

I write this testimony in support of the Steve Gleason Enduring Voices Act of 2017, a bill to revise the Steve Gleason Act of 2015. I write in support of individuals across the country who are unable to communicate via natural speech and must instead rely on Speech Generating Devices (SGDs), an electronic means of communication used by individuals with debilitating conditions such as ALS, MS, Parkinson's Disease, Locked-In Syndrome, cerebral palsy, aphasia, and others. Imagine for a moment, that you have suffered a severe stroke, or that you are living with ALS. It has robbed you of your ability to speak and to write. You cannot control the movements of your body. You are completely aware of and understand the things that are happening around you. Your child comes home from school and tells you he has been elected class president. You are so incredibly proud, yet you cannot tell him. You would dearly love to give him advice, but you cannot. Later that night, as your wife helps you get ready for bed, you want to tell her what she means to you, tell you how much you love her. But you cannot. This is what communication devices allow individuals to do – participate in the various communication opportunities that arise on a daily basis.

The Steve Gleason Act of 2015 removed SGDs from the category of capped rental and reinstated them in the category of frequently purchased equipment. Simply put, it ensured that beneficiaries would have access to their necessary and personalized communication technology, even in the event of residence in nursing home, hospital, or hospice. The Steve Gleason Enduring Voices Act of 2017 will remove the sunset date, protecting extremely vulnerable Medicare beneficiaries from ever having to relinquish their only means of communication.

Communication devices have been a covered benefit under Medicare since 2001. Putting them in the category of rental equipment does **not** change this. What it **does** change is the ability of those most vulnerable to continue to use their technology. If an SGD is a frequently purchased device, Medicare pays the manufacturer in one lump sum. The beneficiary then owns the device and can take it with her, even if she must move out of her home and into a hospice, hospital, or nursing facility, or begins to receive hospice services at home. While communication is always important, it is uniquely crucial

when circumstances, providers, and caregivers change. Under capped rental, instead of Medicare making a payment in one lump sum to the manufacturer, payment is made in 13 monthly increments. Therefore, the beneficiary does not own the device until the 13 months have passed. So if the device is not paid for and the beneficiary must change residence (sometimes even briefly), Medicare no longer pays for the device and the user cannot communicate.

Communication devices are uniquely configured to individual patients. Not everyone wants to say the same thing. One person's end of life wishes are not the same as another's. Some people have such limited movement that uniquely customized physical access such as eye gaze is required. Individuals may have hundreds of phrases stored to facilitate quick and meaningful communication. Current technology allows an individual to use message banking, a process where a user with an acquired condition can store messages in his own voice and then customize those messages to be available in his SGD. Nursing homes, hospitals, and hospices are unable to provide a uniquely configured substitute SGD when one has been taken away.

The impact of losing a voice under capped rental is incalculable. No one ever knows if/when their situation will change. The only way to keep a personally configured communication device with the individual who needs it at all times is up-front purchase. There was a 6-month period in 2014 when capped rental was in place. This resulted in people delaying critical care because they feared loss of their communication device. People died without being able to say goodbye to their loved ones.

While unintended, these consequences were and would be devastating.

I'd like to end by sharing a note I received from the family of an ALS patient one week after she passed away. It said: *Dear Lisa, Debbie's last words were spoken on the ALS eye gazer [communication device] 2 hrs before she passed. "Love you all". That included you and the ALS staff I'm sure. Thanks.*

Please help ensure that patients who cannot speak have unrestricted access to the communication

devices they require and pass the Steve Gleason Enduring Voices Act of 2017.

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## Summary

- Individuals who are unable to communicate verbally using natural speech can do so using Speech Generating Devices (SGDs), also known as communication devices.
- These devices are an electronic means of communication, allowing the individual to access stored messages and also to generate novel messages using text, words, pictures, or any combination thereof.
- SGDs have been a Medicare covered benefit since 2001.
- The Steve Gleason Enduring Voices Act permanently retains communication devices in the payment category determined by the original National Coverage Decision.
- This permanent legislation is necessary because of a 2015 CMS rules change that on the surface wouldn't have seemed devastating, but when implemented caused people to have their "voices" taken away when they were most vulnerable.
- Although the Act is named for Steve Gleason, a former NFL player who has ALS, the disease is only a small percentage of the conditions whose patients benefit from the acquisition of communication devices.

## Testimonials (appendix)

My name is Diane Georgoudakis, and I am writing this to you with the help of my mother who is writing down words I want to say from nodding my head to the alphabet. This is very time consuming and tedious for both of us. Normally, I would use my speech generating device, but it has been in for repair for quite some time now. It seems like forever being that I use it on a daily basis. I am very miserable without it since I have been using a device for 10 plus years now.

Stroke is a brain attack and one of the leading causes of long term disability.

Without my device, I am unable to express my thoughts or join in conversation with others in the same room; and/or do activities on my own that help keep my brain stimulated.

I do so much with my device; it is my access to the outside world. For instance, I belong to an on-line stroke support group where I have made many friends. We all give each other advice, support, and encouragement. I keep in touch with family and other friends via e-mail, and social media. My sister and her family live out of state, and my sister sends me pictures on the internet of my growing niece and nephew who are particularly important to me.

I also shop on-line giving me the independence to pick out my own clothing, and any other items I might need. I was very independent before my stroke, so this helps.

Being 22 when I had my stroke was such an overall shock to the system, that any independence helps a great deal.

I like to keep up on the latest research and breakthroughs and tell my doctors if need be.

I do this with the help of my speech generating device by preparing a message beforehand.

I also like to research political candidates and keep up with current events. I belong to an on-line association where I am able to e-mail senators, heads of corporations, etc, and make my voice heard.

As you can see, I do many things with the internet capability on my speech generating device.

That being said, do keep in mind that I, not Medicare, pay for my own cost of having internet accessibility. Please take into consideration that others need this capability as well!

Thank you for taking the time to read this.

Sincerely

Diane Georgoudakis

CS, wife of a person with ALS, describing her husband's end of life experience. *"He was having a great deal of difficulty breathing and simply could not get comfortable in his hospital bed or wheelchair. We decided to go with in-hospital hospice since his pain management was not well controlled. In hospice, he regularly used his [eye gaze-accessible] SGD to tell us what he wanted and what he didn't want. I am so grateful that he was able to use it extensively during the last few days of his life. I don't know what we would have done without it."*

