Introduction to Medicare for People with Multiple Sclerosis

Judith Stein
INTRODUCTION TO MEDICARE FOR PEOPLE WITH MULTIPLE SCLEROSIS*

By Judith Stein**

INTRODUCTION

People with chronic conditions and long-term illnesses are too often denied Medicare coverage. Because Medicare is often the sole or primary insurance for this population, Medicare coverage denials often result in the loss of necessary health care. This is true, for example, for people with Diabetes, Parkinson’s disease, Alzheimer’s disease, and Multiple Sclerosis (MS). Because their underlying illnesses will not be cured, these individuals are frequently denied Medicare coverage for an array of health care services including home care and physical therapy. These services are often key, not only to the health and welfare of the individuals, but also to the ability to access Medicare coverage for other necessary health services.

Because Multiple Sclerosis is generally diagnosed early in life, restrictive Medicare coverage determinations present particularly dangerous and long-lasting obstacles to obtaining health care for people with MS. Since the Center for Medicare Advocacy’s founding in 1986, these individuals have comprised a disproportionate share of our clientele; they need advocacy to obtain Medicare coverage for critically important health care. This article presents a summary of the challenges and opportunities facing Medicare patients who have MS and other long-term conditions.

* An article with similar content has been posted on the National MS Society web site, at http://www.nationalmssociety.org/medicare_faqs.asp.
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WHAT IS MEDICARE?

Medicare is the national program that serves as the primary source of health insurance for older people and many people with permanent disabilities. The program was enacted in 1965 as Title 18 of the Social Security Act. Medicare has evolved significantly over the years. Major changes were made in 2003. Pursuant to the 2003 law, Medicare now includes a prescription drug discount card program. In 2006, beneficiaries will be offered a limited prescription drug benefit.

WHAT HEALTH CARE SERVICES DOES MEDICARE COVER?

Medicare works like other health insurances. It pays a portion of the cost of certain necessary medical services. Under the Medicare Act, Medicare covers services that are "reasonable and necessary for the diagnosis or treatment of illness or injury or to improve the functioning of a malformed body member." Often cost sharing is required of the individual Medicare beneficiary, including premiums, deductibles and co-payments.

The Medicare program is divided into parts. Part A covers inpatient hospital care, skilled nursing facility (nursing home) care, home health care, and hospice care. Part B, which is optional and has monthly premiums; covers medical care provided by doctors and other health care providers; long-term home health care; durable medical equipment; outpatient hospital services; and physical, speech, and occupational therapy. Part C of Medicare, also known as Medicare Advantage, provides payment mechanism options including managed care plans. Medicare Part D is the new prescription drug program, which will be effective January 1, 2006.

WHO IS ELIGIBLE?

Social Security retirement recipients who are over sixty-five years old and individuals who have received Social Security disability benefits for twenty-four months are eligible for Medicare. In addition, individuals who receive Railroad Retirement Benefits and individuals who have End Stage Renal Disease (ESRD) or Amyotrophic Lateral Sclerosis (ALS or "Lou Gehrig’s Disease") are also eligible for Medicare.

Medicare is not a welfare program and should not be confused with Medicaid. While Medicaid is a state-run health care financing program for low-income people, Medicare is a federal program and an individual's income and assets are not considered when determining eligibility.

As for others, people with Multiple Sclerosis (MS) can qualify for Medicare coverage before age sixty-five if Social Security determines that they are permanently disabled and they have received Social Security disability benefits for twenty-four months. People with MS will also be eligible for Medicare when they reach age sixty-five if they receive Social Security or Railroad Retirement benefits. Individuals who retire early, and decide to receive Social Security retirement benefits at age sixty-two, must still wait until they are sixty-five to receive Medicare.

HOW DO PEOPLE ENROLL?

