



Keeping Communication Open

Has ALS/MND impacted your ability to speak or otherwise communicate?

Father Sophronios from Chania Crete offers his perspective on how to keep communication open. In his words, “Although I may have lost my voice, I have not lost my ability to communicate. Thanks to my computer system I am in regular communication with friends and loved ones. I feel alive through this communication. I have meaning and purpose. I don’t feel closed in or cut off. Please don’t shut down; open up and communicate.”

Being able to communicate with family, colleagues and friends helps maintain independence and positive feelings. Muscle weakness, atrophy and paralysis cause speech to become difficult or impossible for someone living with ALS/MND. However, communication can be continued through other means.

Many clinics provide access to a speech therapist who teaches strategies to combat slurred speech, improved breath projection and strengthening exercises for the tongue, lip and palate muscles. Exercises can be as simple as practicing exaggerated enunciation by reading a book or newspaper out loud for a few minutes each, pronouncing each syllable slowly and loudly and taking deep breaths to assist projection. Even though a person’s ability to speak may be diminished, continuing to speak helps maintain the ability to speak. Fortunately, technology has advanced significantly so that alternative forms of communication are available to help express ideas, thoughts and needs.

Computers:

Computers offer tracking and eye gaze interaction programs today that are both affordable and easy to operate. Tobii Technology and DynaVox EyeMax are two of the more popular systems available. Complete operations are possible through an eye gaze system or one that functions through a small dot on the forehead. Light touch switches, such as the Micro-Light or NeuroSwitch are also available alternatives. Improvements to these systems are constantly being made. Some clinics have samples available so that deciding which type of system is preferable can be made through a hands on experience. Many products are covered by Medicare and private insurers as well.

Software developer Julius Sweetland developed OptiKey, a new program that allows



ALS
worldwide

Personal Experience
Unwavering Optimism
Passionate Collaboration

patients to utilize a computer keyboard using only their eyes for just a fraction of the cost of traditional eye tracking software after his aunt passed away from ALS/MND. OptiKey can be used on a Windows computer for as low as \$100, which includes the purchase of an eye tracker. (It can also be used on Mac computers by using a program called Parallels.) Sweetland is currently in the process of getting a formal trial arranged with the Putney Royal Hospital for Neurodisability in London, but until then, OptiKey itself is completely free, open-source, and downloadable at OptiKey.org.

iPhones and iPads:

Apps for mobile devices, like phones and tablets, offer portability, are easy to use and can provide a less expensive option. [Small Talk-Dysphagia](#) provides a vocabulary of pictures and icons that speak in a natural human voice. [Small Talk – Oral Motor Exercises](#) offers videos of strengthening exercises for the mouth, tongue and lip. Both cost \$19.95. However, Small Talk - Aphasia is free and provides a vocabulary of pictures and videos that resemble a natural human voice. [Ispeech](#) is new on the market is an excellent app with many voice options to choose from. Another alternative is the [Predictable App](#) which offers text to speech scanning but is more expensive at \$159.99.

Low-tech Boards:

Partner-assisted scanning with low-tech boards can be a stop-gap option to consider, even as high-tech options are explored further. Essentially, the partner points to individual letters, words, or sentences and the person with ALS/MND signals their selection with a hand gesture, nod, blink or agreed upon indication.

The Waisman Center at the University of Wisconsin-Madison—dedicated to research about developmental disabilities and neurodegenerative diseases—has created a series of [free training videos](#) in Augmentative and Alternative Communication on their website, an excellent resource for communication exploration.