“The eyes have but one language everywhere.”

–George Herbert, English poet and clergyman (1593–1633)

Four centuries after
George Herbert first offered those words, the message applies to Wayne Carter of Los Angeles and Daniel Sargent of West Palm Beach, Fla., in a fresh way.

The men see their eyes as the ticket to enjoying a dependable voice and ordinary acts they once gave little thought to, like calling their wives, talking sports with buddies or changing TV channels.

Confronted with declining natural speech and physical movement from the effects of amyotrophic lateral sclerosis (ALS), Carter, 55, and Sargent, 50 (Sargent lost his battle with ALS last November), integrated eye-controlled augmentative and alternative communication (AAC) technology into everyday life. It eased the challenge of living with the progressive neurological condition, also known as Lou Gehrig’s disease.

See & Say
The technology, developed on the same principles as eye-gaze systems historically associated with military maneuvers, provides ready access to conversational language, the Internet and consumer electronics for people who cannot speak comprehensibly and typically rely on wheelchairs for mobility.

Eye gaze is often a preferred method of communication access for adults with ALS who cannot reliably select vocabulary or command buttons from the dynamic display on an AAC device by hand, head or other body movements.

Instead, they use an accessory attached to the device and calibrated to the movements of their eyes. It follows the movements with a camera, and when the person blinks in a deliberate, relaxed manner, the device speaks their desired words or executes specific commands such as sending an e-mail or text message. Some people, particularly when fatigued,
forego blinking and access the device by fixing their gaze on a selection for a few seconds before it is activated.

Sophisticated electronic eye-gaze systems with voice output, like those used by Carter and Sargent, bring communication into real time and keep it dynamic.

New Lease on Life

Sargent and his wife, Mary, pursued that option after hearing about the technology at an ALS support group meeting and seeing it on TV. When it became apparent Dan’s speech would not always be intelligible, his clinicians at the University of Miami ALS Clinical and Research Center referred him to the speech clinic at Nova Southeastern University (Fort Lauderdale, Fla.) for an AAC assessment. He then decided the eye-gaze system was his best option.

“We started early,” says Mary. “We heard from several people not to wait until you’re in desperate need of it.”

They’re glad they listened. Dan used the system to direct his daily care. Through its text-messaging capabilities, he could reach his daughter Kelley and son Sean easily. Mary says Dan even texted her when she was in another room at home. She worried less about little things.

“He’d be watching TV and it would go to some stupid show,” she says. “He had no way of changing the channel.”

Dan’s use of residual speech to communicate was more practical at some times than others. After obtaining the AAC system, a DynaVox EyeMax System, a little over a year ago, he said it gave him “a new lease on life” in a thank-you note to Nova staff.

The system made him the center of attention at a niece’s graduation party. He went up to people he hadn’t seen in a while and conversed fluently.

“A lot of people might be intimidated by it, but it’s quite easy,” Dan said.

Magical Conversation

Carter, a U.S. Army veteran, got a similar system following a speech-language assessment at the Greater Los Angeles VA Healthcare System. After seven years of service in Washington state, Korea, Germany, and Hawaii, he and his...
wife, Christine, settled in Southern California, where he was stationed last. Wayne tweaked plans for a career as a locksmith with news of his ALS diagnosis in 2003. Religious faith saw him through the ensuing changes.

An exciting turning point came on February 14, 2011, with Wayne’s acquisition of the AAC device. He wished Christine and his nurses a happy Valentine’s Day in one of his first messages conveyed through it.

“I was computer illiterate,” says Wayne. So he asked lots of questions about the technology and became acclimated to it by hands-on exploration. “I like challenging myself.”

The consistent setup of device content helps Wayne and his conversation partners. He uses a combination of preprogrammed vocabulary and the device keyboard. Wayne shares with other residents information he receives as vice president of the CLC resident council. His smooth transition to eye-gaze communication as his natural speech fades leaves friends in awe.

In addition to the eye-gaze component, Wayne uses a telephone accessory with the device to call his wife, who lives 45 minutes away and travels by bus for their daily visits. They find something almost magical in the flow of their conversations and have adapted to new realities of talking in person, such as Wayne’s need to look at the device screen, not his partner, when composing messages on the system.

Once new partners see what he’s doing, they intuitively understand and wait.

“I make eye contact after I have used the device,” says Wayne. “They can look at my facial expressions, and I can see their reaction. I also make eye contact when they talk.”

**Art Is in the Eye**

For many others, eye access proves the fastest, easiest and most accurate means of self-expression, says Stephanie Adkins, MA, CCC-SLP, senior speech-language pathologist at Texas Children’s Hospital in Houston.

“You definitely have to build up a tolerance for it,” she says. Once that happens, many achieve greater success than by pressing a switch.
Megan Fry, 12, of The Woodlands, Tex., has cerebral palsy and used switch access for years before transitioning to an eye-gaze AAC system that connects to her personal computer.

A budding artist, Fry uses eye gazing to run her painting software. A longtime horseback rider, she donated her painting of a horse for a charity art auction benefiting the SIRE therapeutic equestrian program last year. The painting sold for $7,500.

**What’ll You Have?**

Assistive technology specialist Phyl T. Macomber, MS, ATP, offers two analogies when discussing the etiquette of communicating in this manner.

Choosing your words from a display via eye-gaze techniques, she says, is like ordering in a restaurant. Listeners must give the augmented speaker a chance to look at the menu of vocabulary selections and compose a message. It is understood that the speaker is ready to convey the message when he/she resumes eye contact, as a waiter may know customers are ready to place an order. After delivering the message, the speaker maintains eye contact while waiting for a response, as diners do when anticipating a waiter’s comments.

Augmented speakers need to see partners from a comfortable angle. With the AAC equipment between them, it’s natural for partners to move behind the person using it or to the side, but it’s often better that they stay in front of the device so the speaker doesn’t have to turn to see them.

Taking breaks is important while using an eye-gaze system, Macomber says, and have a designated spot nearby to rest your eyes.

Eye access has varying degrees of effectiveness, depending on eye moisture, color and shape. Drooping of the upper eyelids (ptosis) may preclude its use. It may not work with certain types of eyeglasses, or for individuals with conditions affecting eye movement or alignment, such as nystagmus, presbyopia, or strabismus.

For more information, visit dynavoxtech.com/products/eyemax.