Generally, individuals who are sixty-five and are entitled to Social Security or Railroad Retirement benefits are automatically enrolled in Medicare Part A and will be deemed to have also enrolled in Part B. Individuals must enroll in Part A during an "initial enrollment period," which begins in the third month before the person reaches age sixty-five (or reaches age sixty-five and becomes a U.S. citizen, or a permanent resident who has lived continually in the U.S. for the five years immediately preceding application for Medicare). The initial enrollment

11. Id.
15. Id.
period extends for the next seven months.\textsuperscript{16} An application for Social Security or Railroad Retirement will also suffice for Medicare. A separate application is not necessary. Individuals who choose to take early Social Security retirement benefits will be automatically enrolled in Medicare when they attain age sixty-five.\textsuperscript{17}

Those who are sixty-five but who delay receipt of Social Security benefits may still enroll in Medicare but must file an application.\textsuperscript{18} Individuals who qualify for Medicare because they have received Social Security or Railroad Retirement disability benefits for twenty-four months are entitled to Medicare but also must file an enrollment application.\textsuperscript{19}

Applications for Medicare may be made with Social Security after receiving disability benefits for twenty-one months.\textsuperscript{20} Effective July 1, 2001 the twenty-four-month waiting period was eliminated for disabled persons diagnosed with ALS.

Medicare coverage can be extended up to seventy-eight months after disability benefits are terminated if the beneficiary is engaged in an approved nine-month trial work period after a period of disability.\textsuperscript{21} The previous period of disability benefits will count toward the twenty-four-month eligibility requirement, should the beneficiary seek to reestablish Medicare eligibility.\textsuperscript{22}

\textbf{PART B ENROLLMENT}

Individuals who miss the initial enrollment period must wait for a “general enrollment period” to enter Medicare Part B.\textsuperscript{23} The general enrollment period is the first three months of each calendar year (January 1 through March 31).\textsuperscript{24} Medicare Part B benefits do not begin until July of that year.\textsuperscript{25}

\textsuperscript{16} 42 U.S.C.A. § 1395p(d) (West 2005).
\textsuperscript{17} 42 U.S.C.A. § 1395p (West 2005).
\textsuperscript{18} Id.
\textsuperscript{19} 42 C.F.R. § 406.10 (2005).
\textsuperscript{20} 42 C.F.R. § 406.12 (2005).
\textsuperscript{21} Id.
\textsuperscript{22} Id.
\textsuperscript{23} 42 U.S.C.A. § 1395p(g)(3) (West 2005).
\textsuperscript{24} 42 U.S.C.A. § 1395p(e) (West 2005).
\textsuperscript{25} 42 U.S.C.A. § 1395p (West 2005).
PART D ENROLLMENT

When the new Part D prescription drug benefit goes into effect in 2006, individuals will have to enroll in a prescription drug plan if they want the benefit. The initial enrollment period will occur from November 15, 2005 through May 15, 2006. Every year after the initial period individuals will only be able to enroll in a Part D drug plan or change the plan in which they have enrolled from November 15 through December 31 of each year.

Penalties apply for late enrollment under Part A, Part B, and Part D. Under Part A, a ten-percent penalty, based on the monthly Part A premium price, is imposed for every month of late enrollment up to twice the number of months for which the beneficiary has failed to enroll. Under Part B, a ten-percent penalty is also imposed. The penalty is for each full year (twelve-month gap) of late enrollment. Unlike Part A, there is no end point to the penalty under Part B. Under Part D, the penalty will be the greater of an amount that is actuarially sound for each uncovered month or one percent of the national average monthly beneficiary base premium for each uncovered month. As with Part B, there is no end point to the penalty.

HOW ARE MEDICARE BENEFITS PROVIDED?

Historically Medicare benefits were provided to all beneficiaries in the same way throughout the country, in a manner similar to traditional private health insurance. However, beginning in the mid-1990s, managed care plans became part of the Medicare program, which created different delivery systems in different parts of the country. The advent of Medicare Part C in 1997 caused more kinds of benefit plans to become available. The plans are known as Medicare Advantage (MA, formerly known as Medicare+Choice). The options include "coordinated care

33. MMA, supra note 2, at § 101(a), adding Social Security Act § 1860D-13(b).
plans" (the term used in the law for managed care plans) as well as preferred provider organizations, medical savings accounts, private fee-for-service plans, and other options. In most parts of the country the only available Medicare Advantage options are managed care plans. A majority of beneficiaries are part of the traditional Medicare program. However, a significant number receive their Medicare through Medicare Advantage plans.

