can appeal decisions regarding the services they receive, coverage limits or payment decisions. See Resources for Medicare contacts and organizations that help with issues related to protecting these rights, filing claims and obtaining assistance.

## **Other Resources:**

### **Center for Medicare Advocacy, Inc.**

P. O. Box 350

Willimantic, CT 06226  
(860) 456-7790  
(800) 262-4414  
[www.medicareadvocacy.org](http://www.medicareadvocacy.org)

A nonprofit organization that provides education, advocacy and legal assistance to elderly and persons with disabilities to help them obtain healthcare.

### **The Kaiser Family Foundation**

2400 Sand Hill Road  
Menlo Park, CA 94025  
(800) 656-4533  
[www.kff.org](http://www.kff.org)

Publishes "Talking With Your Parents About Medicare and Health Coverage," "Medicare Chart Book," and other information and research through "The Medicare Policy Project."

### **Medicare Rights Center**

1460 Broadway, 11<sup>th</sup> Floor  
New York, NY 10036  
(212) 869-3850 (888) 466-9050 (HMO appeals hotline)  
[www.medicarerights.org](http://www.medicarerights.org)

Information and assistance about rights and appeals dealing with Medicare and related insurance issues; low-cost prescription drug information; glossary of Medicare terms.

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<sup>1</sup>"Medicare Chart Book," Second Edition, Fall 2001, The Henry J. Kaiser Foundation (see Resources).

<sup>2</sup>"Medicare Chart Book," *ibid.* <sup>3</sup>*Wall Street Journal*, March 29, 2002.

<sup>4</sup>"Perception of Medicare Long-Term Care Coverage Among Those Aged 65 and Over in the United States," June 2001, CareQuest National Work & Family LTC Solutions, Madison, WI.

<sup>5</sup>"Medicare Chart Book," *ibid.*

<sup>6</sup>"Developments in Aging: 1997 and 1998", Volume 1, Report 106-229, February 2000, Special Committee on Aging, United States Senate, Washington, D. C.

**DIRECTORY:**  
**CAREGIVER SUPPORT ORGANIZATIONS AND ELDER SERVICES**  
**MIAMI-DADE COUNTY<sup>5</sup>**

Please note: The Center on Aging is not affiliated with the agencies listed below. The following information is provided as REFERENCE only. Most are community-based services, but some may be fee-for-service. Please, contact each individual organization for more information. In addition to the entities listed in this page, you can also consult your telephone directory for more services available for you.

**ALLIANCE FOR AGING, INC**

9500 S Dadeland Blvd.  
Suite 400  
Miami, FL 33156  
(305) 670-6500

**ADVOCATE SENIORS COUNTY COURT  
SERVICES**

(305) 324-0550

**CAMILLUS HOUSE**

336 NW 5<sup>th</sup> Street  
Miami, FL 33128  
(305) 374-1065

**GREATER MIAMI JEWISH  
FEDERATION INFORMATION AND  
REFERAL**

4200 Biscayne Blvd.  
Miami, FL 33137  
(305) 576-4000

**ALZHEIMER'S FOUNDATION**

Greater Miami Chapter  
(305) 891-6228

**ALZHEIMER'S CLINICAL RESEARCH  
GROUP**

Baumel-Eisner Neuromedical Group  
1135 Kane Course, 3<sup>rd</sup> Floor  
Bay Harbor Island, FL 33154  
(305) 865-0063

**DADE COUNTY MEDICAL ASSOC.**

www.miamimed.com  
1501 NW North River Dr.  
Miami, FL 33125  
(305) 324-8717

**UNITED WAY OF MIAMI DADE  
HELPLINE**

305-358-HELP (4357)

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<sup>5</sup> Credits: The Florida Caregivers Handbook: An Essential Resource Guide for Caregivers and Their Older Loved Ones, 1993, Edited by: Creston Nelson-Morril. (Tallahassee, FL: Health Track Books) Family Caregiver Alliance, 1999, Caregiving ([http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=392](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=392)) Retrieved: December 12, 2003.

