



People with ALS Should Have Access to the Medicare Home Health Benefits They Deserve

The ALS Association is ramping up its efforts to make sure people with ALS who rely on Medicare have access to home health care benefits.

“Many people in the community, including people with ALS, people within our chapters, and our clinical partners, have told us about the serious and persistent challenges faced by Medicare beneficiaries with ALS,” said Dr. Neil Thakur, executive vice president for mission strategy at The ALS Association. “Many such beneficiaries, despite being fully qualified, are turned down for the home health benefits they deserve. Other beneficiaries are able to receive Medicare home health but deal with inadequate hours of service and inappropriate termination from care.”

“The root of the Medicare home health access problem is that laws and regulations discourage providers from adequately serving people with ALS,” Dr. Thakur added. “The current system limits the number of high-cost patients a home health agency can serve. It also underpays for such patients by at least 20 percent.”

The ALS Association is working to convince policy makers to change the law and regulations. Here are a few actions we are taking to do that:

- This summer, we talked with the top officials at the Centers for Medicare and Medicaid Services (CMS) – advocating on home health, hospice, and durable medical equipment.
- We submitted formal comments to CMS in late September, urging the agency to: 1) take action to stop stopping avoidance, underservice, and inappropriate discharge of people with ALS and to 2) find ways to fix the reimbursement system so that people with ALS can be adequately served.
- On October 22, we had hosted a focus group meeting with nearly 40 key staff from our chapters. The meeting focused on solutions for people living with ALS, particularly how to improve access to home health benefits.
- We are seeking funding for a wide range of other advocacy initiatives related to the Medicare home health benefit – including research to collect the data needed to change legislation and regulations.

CMS is responsible for reimbursement and regulation of the Medicare home health benefit. The agency spent about \$18.1 billion on home health care services to serve more than 3.5 million Medicare beneficiaries in 2015.

As mentioned previously, flaws in Medicare's reimbursement system make it hard for people with ALS to access the benefits they need – even if they meet all criteria. To be eligible for Medicare's home health benefit, a beneficiary must be home-bound and require skilled nursing or therapy.

In addition, a physician must order and supervise care for a 60-day period – which may be renewed as many times as needed. Find out more about the benefit here.