Beneficiaries can receive Medicare through a managed care plan by filing an enrollment form. Once the choice is made, the beneficiary generally must receive all of his or her care through the plan in order to receive Medicare coverage. Beneficiaries can change their minds, disenroll from their managed care plan, and return to "original" Medicare. An election to enroll or disenroll from a Medicare Advantage plan becomes effective the month in which the election is made, regardless of the date of the election.

The Medicare managed care benefit is different from the traditional Medicare "fee-for-service" system, but coverage should theoretically be the same or better. Often a Medicare managed care plan administers the health care treatment of an enrollee by the use of a physician (known as a "gatekeeper") who must approve the patient's referral to specialized care. Some Medicare managed care plans permit beneficiaries to go directly to a specialized care provider, without the gatekeeper's approval, in return for payment of an extra premium.

**DOES MEDICARE COVER PRESCRIPTION DRUGS?**

Historically Medicare has not covered prescription drugs; however, that is changing. There are now a number of ways in which Medicare beneficiaries in general, and people with MS in particular, can receive some assistance with the cost of some of their medications from Medicare.

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MEDICARE FOR MS PATIENTS

MEDICARE PART B FOR CERTAIN INTRAMUSCULAR INJECTIONS

Medicare will cover intramuscular injections that are administered in a physician's office for medications, such as the MS drug "Avonex." Coverage is generally available only for intramuscular, not intravenous injections, and only when Medicare presumes that people in general, not the particular patient, cannot self-inject the drug. This presumption has been made for Avonex. To be covered, the drug and administration must be provided in the physician's office and the services are subject to the Part B annual deductible and twenty-percent copayment. A few Medigap insurance policies will cover the copayment.

MEDICARE DRUG DISCOUNT CARD PROGRAM

From June 2004 to December 31, 2005, Medicare has a discount drug card program. People with Medicare can choose one card for 2004 and another for 2005, to receive a discounted price on those drugs included on the card's drug formulary. While there are dozens of cards to choose from, many do not offer discounts on all (or any) key MS drugs: Avonex, Betaserone, Copaxaone, and Rebif. Individuals need to look carefully to ensure that the card they choose has the best price on the drugs that are most necessary and most expensive for them. Unfortunately, card sponsors may change the drugs and discounts weekly. To find information about the specific cards go to the Medicare agency's website, www.medicare.gov, or call 1-800-MEDICARE.

MEDICARE PART B DRUG REPLACEMENT DEMONSTRATION PROJECT

A Medicare "demonstration project" provides a potential

41. Id.
42. 42 U.S.C.A. §§ 1395l(a)(1), 1395l(b) (West 2005).
44. 42 U.S.C.A. § 1395w-141 (c)(1)(C) (West 2005).
option for assistance for a limited number of people. The Medicare law, passed in December 2003, authorized a demonstration project for 50,000 people for certain drugs specifically related to certain identified diseases, including MS. The other diseases include some cancers, rheumatoid arthritis, osteoporosis, and hepatitis C. There was $500,000 appropriated for this project of which approximately forty percent will be devoted to anti-cancer drugs. Participants for the project are chosen by lottery. The first lottery was on September 1, 2004. Application forms are available on the Medicare agency's website, www.medicare.gov.

**MEDICARE PART D DRUG PLAN**

Beginning on January 1, 2006, Medicare will have a new Part D which will offer some assistance with the cost of prescription drugs. The Part D program will be administered by private entities. Coverage will be available for those beneficiaries who choose to enroll, meet the deductible, and pay a monthly premium. Medicare will then pay for part of the cost of those drugs that are on the chosen plan's drug formulary. After Medicare has paid a set amount of dollars, the beneficiary will be required to meet a second, larger deductible, which has become known as the "doughnut hole." At that point, additional coverage with a lower beneficiary copayment responsibility will begin. Beneficiaries with low incomes will be eligible for assistance with the cost-sharing responsibilities. People eligible for both Medicare and Medicaid will begin receiving drug coverage under Medicare rather than Medicaid.

