

The silence and isolation that comes from losing the ability to communicate does not discriminate between types of injuries, diseases, accidents or conditions. Speech Generating Devices (SGDs) are a critical pathway out of the silence and isolation for those who have experienced strokes, traumatic brain injury, cerebral palsy, Parkinson's, ALS, spinal cord injuries, chemical accidents, many other types of injuries, and other complex neurological conditions.

I have ALS (Lou Gehrig's Disease). When I was diagnosed in 2011, I was expected to fade away quietly and die, much like Lou Gehrig did after his famous speech 75 years ago. I am unable to move my body, except for my eyes. Through the use of eye tracking technology, I communicate through a device much like a tablet computer. This tablet is called a Speech Generating Device - SGD. The SGD allows me to maintain contact with the world around me – to express my thoughts, feelings and needs. It allows me to participate in everyday life with my family, friends, and community, to retain some independence. To continue living productively and purposefully.

A few others who have used SGD's to communicate include Professor Stephen Hawking, and critic Roger Ebert. Imagine a world where they were silenced. Just as important are the tens of thousands who use this technology daily to continue living their lives with purpose. Teachers continuing to teach, architects continuing to design, veterans reentering society, and parents continuing to parent.

Congress is on the verge of considering legislation, known as the Steve Gleason Enduring Voices Act of 2017, that continues to allow Americans covered by Medicare to have uninterrupted coverage of their ability to communicate. Without this legislation, Medicare could once again take away a person's SGD if they have to leave their home to be admitted into a

health care facility. Without the current Steve Gleason Act, Medicare took away a person's SGD if they chose to elect home hospice care. Without the Steve Gleason Act, Medicare may not have covered the accessories that are necessary to make an SGD work properly. Without this removing the sunset to the Steve Gleason Act and passing the Steve Gleason Enduring Voices Act, we will be turning the dial back to the days of Lou Gehrig, when people with debilitating diseases were simply expected to fade away quietly and die. That is not ok.

The Steve Gleason Enduring Voices Act removes barriers to continuous, effective SGD Medicare coverage. It provides complete confidence and security. If a person qualifies for an SGD, they will be allowed to communicate for the rest of their lives. Medicare will not take away their SGD nor ability to communicate, and be productive. They will not be silenced nor isolated when they are the most vulnerable.

The Senate and House passed the previous Steve Gleason Act unanimously. It was signed into law and proven successful with no fiscal impact.

People who use SGDs are assured they have access to communication without fear of being silenced and isolated. People may have come to need SGDs by way of many types of injuries, diseases, accidents, or conditions, but like everyone, they all share a fundamental human need to communicate and live purposefully.

We need your support to help pass the Steve Gleason Enduring Voices Act. Every day that passes without this legislation means people who want to be productive, fear they will be forced to fade to a silent death.

