

This ongoing series provides information on how to develop programs to educate Medicare beneficiaries and their families. Additional information about this and other projects is available on the Center for Medicare Education's Web site: www.MedicareEd.org. This material may be reprinted only if it includes the following: Reprinted with the permission of the Center for Medicare Education.

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A project of the American Association of Homes and Services for the Aging with funding from the Robert Wood Johnson Foundation.

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Explaining Medicare to Caregivers

ABOUT THIS BRIEF

In addition to providing help with tasks such as bathing, dressing and preparing meals, many caregivers also assist with health-care decision making, including making choices about Medicare. Caregivers therefore may require education about issues related to Medicare benefits. In this brief we explore the special Medicare education needs of caregivers.

Special thanks to our guest author, Diana Petty, writer, consultant and former executive director of the Family Caregiver Alliance in San Francisco.

As people live longer and develop more chronic health conditions, more people will assume a caregiving role, whether it is for parents, a spouse, a sibling, or another relative or friend. Informal caregivers (i.e., those who are not paid for the caregiving work that they do) often must make decisions about another person's health care and how to pay for it.

Studies vary in their definitions and criteria of unpaid caregiving in the United States, but as many as 52 million informal and family caregivers may provide care to someone aged 20 or older who is ill or disabled. One study found that nearly one out of four U.S. households (22.4 million) is involved in caregiving of persons aged 50 and older. For individuals over age 65, the overwhelming majority of Medicare's beneficiaries, assistance with everyday activities is provided by 5.8 to 7 million family members, friends and neighbors.¹

In considering what these informal caregivers need to know about Medicare, it is important to recognize that the average age of family caregivers is in the mid-40s.² That means that the average caregiver is not a Medicare recipient and, therefore, is unlikely to have personal knowledge of Medicare when the caregiving role begins. Ethnicity also is an important consideration, because members of non-white racial groups and families with origins outside the United States are reported to provide a higher percentage of informal care than do white families.³ The majority of caregivers are women, but a recent study found that 46 percent of caregivers are men.⁴

American adults are largely uninformed about what Medicare does and does not cover. In a study by AARP of long-term care, a majority of respondents age 45 and older did not know that Medicare limits coverage of nursing home stays and in-home care. A majority also did not know that Medigap supplemental insurance does not cover extended care. Nor are Americans fully prepared for the out-of-pocket costs that Medicare recipients must pay. Only 15 percent of AARP study respondents came within 20 percent of correctly estimating the national average monthly cost of nursing home care. The AARP researchers also found a disparity between those adults who believe that they have long-term care coverage from any source, including private insurance, and those who actually do. Yet nearly 60 percent of respondents said they knew a relative who had received or was currently receiving long-term care.⁵

What Do Caregivers Need to Know?

No matter how an individual or family comes to caregiving—through sudden, acute illness or as a result of gradual progression—and no matter the age of the care recipient, knowledge of Medicare is critical. When a beneficiary is incapacitated (perhaps in a coma or in the late stage of dementia), his or her caregiver needs to know the same things any person with Medicare must know: eligibility and enrollment rules, benefits and coverage limitations, out-of-pocket costs, and other sources of insurance or financial assistance. They may need to know more about some aspects, such as the hospice benefit, appeal rights, and how to uncover information about the beneficiary’s coverage.

Here are some basic questions you can ask caregivers, and then lead them to sources for answers:

- Does the person you care for currently receive Medicare and, if so, in what form (Original Medicare, Parts A and B, or Medicare+Choice (a Medicare health maintenance organization) or private fee-for-service)?
- If the person is not receiving Medicare, do you think he or she might be eligible for it?
- What other provisions have been made to cover out-of-pocket costs? Is the person covered by other supplemental insurance, such as Medigap insurance, employer-sponsored health insurance, a medical savings account, long-term care insurance or auxiliary insurance for special needs? Or is the person eligible for Medicaid or other low-income assistance programs?
- Do his or her health-care providers “accept assignment”—that is, do they participate in Medicare or the patient’s other insurance plans? Are there other things that keep that person from getting the care that he or she needs (e.g., living in a rural area, lack of transportation, etc.)?
- Most significantly, does the caregiver understand the limitations of both Medicare and other forms of health insurance?