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46. See CMS Demonstrations Projects under the Medicare Modernization Act (MMA), Center for Medicare & Medicaid Services, at www.cms.hhs.gov/researchers/demos/drugcoveragedemo.asp (last modified Apr. 6, 2005).
47. MMA, supra note 2, at § 641(d).
48. Id.
52. Id.
STATE PHARMACEUTICAL ASSISTANCE PROGRAMS

Approximately thirty states have their own state legislated and administered programs that provide assistance with the cost of prescription drugs, usually for individuals who meet certain income guidelines. To learn more about a particular state's benefit, contact the state agency that administers their Medicaid program.

CAN PEOPLE WITH MS AND OTHER LONG-TERM ILLNESSES RECEIVE MEDICARE COVERAGE?

There is a long-standing myth that people with long-term illnesses and those in need of long-term care are not covered by Medicare. This is not true. Unfortunately, beneficiaries are too often denied Medicare coverage for a variety of services on the grounds that they have a chronic or stable condition, that their condition will not improve, or that the services are to maintain and not to improve their condition.

Medicare coverage determinations should be based on what is medically necessary and on the specific qualifying criteria for the particular health care setting and services. The Medicare Act excludes certain services from coverage, and other coverable services may not meet the qualifying criteria in a given case. However, people should not be denied benefits for otherwise coverable services simply because they have a long-term illness such as MS. Further, beneficiaries are legally entitled to an individualized assessment of their qualification for coverage. These assessments should be made based on valid standards for the particular services at issue, not on generalized assumptions about people with similar diagnoses. This is important for people with MS who are too often erroneously denied Medicare coverage for physical therapy, home health care, and other important and necessary services.

IS MEDICARE COVERAGE AVAILABLE FOR LONG-TERM SERVICES AND LONG-TERM CARE?

Medicare may cover some services for long periods of time. People with MS and other chronic conditions may be eligible for

physical, occupational, and speech therapy as long as the services are skilled and medically necessary. This is so even if the services are needed to maintain the individual's condition rather than to restore prior function.

In addition, while Medicare covers a limited amount of nursing home care in a limited number of circumstances, the Medicare home health benefit, and sometimes the hospice benefit, can be a source of long-term care and coverage for beneficiaries. Indeed, in 1980, Congress made an affirmative decision to extend the Medicare home health benefit to individuals who have not necessarily experienced an acute illness and who need home care for long periods of time. The 1980 statutory changes removed the requirement that the beneficiary have a prior hospital or skilled nursing facility stay in order to obtain home health coverage, and eliminated a 100 visit limitation on coverage.

**Physical, Occupational, and Speech Therapies**

People with MS are often denied necessary physical therapy services on the grounds that they are not going to improve. Importantly, restoration is not the deciding factor in determining the right to coverage. The question for determining the right to coverage should be: Are the skills of a therapist necessary to establish, provide, or supervise the services? Skilled therapy can be needed to maintain the individual's condition or to arrest further deterioration. In such cases, Medicare coverage may be warranted. Each person is entitled to an individualized assessment of his or her right to Medicare coverage. For many years there was a cap on the annual Medicare payment for physical, occupational, and speech therapy. This dollar limit was lifted by Congress in 2003. It will be reviewed again for services beginning in 2006.

58. Id.
60. Id.
62. MMA, supra note 2.
63. Id.
64. Id.
HOME HEALTH CARE

Unlike the Medicare skilled nursing facility benefit, which provides coverage for a short period of time, Medicare coverage can be available for long-term home health care if the qualifying criteria are met. There is no legal limit on the duration of time for which home health coverage is available. Further, Medicare covers home health services in full, with no required deductible or co-payments from the beneficiary. Services must be medically necessary and reasonable and the following criteria must be met:

1. A physician has signed or will sign a plan of care.

2. The patient is or will be homebound. This criterion is met if leaving home requires a considerable and taxing effort, which may be shown by the patient needing personal assistance, the help of a wheelchair or crutches, and so on. Occasional but infrequent "walks around the block" are allowable.