**LEGAL SERVICES OF GREATER  
MIAMI, INC**  
(305) 576-0080

**MEALS ON WHEELS**  
(305) 347-4650

**ELDERCARE**  
(305) 674-2052

**PROJECT INDEPENDENCE**  
(305) 751-3045

**COUNTY ELDERLY SERVICES  
DIVISION**  
(305) 375-5335

**HRS AGING AND ADULT SERVICES**  
401 NW 2<sup>nd</sup> Ave  
Miami, FL 33128  
(305) 377-5021

**LONG-TERM CARE OMBUDSMAN  
COUNCIL**  
(305) 663-2085

**NORTH MIAMI FOUNDATION FOR  
SENIOR CITIZEN SERVICES, INC**  
(305) 893-1450

**CHANNELING**  
(305) 758-0021

**DEPARTMENT OF INSURANCE  
CONSUMER SERVICES (MIAMI)**  
(305) 377-5235

## **TRANSPORTATION SERVICES**

**DIAL-A-RIDE**  
*Opa Locka only*  
(305) 688-4611

**WRP TRANSPORTATION INC**  
9822 NE 2ND AV  
MIAMI SHORES, FL  
(305) 759-7882

**SENIOR RIDE**  
*Miami Beach only, for medical  
appointments*  
(305) 673-8658

**ACTION**  
*Transportation for Miami Residents only*  
Tel. (305) 545-9298

**COMPLETE MEDICAL  
TRANSPORTATION**  
1425 NW 82ND AV  
MIAMI, FL 33126  
(305) 406-0051

**METRO DADE COUNTY TRANSIT  
ADMINISTRATION**  
(305) 375-4644

**PROJECT HELP**  
*North Miami Residents only*  
(305) 948-2902

## **HOSPICE**

**CATHOLIC HOSPICE INC**  
www.CatholicHospice.com  
14100 Palmetto Frontage Rd  
Tel. (305) 822-2380

**HOSPICE CARE OF SOUTH FLORIDA**  
7270 NW 12<sup>th</sup> Street  
(305) 591-1606

**HOSPICE FOUNDATION INC**  
777 17<sup>th</sup> Street  
(305) 538-9270

**HOSPICE CARE OF SOUTHEAST  
FLORIDA INC.**  
www.hospicecareflorida.org  
1200 NW 7<sup>th</sup> Ave  
(305) 599-7755 / (800) 372-1757

## **ELDERLY PROGRAM SENIOR AND ADULT DAY CARE CENTERS**

**FLORIDA CITY / HOMESTEAD**  
1600 NW 6<sup>th</sup> Court  
Florida City, FL  
(305) 242-7650

**HARRY CAIN**  
490 NE 2<sup>nd</sup> Ave  
Miami, FL 33127  
(305) 372-7646

**FIRST UNITED METHODIST CHURCH**  
400 Biscayne Blvd.  
Miami, FL 33128  
(305) 371-3392

**EDISON / LIBERTY CITY**  
200 NW 55<sup>th</sup> Street  
Miami, FL 33127  
(305) 751-4342

**PERRINE**  
17901 Homestead Ave.  
Perrine, FL 33157  
(305) 234-4986

**BETHUNE / BROWNSVILLE**  
2900 NW 43<sup>rd</sup> Terrace  
Miami, FL 33127  
(305) 638-4354

**SOUTH MIAMI**  
6701 SW 62<sup>nd</sup> Ave  
South Miami, FL  
(305) 669-0712

**OPA LOCKA SENIOR FOCAL POINT**  
16405 NW 25<sup>th</sup> Ave  
Opa Locka, FL 33054  
(305) 628-4354

**THE LEO GELVAN AND FAMILY  
COMMUNITY CARE ADULT DAY  
HEALTH CENTER**

5200 NE 2<sup>nd</sup> Ave  
Miami, FL 33137

**JACK ORR**

550 NW 5<sup>th</sup> Street  
Miami, FL 33128  
(305) 579-5588

**PINE WOODS VILLA**

8420 SW 188<sup>th</sup> Terrace  
Miami, FL 33157  
(305) 235-8260

**DOUGLAS GARDENS**

CITY SENIOR ADULT DAY HEALTH CARE  
CENTER  
6447 NE 7<sup>th</sup> Ave  
Miami, FL 33138  
(305) 754-1777

**JESCA Senior Center**

2350 NW 54<sup>th</sup> Street  
Miami, FL 33142

**KENDALL ADULT DAY AND RESPITE  
CARE CENTER**

9820 N Kendall Dr  
(305) 271-6311

**NORTH DADE ADULT DAY CARE**

60 NE 166<sup>th</sup> Street  
NMB, FL 33162  
(305) 940- 0075

**GOODLET ADULT CENTER**

Hialeah  
(305) 825-4947

**IVES DAIRY-**

COL. HARRY ZUBKOFF  
55 NW 199<sup>th</sup> Street  
NMB, FL 33169  
(305) 770-3137

**DEEDCO GARDENS**

104 SE 12<sup>th</sup> Avenue  
Homestead, FL  
(305) 242-7671

**DOWNTOWN SENIOR CITIZENS  
COMMUNITY CENTER**

Gesu Church  
118 NE 2<sup>nd</sup> Ave  
Miami, FL 33132  
(305) 374-6099

**WEST DADE ADULTS DAY CARE**

5895 W Flagler St.  
Miami, FL 33144  
(305) 261-5278

**LITTLE HAVANA ACTIVITIES AND  
NUTRITION CENTERS, INC.**

(305) 858-0887

**JEWISH COMMUNITY CENTERS**

Dave and Marty Alper-11155 SW 112<sup>th</sup>  
Ave  
(305) 271-9000  
610 Española Way, MB  
(305) 673-6060  
Michael-Ann Russell-18900 NE 25<sup>th</sup> Ave,  
NMB  
(305) 932-4200

## NATIONAL AND STATE ORGANIZATIONS

### **AARP**

601 "E" Street, NW  
Washington, DC 20049  
(800) 424-3410  
(202) 434-2277 (publications on  
caregiving)  
[www.aarp.org](http://www.aarp.org)