No issue causes more consternation to caregivers and beneficiaries than the limitations and unfunded costs of Medicare and other insurance programs. As a service professional and Medicare educator, you will need to explain up front to the caregivers you work

with what Medicare is NOT and what it does NOT do:

- Medicare is NOT “free” health care.
- Medicare does NOT cover prescription medicines.
- Medicare generally does NOT cover extended, long-term care.
- Medicare does NOT cover services that are deemed to be medically unnecessary (such as “custodial care,” or help with bathing, dressing, eating and more).
- Medicare does NOT cover all preventive care, especially routine annual physicals or eye, dental or foot care.

Basic Information Needs

Some important points that will be helpful to caregivers are:

ELIGIBILITY AND ENROLLMENT

You may need to explain the enrollment process. Although Medicare is automatic for Social Security recipients at age 65, many do not know how enrollment occurs. Caregivers also should know that those who do not receive Social Security, younger disabled adults, and persons with specific conditions such as end-stage renal disease (ESRD) or amyotrophic lateral sclerosis (ALS, also known as Lou Gehrig’s disease) can apply for Medicare under certain circumstances, although there may be additional costs involved.

TYPE OF MEDICARE

The differences between Original Medicare and Medicare+Choice are also important. Caregivers will need to learn which program their loved one has chosen (or should choose), how to compare the benefits and costs, and how to switch from one to the other. For Original Medicare, does the caregiver know that enrollees can decline Part B (medical insurance)? Are they aware that there may be penalties for declining Part B if one enrolls in it at a later date? Is the caregiver aware of open enrollment periods?

Some Medicare options (mainly health maintenance organizations, or HMOs) may provide benefits not offered under Original Medicare, such as prescription

drugs. But caregivers should examine potential pitfalls, such as drug formularies, caps for prescription drug costs, whether the patient can continue with the same personal physician, and whether a plan may pull out of a particular area.

MEDICARE COSTS

The costs associated with Medicare, such as premiums, deductibles and out-of-pocket costs, can be a rude awakening to caregivers who may be paying the bills. In fact, the Henry J. Kaiser Family Foundation reports that Medicare pays just 56 percent of beneficiaries' total health-care costs, with the balance paid out of the individual's own pocket or by other insurers.⁶ Caregivers need information about how to cope with the cost of services that are not covered.

FILLING IN COVERAGE GAPS

Caregivers are likely to be unaware of the continuing role played by private insurance in health care for seniors and persons with disabilities. Or they may be unaware that their loved one is eligible for or already receiving other public assistance. Caregiver education should explain why supplemental insurance and other assistance is needed, how to learn more about what is available, and how to obtain it. A few considerations:

➤ **Medigap and other supplemental insurance:** Without supplemental insurance, according to the Henry J. Kaiser Family Foundation, "Medicare beneficiaries tend to experience substantial problems with access to care."⁷ Many organizations (such as the Centers for Medicare and Medicaid Services and AARP) publish or include on their Web sites information that explains the 10 standardized Medigap supplemental insurance plans, provides tips for selecting such insurance and, in some cases, includes interactive help for selecting an appropriate plan. *[Note that the under - 65 disabled population is currently able to purchase Medigap insurance only in those states that require coverage of this younger age group. In other states, insurers may choose to sell Medigap plans to the under 65 Medicare population, but it is not required.]*

➤ **Employer-sponsored insurance:** Not all health-care coverage by employers stops when Medicare starts. Many Medicare recipients

continue to receive some form of employer-sponsored insurance coverage because they either are still working or are covered by a retiree plan. A Medicare beneficiary may have continued to purchase insurance privately under the COBRA laws. You may need to explain the limitations of employer-sponsored insurance, including the impact of turning down Part B under Medicare and the trend by employers to cut back employee insurance programs in general and retiree programs in particular.