3. The patient needs or will need physical or speech therapy or intermittent skilled nursing.

4. The home health care is provided by, or under arrangement with, a Medicare-certified provider.

If the triggering conditions described above are met, the beneficiary is entitled to Medicare coverage for home health services. Home health services include:

- part-time or intermittent nursing care provided by, or under the supervision of, a registered professional nurse
- physical, occupational, or speech therapy
- medical social services under the direction of a physician
- part-time or intermittent services of a home health aide to the extent permitted in the regulations

66. Id.
The Balanced Budget Act of 1997 (BBA) made significant revisions to the Medicare home health benefit.\textsuperscript{67} These changes were effective for services provided on or after January 1, 1998.\textsuperscript{68} While the BBA did not change the Medicare home health coverage criteria, the changes did alter the payment structure and, in practice, this change resulted in reduction in services, particularly for individuals in need of long term or extensive care. As with the skilled nursing facility (SNF) benefit, denials of Medicare home health coverage should not be predicated upon particular diagnoses or the fact that a patient's condition is chronic or unlikely to improve. Each patient should be provided with an individualized assessment of his or her right to coverage in light of the qualifying criteria. Additional advocacy tips include the following:

1. Medicare coverage should not be denied simply because the patient's condition is "chronic" or "stable." "Restorative potential" is not necessary.

2. Resist arbitrary caps on coverage imposed by the intermediary. For example, do not accept provider or intermediary assertions that aide services in excess of one visit per day are not covered or that daily nursing visits can never be covered.

3. There is no legal limit to the duration of the Medicare home health benefit. Medicare coverage is available for necessary home care even if it is to extend over a long period of time.

4. The doctor is the patient's most important ally. If it appears that Medicare coverage will be denied, ask the doctor to help demonstrate that the standards above are met. \textit{Home care services should not be ended or reduced unless the doctor has ordered it.}

5. In order to be able to appeal a Medicare denial, the home health agency must have filed a Medicare claim for the patient's care. You should request, in writing, that

\textsuperscript{67} See, e.g., 42 U.S.C. 1395d(a) (2005).
the home health agency file a Medicare claim even if the agency told you that Medicare will deny coverage.

**SKILLED NURSING FACILITY CARE**

Medicare provides a limited benefit for nursing home coverage for a limited period of time. Nursing homes are referred to in Medicare as skilled nursing facilities (SNFs). The benefit is available for a short time at best (for up to 100 days during each spell of illness). If Medicare coverage requirements are met, the patient is entitled to full coverage of the first twenty days of SNF care.\(^{69}\) From the 21st through the 100th day, Medicare pays for all covered services except for a daily coinsurance amount ($114 per day in 2005).\(^{70}\) The SNF patient will not be entitled to any Medicare coverage unless he or she was hospitalized for at least three days prior to the SNF admission and, generally, was admitted to the SNF within thirty days of the hospital discharge.\(^{71}\)

There are certain requirements that must be met in order for a patient to receive Medicare coverage which include:

1. A physician must certify that the patient needs skilled nursing facility care.

2. The beneficiary must generally be admitted to the SNF within thirty days of a three-day qualifying hospital stay.

3. The beneficiary must require daily skilled nursing or rehabilitation.

4. The care needed by the patient must, as a practical matter, only be available in a skilled nursing facility on an inpatient basis.

5. The skilled nursing facility must be a Medicare-certified provider.

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\(^{71}\) 42 C.F.R. § 409.36 (2005).
If coverage is available, the benefit for SNF care is intended to cover all the services generally available in a SNF:

- nursing care provided by registered professional nurses
- bed and board
- physical therapy
- occupational therapy
- speech therapy
- social services
- medications
- supplies
- equipment
- other services necessary to the health of the patient.