### **Eldercare Locator**

927 15th Street, NW, 6th Floor  
Washington, DC 20005  
(800) 677-1116 (nationwide Area  
Agency on Aging listings)  
[www.aoa.dhhs.gov/elderpage/locator.html](http://www.aoa.dhhs.gov/elderpage/locator.html)

### **Well Spouse Foundation**

P.O. Box 30093  
Elkins Park, PA 19027  
(800) 838-0879  
[www.wellspouse.org](http://www.wellspouse.org)  
Email: [info@wellspouse.org](mailto:info@wellspouse.org)

### **Food From Home**

236 Falls Rd.  
Hudson, NY 12534  
(888) DINNERS  
[www.foodfromhome.com](http://www.foodfromhome.com)

### **Cancer Care and the National Cancer Care Foundation**

1180 Ave of the Americas  
New York, NY 10036  
(212) 302-2400

### **FLORIDA DEPARTMENT OF INSURANCE**

<http://www.doi.state.fl.us>  
Division of Insurance Consumer Services  
Larson Building  
200 East Gaines Street

### **Children of Aging Parents**

Woodburn Office Campus  
1609 Woodburn Rd., Ste. 302A  
Levittown, PA 19057  
(215) 945-6900  
(800) 227-7294

### **Interfaith Caregivers Alliance**

112 West 9th St.  
Kansas City, MO 64105  
(816) 931-5442  
[www.interfaithcaregivers.org](http://www.interfaithcaregivers.org)  
Email: [info@interfaithcaregivers.org](mailto:info@interfaithcaregivers.org)

### **Home Instead Senior Care**

1104 S. 76th Ave., Suite A  
Omaha, NE 68124  
(402) 391-2555  
[www.homeinstead.com](http://www.homeinstead.com)

### **American Bar Association Commission on Legal Problems of the Elderly**

1800 M St. NW  
Washington, DC 20036  
(202) 331-2297

### **Elderly Referral Panel Florida Bar Lawyer Referral Service**

(904) 222-5286

Tallahassee, FL 32399-0322  
1-800-342-2762

## **DISEASE SPECIFIC ORGANIZATIONS**

Call or check your telephone directory for local chapters.

**ALS Association**  
(800) 782-4747  
[www.alsa.org](http://www.alsa.org)

**American Cancer Society**  
(800) 227-2345  
[www.cancer.org](http://www.cancer.org)

**Huntington's Disease Society of America**  
(800) 345-HDSA  
[www.hdsa.org](http://www.hdsa.org)

**National Prevention Information Network (NPIN)**  
(800) 458-5231  
[www.cdcpin.org](http://www.cdcpin.org)

**Stroke Connection**  
(800) 553-6321  
[www.americanheart.org](http://www.americanheart.org)

**American Brain Tumor Association**  
(800) 886-2282  
[www.abta.org](http://www.abta.org)

**Brain Injury Association**  
(800) 444-6443  
[www.biausa.org](http://www.biausa.org)

**Multiple Sclerosis Society**  
(800) FIGHT-MS  
[www.nmss.org](http://www.nmss.org)

**National Parkinson Foundation**  
(800) 327-4545  
[www.parkinson.org](http://www.parkinson.org)

**Alzheimer's Association**  
(800) 272-3900  
[www.alz.org](http://www.alz.org)

## ONLINE SUPPORT GROUPS FOR CAREGIVERS

### **National Organization for Empowering Caregivers**

[www.nofec.org](http://www.nofec.org), [www.care-givers.com](http://www.care-givers.com)

The New York-based organization that provide assistance, education, support and referrals for informal family caregivers, as well to promote public awareness about the realities of caregiving. They are committed to encouraging collaboration with other caregiving organizations in order to create a user-friendly clearinghouse of existing programs dedicated to helping family caregivers.

Online Community:

<http://www.care-givers.com/community/community.html>

### **Family Caregiver Alliance**

[www.caregiver.org](http://www.caregiver.org)

Nonprofit organization that address the needs of family and friends providing long-term care.

Caregiver Online Group:

[http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=486](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=486)

Participants send and receive e-mail to participate in discussion.

### **HealthBoard.Com**

Online communities for different health-related topics.

<http://www.healthboards.com/cgi/forumdisplay.cgi?action=topics&number=30>

### **Caregiver Media Group**

[www.caregiver.com](http://www.caregiver.com)

Provider of information, support and guidance for family and professional caregivers.

Founded in 1995, we produce *Today's Caregiver* magazine, the first national magazine dedicated to caregivers, the "Sharing Wisdom Caregivers Conferences". Their website includes topic specific newsletters, online discussion lists, back issue articles of *Today's Caregiver* magazine, chat rooms and an online store.

Online Community:

<http://www.caregiver.com/chat.html> (see schedule)

### **AARP**

Message Board: <http://community.aarp.org/n/mb/listsf.asp?webtag=rp-lifeanswers&ctx=128>

*en español:*

<http://community.aarp.org/rp-espanol/start>

**Free on-line courses for caregivers:** <http://www.aarp.org/learn/course/>