

ALS patients face loss of Medicare coverage for speech-generating devices

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Beginning December 1, people with ALS, which impairs motor function so people often cannot talk or even move, could lose access to devices that help them communicate, Kaiser Health News reports. The change is the result of a federal review of what is covered under Medicare, the social insurance program for the elderly and disabled administered by the federal government.

People with ALS, or amyotrophic lateral sclerosis, rely on speech-generating devices and other technology to communicate. Medicare has historically covered 80 percent of the cost of basic speech generating devices. Patients could then pay out-of-pocket for upgrades to connect the device to the Internet and to perform services such as opening doors.

In February, however, the Centers for Medicare and Medicaid Services (CMS) posted a “coverage reminder” noting that the program does not cover the cost of the upgradable devices. This means that Medicare will only cover the cost for basic speech-generating devices, not the models that can be upgraded to perform tasks beyond speech generation, or tasks not considered “medical.”

CMS spokesman Aaron Albright told Kaiser in an email the “coverage reminder” was part of a review by Medicare contractors to make sure the devices used by ALS patients “comply with our coverage rules and the Medicare law.” Albright said the review had been suspended until December to address ALS advocates’ concerns. If the change takes effect, it will effectively bar patients from the type of machines they have been able to obtain from Medicare for years.

According to the ALS Foundation, approximately 75 percent of all people diagnosed with ALS will need some form of communication assistance as the disease progresses. While speech disturbance varies from

patient to patient, most will experience a severe communication disorder during the last few months of life. The foundation notes that a study of ALS hospice patients found that only 25 percent could speak understandably during the terminal stage of the illness.

The cost of a speech-generating device (SGD) begins at around \$4,000. As patients purchase additions, however, such as eye-tracking technology, the price tag can rise to \$15,000 or more. Under the new rule, Medicare insured ALS patients would only be covered for basic, non-upgradable SGDs, not those that can be connected to the Internet, or that perform basic functions such as turning on room lights.

Patients would thus be denied access to a range of free and relatively low-cost technologies available on the Internet enabling them to communicate and perform basic life functions. While the costs of these upgrades have never been covered, the change would mean that patients would have to pay the entire cost of the upgradable device, making their availability out of reach for the majority of patients and their families.

The threat of this cruel rule change comes on the heels of another federal rule change that took effect in April, which requires Medicare patients to rent SGDs for 13 consecutive months before being allowed to own them. ALS advocates also say that Medicare has already begun denying claims for eye-tracking technology, which uses patients’ eye movements to input commands in speech-tracking devices. The technology is vital to those patients who are “locked in,” those who are conscious but cannot move or talk.

Under this requirement, ALS patients can temporarily lose access to the machines they have been renting if they go to hospice or are admitted to the hospital, because Medicare suspends payments for the machines under such circumstances. Although patients in these

facilities are supposed to be provided with SGDs, the devices are often not appropriately customized for patients needs. Also, once patients are released, the 13-month rental period begins anew and they may not be able to claim their previous devices.

The 13-month rental requirement, combined with the possible denial of coverage for the upgradable speech-generating devices, poses a particular hardship to ALS patients in the final stages of the disease. While the denial of Medicare coverage for eye tracking is often reversed on appeal, this may come too late for those who are deprived of their one means of communication in the final days of life.



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