Examples of services recognized as skilled by Medicare include the following:

- overall management and evaluation of care plan
- observation and assessment of the patient's changing condition
- patient education services
- Levin tube and gastrostomy feedings
- ongoing assessment of rehabilitation needs and potential
- therapeutic exercises or activities
- gait evaluation and training.

Unfortunately, Medicare coverage is often denied to individuals who qualify under the law. In particular, beneficiaries are often denied coverage because they have certain chronic conditions such as MS, Alzheimer's disease, Parkinson's disease, or because they need nursing or therapy to maintain their condition. These are not legitimate reasons for Medicare denials of SNF care. The question to ask is: Does the patient need skilled nursing or therapy on a daily basis; not, does the patient have a particular disease or will he or she recover? Other important advocacy tips include the following:

1. The restoration potential of a patient is not the deciding factor in determining whether skilled services are needed.
2. As previously stated, the doctor is the patient's most important ally. If it appears that Medicare coverage will be denied, ask the doctor to help demonstrate that the standards described above are met.

3. The management of a plan involving only a variety of "custodial" personal care services is skilled when, in light of the patient's condition, the aggregate of those services requires the involvement of skilled personnel.

4. The requirement that a patient receive "daily" skilled services will be met if skilled rehabilitation services are provided five days per week.

5. If the nursing home issues a notice saying Medicare coverage is not available and the patient seems to satisfy the criteria above, ask the nursing home to submit a claim for a formal Medicare coverage determination. The nursing home must submit a claim if the patient or representative requests. The patient is not required to pay until he or she receives a formal determination from Medicare.

**HOSPICE CARE**

Since 1982, Medicare has provided coverage for hospice care. Hospice care is intended to provide palliative and supportive care for the terminally ill and their families rather than treatment for the underlying condition. With the passage of the BBA in 1997, Medicare now covers two ninety-day periods of hospice care and an unlimited number of additional periods of sixty days each. Formerly, Medicare coverage was available for two ninety-day periods, for one thirty-day period, and for a fourth, unlimited period of hospice care.

In order to receive Medicare hospice coverage, a patient must elect to opt into hospice coverage and, as a consequence, out of most other Medicare coverage for treatment of the

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underlying terminal condition. The hospice care must generally be provided by, or under arrangement with, one Medicare-certified hospice program during each period.

To receive Medicare coverage for hospice care, the patient must be certified as terminally ill by the patient's physician or the hospice staff physician, and the hospice care must be part of a written plan of treatment established by the attending physician and hospice medical professionals. If coverage conditions are met, Medicare is available for an array of services, including:

- nursing care
- physician services
- counseling services for the patient and the family or other caretakers
- medical social services
- general inpatient care
- respite care
- home health aides
- homemaker services
- medical supplies, equipment appliances, and biologics (including pain medication)
- physical, occupational, and speech therapy.

**What Can Be Done to Contest a Medicare Denial?**

Because of the size and complexity of the Medicare program and because of the desire to contain costs, Medicare coverage is often denied when it should be granted. Sometimes these denials are a result of errors; sometimes the denials are due to a policy that places cost containment concerns over the needs of individual beneficiaries. Whatever the underlying reasons for the denial, the Medicare program includes an appeals system that is designed, at least in theory, to reverse erroneous denials and to correct mistakes. If the patient's attending physician feels the care in question is medically necessary and the care is not simply excluded from Medicare coverage (e.g., hearing aids, dental

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76. 42 C.F.R. §§ 418.80, 418.82-.84, 418.86, 418.88, 418.90, 418.92, 418.94, 418.96, 418.98, 418.100 (2005).
care, skilled nursing facility care when there was not a prior hospital stay), the beneficiary should appeal.

**WHAT HELP IS AVAILABLE TO PEOPLE WITH MS WHO HAVE QUESTIONS ABOUT MEDICARE?**

The National Multiple Sclerosis Society has an agreement with the Center for Medicare Advocacy to help MS Society staff better understand Medicare and help people with MS obtain the Medicare coverage they are entitled to for necessary health care services.

The following contact information may be useful to advocates and clients:

- National MS Society Information and Referral Center, 1-800-FIGHTMS;