➤ **Long-term care and specialized insurance:**

The AARP study of long-term care found that many Americans think they have long-term care insurance but, in reality, do not. For those who do, very little is standardized.⁸ Many good publications that describe long-term care insurance are available from organizations such as AARP, Consumer Reports and others. Caregivers should explore whether their loved one has enrolled in some form of specialized insurance program, such as disability, home health or cancer-only plans.

➤ **Assistance for people with low incomes:** The incomes of one-half of Medicare beneficiaries fall below \$25,000 per year, and income levels drop lower for older subsets of the population.⁹ This means that you should be prepared to provide information about Medicaid, financial assistance programs (known as the Medicare Savings Programs) offered by Medicare to low-income beneficiaries and state assistance programs.

➤ **Military service:** Those who served in the military may be eligible for healthcare and other services through TRICARE or the Veterans Administration.

Some excellent resources are available to help caregivers learn about Medicare (see the "Resources" box on page 7). In addition, all states offer a State Health Insurance Assistance Program (SHIP) to provide counseling and information about health-care insurance options. To find the SHIP in your state, visit <http://www.Medicare.gov> and click on "Helpful Contacts."

Coverage Limits

Limits on what Medicare covers cause confusion and frustration for both beneficiaries and caregivers. Two examples of the caregiver perspective are listed below:

The disabled husband of a multiple sclerosis patient (who needs “constant care”) wrote in an appeal for assistance to Family Caregiver Alliance: *“I’ve been in touch with the local social services, but they haven’t really been able to provide any relief.... My spouse and I are far from rich, and in fact have limited insurance (Medicare).”*

The daughter of a 64-year-old Medicare patient (who has a progressive form of dementia) wrote: *“Now the problem is that we have tried to secure nurse aides to come and help take care of her, but to no avail. She is a patient of Medicare and they won’t even step in to help.”*

In the absence of care planning and coordination for all phases of a care recipient’s health and social service needs, you can expect the need for education about Medicare’s limitations to be ongoing. In addition to written materials that explain what is and is not covered, caregivers need referrals to agencies or organizations that can help them understand the Medicare beneficiary’s rights and appeal procedures. The most significant problem areas cited by caregivers are:

PRESCRIPTION DRUGS

Spending in the United States on prescription medications increased more than 17 percent in 2001, the fourth year in a row of increasing costs.¹⁰ However, Medicare does not pay for outpatient prescription drugs. Only three Medigap supplemental insurance policies (H, I, and J) cover prescriptions. All three policies pay up to 50 percent of the cost of prescription drugs and have deductibles and expenditure caps. Even Medicare recipients who have other health coverage through employer insurance, public assistance such as Medicaid, or the managed care plans of Medicare+Choice will find themselves paying some prescription expenses. You can direct caregivers to low-cost programs or those aimed at low-income beneficiaries, including:

- **State Pharmacy Assistance Programs.** As of July 2001, according to the Henry J. Kaiser

Family Foundation, 29 states were offering some form of assistance with the cost of outpatient drugs for Medicare beneficiaries through such vehicles as buying pools, tax credits, price reduction programs or direct benefits. Contact your state offices on aging for more information or visit www.medicare.gov and click on the link to “Prescription Drug Assistance Programs.”

- **Mail order and Internet-based pharmacies, discount pharmacies in the community, membership programs (e.g., AARP) and discount cards.** Savings can be significant from some sources, but caution caregivers and other clients to check with consumer action organizations to be sure these sources are reliable.

- **Discount programs directly from pharmaceutical companies.** As mentioned above, you can find information about these programs at www.medicare.gov. Other on-line programs that provide referrals to these discount programs include Needy Meds (www.needymeds.com) and the Medicine Program (www.themedicineprogram.com).

