

National Academies

**Committee on Amyotrophic Lateral
Sclerosis: Accelerating Treatments and
Improving Quality of Life**

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Health care goals of individuals living with ALS include access to services and items covered by Medicare law:

- Skilled specialists
- Multi-disciplinary coordinated services
- DMEPOS
- Prescription Drugs
- Home health and hospice services – skilled and custodial

Example #1: Need for Skilled Care in Medicare

- Restoration potential is not the deciding factor for deciding whether Medicare coverage is available
 - “Even if full recovery is not possible, a patient may need skilled services to **prevent further deterioration or preserve current capabilities**”

42 C.F.R. § 409.32

- Improvement is not required for a service to be considered skilled

Example #2: Medicare Home Health Coverage is Not Limited in Time

- Home Health coverage continues to be available so long as skilled care is needed and other threshold criteria are met.

Medicare Benefit Policy Manual (MBPM), Ch. 7, Sec. 40.1.1

- Payment can be made for an **unlimited** number of covered visits, and **there is no limit** on continuous recertifications for beneficiaries who continue to be eligible.

42 C.F.R. § 409.48(a)-(b); MBPM, Chapter 7 Secs. 70.1 & 10.3

Example #3: Medicare Coverage for Home Health Aides

How much can be covered – under the law?

- Combined with skilled nursing, can be covered **up to 28 hours &** any number of days per week as long as provided less than 8 hours each day
 - Subject to review on case-by-case basis, coverage may be available for **up to 35 hours** per week

42 U.S.C. §1395x(m)(7)(b); 42 CFR §409.45(b)

Obstacles to obtain access to services and items covered by Medicare law:

- Medicare generally focuses on patients who get better.
- Medigap plans are not available and/or prohibitively expensive.
- Private Medicare Advantage plans are not adequate
- CMS Fraud/Waste/Abuse deterrents interfere with access.
- CMS Payment/reimbursement systems favor short-term improvement goals.

Recommendations to increase access to services and items covered by Medicare law – Congress:

- Pass federal protections for Medigap coverage.
- Remind CMS that Medicare should not discriminate.
- Amend the Social Security Act to expand payment outliers.
- Hold hearings to expose and explore 1. significant obstacles to legally covered services, and 2. MA plans concerns.
- Expand Medicare Savings program to pay Medicare cost sharing – eliminate asset test, increase income thresholds.

Recommendations to obtain access to services and items covered by Medicare law – CMS:

- Design programs that incorporate unique ALS needs.
- Revise the culture of CMS to not always focus on improvement – messaging that other patients secondary.
- Retrain contractors, auditors, and providers to value & respect all patient rights.
- Require more accountability from MA plans.
- Use CMMI to focus on access to necessary services.