Communicating with ALS: A Caregiver's Perspective

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Premise

One of the unfortunate consequences of ALS is the significant problem of communicating with the patient. When the disease progresses to the stage of tracheotomy for continuation of breathing, the ability to communicate verbally is gone and secondary measures need to be implemented.

Observations

The most primitive of these is the letter board. This device is a chart of letters and numbers arranged in rows and columns. The caregiver points to a column until the patient responds by eye movement, then points to items down the rows of the column until selection confirmed. This is terribly slow and tedious usually results in frustration of all parties. This is a last resort option.

Probably the most common technologies offered to ALS people are computer aided communication systems known as Augmentative and Alternative Communication (AAC) devices. These are normally laptop computers running the Windows operating system and the provider's proprietary software. An infrared (IR) camera is mounted on the bottom of the laptop and functions by means of a reflection from the eye(s) which simulate mouse movements on the screen. Embedded software then interprets these movements and allows writing text, which can then be spoken by the computer voice. This also allows controlling things such as TV, DVD, etc., running Windows applications, like browsers and email, and other functions set up for users.

AAC is a great idea in theory, but there are problems associated with this technology. The Windows operating system tends to become bloated with accumulating broken links and data debris and requires occasional tech intervention to keep things running efficiently. These devices are expensive and, for most people, will require some sort of financing, usually provided from a government program and usually with a significant waiting period prior to approval. Most systems are designed for children and/or intellectually challenged persons which results in usage limitations for those with ALS who are largely more mature and intelligent. The learning and adaptation curve is quite long so a large investment and time and effort is required by both users and caregivers who are not necessarily technologically savvy. This can lead to limited and ineffective use of these system. The screens, while fine for interior locations, are not useable in bright light conditions such as outdoors or in a vehicle since they are simply too dim to be seen during daylight hours.

Although there have been tremendous advancements in computers and cameras, the software available is basically unchanged in the 16 years of our usage. Providers of AAC devices have done very little development in their systems and appear to simply put the same software on the newer devices. Perhaps this is because there is no great financial reward for investing in advanced development. This is a relatively limited market and usage, for the most part, ends up being short lived.

Another issue is how to communicate at night when in bed and the AAC is not available. Alarms will go off on the ventilator if things are not within settings, but what if a pressure point develops on a shoulder or the neck starts aching or a mosquito lands on the nose? Caregivers do need sleep occasionally and, even with good scheduling, it's difficult to have eyes on twenty-four hours a day. We've kludged up an alarm using piezo electric disks placed on the forehead (where there is still small movement) and, although effective, this is not a failsafe system due to dead batteries and failed sensors.

Future Hopes

From the caregiver's viewpoint, what do we hope for the future? As stated above, it appears the major providers of AACs are simply repackaging their existing software into newer hardware technology. If there were an effort to rethink the software application, it's likely that more effective systems could result.

Elon Musk, of Tesla electric vehicle fame, is developing a "neuralink system" which involves implanting sensors in the brain. Others, primarily in universities, have been studying this or a form of it with a sensor cap to be worn on the head. To date none of these systems have seen use in the real world. Not really sure how to feel about this solution as of yet and it's apparently some time away

Military aircraft for a couple of decades have been using "heads up displays" (HUDs) where images are visible on the forward windscreen or helmet visors. These give aircraft status, environmental and weapons data to the pilot without having to look down at gauges. Certainly, this technology is mature enough to be adapted to assist disabled persons.

In some industrial processes, cameras are employed to inspect widgets as they pass by at high rates of speed. Such systems are able to process an image through computer algorithms (software) to determine if they are correct or should be rejected. Why shouldn't this type of imaging processing be available to non-communicating people? For example, if a patient is in bed with no AAC set up and

attention is needed, a camera or maybe even a cell phone could be set up to focus on the face. As the eyes open wider, or move left, right, up, down, or close, visual attributes change. These changes, through image processing, could be used to activate an alarm so that assistance would be at hand. Law enforcement and the military are using facial recognition even today, so this is not that big of a reach. With state of the art cell phone cameras and the ability to write apps for them, this should not be a pie in the sky application.

Conclusion

ALS is a very unfortunate disease for people afflicted with it and is traumatic for loved ones and friends. Trying to communicate with patients is frustrating, and sometimes even maddening, for all involved. It's discouraging that in an age of ever advancing information processing technology and software development methods that more progress has not been made in this area.