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.¹¹ Yet, two-thirds of all Medicare beneficiaries live with multiple chronic health conditions, and nearly one-fourth have cognitive limitations, according to the Henry J. Kaiser Family Foundation.¹²

The U.S. Senate Committee on Aging defines “long-term care” as health care that does not have as a goal to cure an illness but “to allow an individual to attain and maintain an optimal level of functioning. Long-term care encompasses a wide array of medical, social, personal, and supportive and specialized housing services needed by individuals who have lost some capacity for self-care because of a chronic illness or disabling condition.”¹³ However, by and large, Medicare does not cover this array of services. In general, it covers only care that is considered to be “medically necessary” and that fits into defined post-hospital benefit periods and outcomes under the direction of a physician and treatment team.

In other words, Medicare does not cover long-term care when that care is extended and “custodial” in nature. Custodial care assists a person with activities of daily living such as bathing, dressing and meal preparation. Medicare’s coverage of skilled nursing, in facilities and at home, is limited to skilled care (changing of sterile dressings, administration of shots, etc.). Home health aides can provide Medicare-covered help only in support of such authorized skilled care. The hospice benefit is more comprehensive but requires a determination of terminal illness.

An especially troublesome area of Medicare coverage for caregivers relates to the physical, occupational and speech therapy benefits following hospitalization for an acute illness or accident. The wife of a 34-year-old stroke patient, in writing to Family Caregiver Alliance, explains the problem. Her husband is paralyzed on the left side of his body and complains of pain when she tries to help with his therapy: *“They discharged him from therapy just about a month ago now. They said he wasn’t making any more progress (plateau).”*

Although a recent administrative directive from the Centers for Medicare and Medicaid Services prevents the automatic termination or denial of therapy benefits for those with certain diagnoses (Alzheimer’s and dementia), rehabilitation limitations remain a problem area for many. Rehabilitation for conditions such as stroke and traumatic brain injury may require years of treatment. If a patient is determined to have reached the restorative limits of therapy, however, Medicare coverage will end.

ACCESS

Caregivers may find themselves spending a great deal of time dealing with several barriers to access to care for people with Medicare. One barrier is whether the beneficiary’s physician accepts assignment (i.e., accepts Medicare patients) and will continue to do so. An increasing number of doctors are dropping out of the Medicare program.¹⁴ Payments to health-care providers are decreasing as Medicare officials attempt to control costs; this may lead to fewer choices and cutbacks in services. Rural areas often have fewer health-care resources, and persons of other ethnic backgrounds may find access limited by language and cultural differences.

Caregiver Education and Assistance

Organizations and services established specifically to assist caregivers have blossomed over the past 20 years. Several national efforts exist, including the recently enacted National Family Caregivers Support Program under the Older Americans Act, administered by the U.S. Administration on Aging and state programs on aging (see Resources). Nine programs in six states offer comprehensive services to caregivers, including California’s 11 regional Caregiver Resource Centers, and a range of such programs is available in other states.¹⁵ Community education and support programs are offered through hospitals, senior centers, local chapters of national organizations and some colleges. Many employee assistance programs offered by private companies have added a caregiver focus. However, the most common place where caregivers find information remains a physician’s office or the social service department of a hospital; these locations should be primary targets of ongoing educational efforts.

With more than 25 years’ experience in designing educational programs for caregivers of adults, Family Caregiver Alliance has learned that information is one of the most frequently cited needs of caregivers and that education is an ongoing process. Some knowledge of the caregiving audience is needed when developing educational programs. In general, the number of caregivers is nearly equal between female and male caregivers, but older people are more likely to be tended by a female relative or friend. Women spend 50 percent more time in caregiving than do men. Non-white persons are more likely to receive unpaid care from family or friends.¹⁶ More than half of caregivers are employed. Caregivers are usually juggling many burdens while tending to family, work and personal needs along with caregiving responsibilities. Their own health may be declining. The many variations within caregiver groups must also be considered—the caregivers’ ages, patients’ diagnoses, relationship of the caregiver to the patient, and so on.

