



A Reason for Hope

National Office

The Amyotrophic Lateral Sclerosis Association

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The ALS Association is the only national not-for-profit voluntary health organization whose sole mission is to find a cure for amyotrophic lateral sclerosis (Lou Gehrig's disease) and improve living with ALS.

Member National Health Council

March 1, 1999

Nancy-Ann Min DeParle
Commissioner, Health Care Financing Administration
US Department of Health & Human Services
Suite 314G, Hubert H. Humphrey Building
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Ms. Min DeParle:

The ALS Association (ALSA) is seriously concerned about Medicare's policy that fails to provide augmentative/alternative communication (aac) devices to people living with Amyotrophic Lateral Sclerosis (ALS). I am writing to ask you to give this issue your highest attention and to provide the necessary leadership to change existing policy that we believe is uninformed and leads to devastating consequences for a small, but vulnerable group of Americans.

ALS is a progressive, fatal neuromuscular disease that attacks and destroys motor neurons leaving the people who are stricken with this disease paralyzed. The progressive paralysis leaves many people without the ability to speak, swallow, move their limbs or breathe. Despite their overwhelming physical disability, the vast majority of people with ALS remain as mentally alert and competent as they were prior to developing ALS.

It is difficult for those of us advocating on behalf of people with ALS to understand the rationale as to why Medicare fails to provide aac devices for its beneficiaries with ALS. We are informed that the Medicare Carriers Manual, section: 60-9 classifies aac devices as durable medical equipment that should be denied because they are items of "convenience." As you might imagine, Medicare's designation of aac devices as "convenience items" for people with ALS is unfathomable to those of us in the ALS community. Knowing that Medicare does cover expenses related to an artificial larynx and the services of speech-language pathologists makes the denial of aac coverage in ALS seem inconsistent and baffling.

People who have lost their ability to speak due to ALS but are fortunate to have an aac device continue to be productive in the workplace and to society, maintain effective personal and family relationships and are able to participate in decisions about their health care. Imagine the world of a totally paralyzed person with ALS who does not have a communication device. They are desirous and capable of being productive, maintaining relationships and being an active partner in decisions about their health care and life, but cannot do any of these things simply because they lack a tool for communication. How can anyone characterize the ability to communicate in this situation as a "convenience?"



Every week ALSA hears from the family members of people with ALS who have no voice. The stories of dying and lost relationships and the reality of mentally competent people locked inside a world without movement or communication put real names and faces on this tragedy.

The ALS Association urges you to make this issue a priority and help people with ALS continue to be productive in the workplace and to society. We are confident that when the reality and consequences of the Medicare language is reviewed, you will agree that change is imperative. ALSA stands ready to work with the agency and to bring ALS and speech pathology experts to assist your review. Steve Gibson, our Vice President for Government Relations in Washington, will follow-up with you next week to answer any questions you may have. Thank you and I look forward to hearing from you in the near future.

Sincerely,

A handwritten signature in black ink, appearing to read 'M. Havlicek', with a long horizontal flourish extending to the right.

Michael W. Havlicek  
President

cc Senator Robert Torricelli, United States Senate  
Congresswoman Lois Capps, United States House of Representatives  
Donna Shalala, Secretary of the Department of Health & Human Services  
Harriett Rabb, General Counsel, Department of Health & Human Services  
Chris Jennings, White House Health Policy Advisor  
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