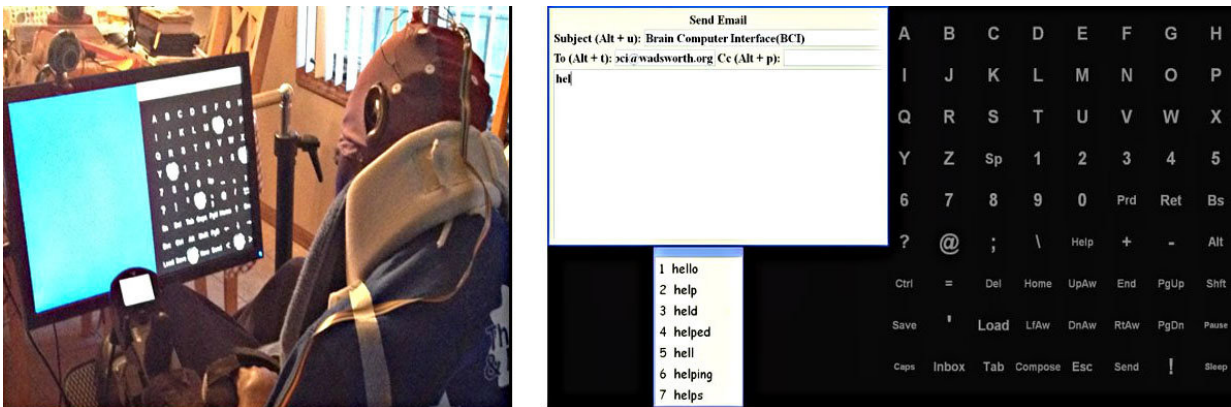


# First in-home test of brain-computer communication by ALS patients offers promise amidst challenges

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Left: A home user operating the BCI. Right: BCI operation illustrated with the email application. The 72-item matrix of possible selections (letters, numbers, functions) is equivalent to a full keyboard. To make a selection, the user pays attention to the desired item as groups of items flash in rapid succession. The email message appears at the top. A predictive speller option is below the email. After spelling "hel," the user can complete the word "hello" quickly by selecting the numeral "1." Credit: Jonathan R. Wolpaw

Laboratory studies have shown the potential for patients with amyotrophic lateral sclerosis (ALS), who cannot move or speak, to communicate using a brain-computer interface (BCI). In the first study of independent in-home use by a group of these patients, the brain wave-

based BCI system was found to be reliable; and of the eight individuals who completed the study, seven chose to keep the device for future use.

A BCI offers individuals with ALS, and other neurological disorders, which can severely impair speech and other movement, a way to communicate using only [brain signals](#) translated into words through a computer interface. The user wears a cap with electrodes that record brain-based EEG signals as the user faces a computer screen. Although these patients may not even be able to control eye movement, their brain signals can indicate when the letter they wish to select flashes. The BCI system detects the EEG signal that is produced when a desired letter flashes and translates that to selection of that letter. Thus, users can type messages. If the array of available selections on the computer screen includes commands (e.g., say something (via a voice synthesizer) to a visitor, write and send an email message), users can communicate these commands without needing to spell out each letter of a word.

BCI technology has been under development with continual improvements for nearly 30 years. The unique aspect of the study was explained by Michael Wolfson, Ph.D., director of the Program in Rehabilitation Engineering and Implantable Medical Devices at the National Institute of Biomedical Imaging and Bioengineering. "BCI use by individuals with ALS has been tested in research laboratories for many years. Those studies featured one patient at a time surrounded by numerous experts and support staff involved with training the individual to use the system, setting things up, and trouble shooting. This is the first study that tested the real practicality of an individual with ALS using such a system independently at home."

The study was an important step in answering the basic question of whether a BCI system can and would be used by ALS patients who are severely disabled and are dealing with the complexities of managing their disease at home—without a cadre of experts to help. In the research

article published in the July issue of *Neurology*, and in an accompanying editorial about the significance of the study, the answer to the central question was a simultaneously frustrating and encouraging, "It's complicated."

The research was led by Jonathan R. Wolpaw and colleagues from multiple VA centers around the country; the editorial was written by Niels Birbaumer and Leigh Hochberg, experts in the field who were not involved in the study.

Participants were all men with advanced ALS. None had progressed to complete locked-in syndrome (CLIS), the condition in which a patient is aware but cannot move or communicate at all due to complete paralysis of all voluntary muscles in the body.

The devastating course of advanced ALS was a significant complicating factor; 12 of the 27 individuals who had the BCI placed in their homes left the study within a few months due to factors that included death or rapid disease progression. Additional reasons individuals left the study included loss of interest in participating and loss of the caregiver who had been trained to assist with use of the system. The caregiver provided about 30 minutes of time per session.

The individuals who mastered BCI use were followed for up to 18 months. During about 40% of total days in the study period, participants were unable to use the BCI because they were hospitalized or too sick at home. Nevertheless, participants used the system on average two days a week and those sessions lasted about one and a half hours each, with users averaging three selections per minute. A selection could include a letter, a word, or an icon or command like "send email."

Wolpaw and the research group concluded that "the BCI system could function reliably and usefully when operated by patients in their homes."

In addition, "patient and caregiver ratings indicated that BCI benefit exceeded burden." And finally, "BCIs that support communication are at present most suitable for people who are severely disabled but are otherwise in stable health."

In the accompanying editorial on the work, Birbaumer and Hochberg point out that the objective measures of how often the individuals used the BCI, and the relative inefficiency of the system would make it easy to conclude that this was another frustrating trial result in ALS.

However, they highlight what they call the "silver lining" in the study, which was the fact that seven of the eight participants who completed the study opted to keep the BCI. They conclude that those seven viewed the system as having either current or future value.

And Wolpaw agrees. "Our results showed that there is a group of ALS patients who have the ability to use the system and that group receives benefit from the system."

Wolpaw, Birbaumer, Hochberg, and their research teams are all working to improve BCI systems to increase efficiency of communication and to help even the most debilitated individuals with ALS continue to communicate. In addition, they all agree that it is essential to combine the rapidly evolving technologies with practical assessments of in-home efficacy of the devices in order to give clinicians the best information available to help guide their patients when making decisions about assistive options.

**More information:** Jonathan R. Wolpaw et al. Independent home use of a brain-computer interface by people with amyotrophic lateral sclerosis, *Neurology* (2018). [DOI: 10.1212/WNL.0000000000005812](https://doi.org/10.1212/WNL.0000000000005812)

Niels Birbaumer et al. A useful communication in brain-computer interfaces, *Neurology* (2018). [DOI: 10.1212/WNL.0000000000005804](https://doi.org/10.1212/WNL.0000000000005804)

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