Medicare education should address access, that is, where a caregiver is likely to look for information. It is a good idea to offer such education at flexible times and in a variety of formats and settings, such as:

- Single-session community workshops and educational forums
- Lectures or series followed by discussion
- Support groups
- Skills-building classes and groups
- Individual counseling and training sessions
- During the process of care coordination and management
- Through technology-based interventions (e.g., the Internet)¹⁷

Programs should be offered during the day for those who no longer drive or go out at night, and at night for those who work. They should be offered at accessible locations such as senior and community centers, churches, hospitals and health fairs. You can also conduct programs in collaboration with employers, near business centers and during the lunch hour. The Internet is breaking ground in offering caregiver assistance and education at times convenient to caregivers and, if they wish, anonymously.

Some other tips for providing information to caregivers and their families:

- Families often have more than one decision maker, and each person involved may have different needs or perspectives.
- Unless a beneficiary is completely unable to understand or communicate information, he or she still has a point of view and should be included in discussions or sought out for desires and opinions.
- Take into consideration the caregiver's background, education, income level, employment status, ethnicity or culture, interests, health status, capacity to hear and retain information, medical condition of care recipients, and so on.
- Help families and decision makers understand the importance of planning for Medicare and health-care needs before a crisis occurs.
- Acknowledge that caregiving presents intense burdens that may make it difficult for the caregiver to follow through. Follow up and offer ongoing guidance and support.

In Conclusion

The world of health care is confusing and can cause anxiety for caregivers. The complexity of paying for medical and supportive care adds to their demands as they strive to understand a loved one's condition, prognosis and care. If you counsel or assist caregivers, remember that, for many, learning about and dealing with Medicare are high hurdles to jump. By providing simple, complete explanations of Medicare and other insurance programs, you can make their job that much easier.

¹ Family Caregiving Alliance: *Fact Sheet: Selected Caregiver Statistics*, San Francisco, 2001.

Family Caregiver Alliance, Statistics quoted are from: U.S. Department of Health and Human Services, "Informal Caregiving: Compassion in Action" (Washington: 1998); U.S. Department of Health and Human Services, National Alliance for Caregiving and AARP, "Family Caregiving in the U.S.: Findings From a National Survey" (Bethesda, MD: National Alliance for Caregiving; Washington: AARP, 1997).

² Ibid.

³ Ibid; AARP: *In the Middle: A Report on Multicultural Boomers Coping with Family and Aging Issues*, Washington: AARP, 2001.

⁴ National Family Caregivers Association: *Survey of Family Caregivers*, Kensington, National Family Caregivers Association, 2000.

⁵ AARP: *The Costs of Long-Term Care: Public Perception vs. Reality*, Washington: AARP, 2001.

⁶ The Henry Kaiser Family Foundation: *Medicare Chart Book*, Second Edition, Menlo Park: The Henry Kaiser Family Foundation, 2001.

⁷ Ibid.

⁸ Lutzky, S. & Alecxih, L. M. "Enabling informed consumer choice in the long-term care insurance market. *Journal of Aging and Social Policy*." (1999): 10(3), pp. 27-44.

⁹ Ibid.

¹⁰ Wall Street Journal, March 29, 2002.

¹¹ CareQuest National Work & Family LTC Solutions. Perception of Medicare Long-Term Care Coverage Among Those Aged 65 and Over in the United States.

MADISON: 2001. CareQuest National Work & Family LTC Solutions.

¹² *Medicare Chart Book*, "The most common chronic conditions are arthritis (57%) and hypertension (55%)." page 8.

¹³ U.S. Senate Committee on Aging, "Developments in Aging: 1997 and 1998," Volume 1, Report 106-229 (Washington: 2000).

¹⁴ *New York Times*. "Many Doctors Shun Patients With Medicare." 2002.

¹⁵ Family Caregiver Alliance. Survey of Fifteen States' Caregiver Support Programs, SAN FRANCISCO: 1999. States with comprehensive programs are California, Florida, Illinois, New York, Pennsylvania and Wisconsin.

¹⁶ Family Caregiving Alliance: *Fact Sheet: Selected Caregiver Statistics*, San Francisco, 2002.

¹⁷ Toseland, R. W. and Smith, T., "Supporting Caregivers Through Education & Training," Program Development Issue Briefs (1999). U.S. Department of Health and Human Services.

Resources to Assist Caregivers

Federal Resources

MEDICARE

1-800-MEDICARE (1-800-633-4227)
<http://www.medicare.gov>

This Web site provides a comprehensive resource on Medicare, including the "Medicare Personal Plan Finder" to help select an appropriate Medicare plan and supplemental insurance and links to low-cost prescription programs (through the Prescription Drug Assistance Program link), publications (such as the "Medicare & You" handbook), helpful contacts and local educational event calendars.

CAREPLANNER

<http://www2.careplanner.org>

This Web site, sponsored by the Centers for Medicare and Medicaid Services, offers a decision support tool which can be used by seniors, caregivers, family, friends and professionals.

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

<http://www.aoa.dhhs.gov/carenetwork/>

This Web site, offer by the U.S. Administration on Aging, offers information on the implementation of the National Family Caregiver Support Program, including a resource guide, issue briefs and resources for caregivers.

Other Resources

AARP

1-800-424-3410
<http://www.aarp.org>

A vast resource for older Americans, including information booklets and research on Medicare basics and related topics. Also offers supplemental health insurance and information about insurance. Discounted prescription medicines available through AARP Pharmacy (www.aarp-pharmacy.com 1-800-456-2277).

CENTER FOR MEDICARE ADVOCACY, INC.

1-860-456-7790 / 1-800-262-4414
<http://www.medicareadvocacy.org>

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

FAMILY CAREGIVER ALLIANCE/ NATIONAL CENTER ON CAREGIVING

1-800-445-8106
<http://www.caregiver.org>

Information, research and services to support caregivers, especially those dealing with cognitive impairments and brain disorders. Professional education, "promising practice" models, public policy conferences and an array of fact sheets and other publications are also offered.

Resources to Assist Caregivers (continued)

Other Resources - continued

THE KAISER FAMILY FOUNDATION

1-800-656-4533
<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

1-212-869-3850
1-888-466-9050 (HMO appeals hotline)
<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.

NATIONAL ALLIANCE FOR CAREGIVING/FAMILY CARE RESOURCE CONNECTION

1-301-718-8444
<http://www.caregiving.org>

A joint venture of the American Society on Aging, U.S. Department of Veterans Affairs, National Association of Area Agencies on Aging, and others. Offers reports, Web site links, training packages and caregiver brochures. The Family Care Resource Connection is a searchable database of reviews and ratings of books, Web sites and other resources for family caregivers.

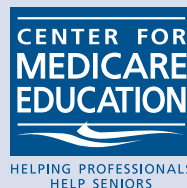
NATIONAL FAMILY CAREGIVER ASSOCIATION

1-800-896-3650
<http://www.nfcacares.org>

Educates, supports, empowers and speaks up for Americans who care for chronically ill, aged or disabled loved ones. Offers RX discount program for members, professional advisory services for caregivers, and training for professionals.

About the Author

Diana Petty is the former Executive Director of Family Caregiver Alliance. She is now a writer and consultant. Founded in 1977, Family Caregiver Alliance serves as a public voice for caregivers, illuminating the daily challenges they face, offering them the assistance they so desperately need and deserve, and championing their cause through education, services, research and advocacy. Long recognized as a pioneer among caregiver organizations, FCA operates at local, state and national levels. FCA is the lead agency and model for California's statewide system of Caregiver Resource Centers. In 2001, FCA established the National Center on Caregiving to advance the development of high-quality, cost-effective policies and programs for caregivers in every state in the country.



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