CASE STORY – Speech Pathology

The information contained in this case story is not based on a single person but on a compilation of clinical experiences. This case story by Sally Pittendrigh (Speech Pathologist) aims to introduce and summarise the various technologies currently available to support communication.

AM is a 46 yr. old gentleman who has advanced Amyotrophic lateral sclerosis with significant respiratory involvement, a moderate upper motor neuron dysarthria and weak phonation. AM lives with his wife, who is his primary carer, and also receives care support during the day.

AM was evaluated in his home. He required constant oxygen support with a full-face mask, during both the day and overnight. On observation he spoke short phrases with significantly reduced volume. The speech pathologist occasionally had to seek clarification as AM’s speech volume was insufficient to be heard through this mask. After approximately a 1 hour consultation it was very clear that he was exhausted.

AM reported finding communication increasingly effortful and exhausting. He indicated that this severely restricted his participation in general conversation and found the progressive deterioration of his communication very isolating. AM reported that he had trialled voice amplifiers without success and that his speech was mostly used for urgent communication. He used non-verbal communication to support his speech in the form of an eye gaze/dwell in response to Yes/No questions.

The eye gaze AM and his wife used was effective - as his primary carer she had become very familiar with AM’s needs, routines and preferences and she was able to anticipate much of his communication. The involvement of other carers added a new dynamic to AM’s communication and he found quick messaging quite complicated. There were increasing episodes of family and carers not understanding AM and with 2 or more people in the room he was unable to be understood.

Both AM and his wife also expressed very specific concerns regarding his difficulty to communicate successfully during the night. His wife slept in a separate room due to the sound of the oxygen, but this made it difficult for AM to get her attention.

It was decided that AM required an alternative communication system to supplement and eventually replace his speech. An alternative communication system would enable him to effectively provide clear instructions to carers; alert family and carers to essential or emergency needs without needing to clarify; and interact more broadly with friends, family and carers. The system would reduce the isolation AM was experiencing, create the opportunity for participation in conversation, and help him to access the broader community.

AM’s general function was evaluated to support assessment decisions. He had no functional upper limb movement but a small amount of right foot movement and some lateral head
movement. He was normally seated in a power chair during the day and slept in a hospital bed at night.

Eye tracking technology and head tracking movement were investigated as options. Head tracking was excluded quickly due to the fatigue associated with volitional head movement. The head movement required was not consistent or accurate enough to allow the attached head tracking device (used instead of a hand held mouse) to track/scan/select items on the main computer screen.

Eye gaze technology was trialled using an eye tracking camera and eye gaze software installed on a laptop/ tablet. The camera operates to track eye movement in order to access and operate a computer. AM demonstrated success with this device. The tablet could be positioned on a mount above his line of sight so he was looking up at the tablet rather than trying to see over his face mask. This system was calibrated to allow him to use his eye movements to click, drag, select and type using software installed on the tablet. The tablet also included software that allowed AM to type messages that could then be converted to speech output. This software was able to interface with general computer applications and programs that AM was keen to continue using such as music, email, Facebook, and the internet. The tablet software also gave him broader environmental access including the ability to turn on/off the lights and T.V.

Positioning issues were difficult to resolve. The success of the eye tracking software is dependent on the ability of the camera to reliably track eye movements. In AM’s case this required his power chair to be tilted while using the device to maximise eye position in relation to the camera and reduce the impact of glare on eye movements. However, this tilted position was not comfortable for extended periods of time. AM found he needed time seated more upright and consequently time away from the eye gaze system for general comfort.

AM and his wife agreed that his primary communication needs during the night were very fixed and predictable, including: repositioning the oxygen mask, support with accessing fluids, and toileting. As such, all that was required was an alert to assist with waking AM’s wife so she could resolve the identified issue. A footpad alarm was trialled successfully.

The eye gaze system in this context provided back up to help with communication if the problem identified was either not within the fixed set of needs and/or couldn’t be resolved with their existing nonverbal Yes/No eye gaze communication.

A communication board using written phrases was established for times when AM was not using the eye gaze technology and for simple high frequency communication needs (relating to care, self-care and general requests). This took the form of large A3 charts installed in various rooms within the house. These were room-specific charts detailing high frequency communication specific to the needs of that room i.e. bedroom, bathroom, dining room, and living room. There was also a general high frequency communication chart in each location with more general phrases. A laser pointer was trialled to assist AM with phrase selection, but was unreliable due to fatigue impacting upon the accuracy of pointing. Partner assisted scanning was deemed the most successful access method, and training was provided to all
involved. Clear instructions were also kept with the charts in case care staff changed unexpectedly.

With this multi modal approach to communication, AM's communication goals were positively impacted. These systems combine to reduce the amount of effort AM expends in communication, reduce the burden upon his carers and wife, and can be used with relative speed and accuracy. AM's wife and care staff regularly use partner-assisted scanning of communication charts to support quick messaging, and the alarm system for overnight is working well. The environment controls, voice output, and general computer access combined with eye-gaze technology give AM a tremendous amount of independence and have reduced his sense of isolation. AM is able to type messages reliably and accurately for carers and family, and enjoys accessing computer applications that he used during his employment.

Eye gaze technology has evolved significantly in recent years to provide communication and computer access. The use of a variety of these systems with computer technology provided a more comprehensive approach to communication.

Popular software used within ALS populations and the technology described above include:

- Tobii PC Eye Go with Tobii Communicate Software
- Intelligaze
- Grid 2 or Grid 3 Software
- Tracker Pro or Smart Nav

There are many other options and different systems will suit different users.

Sally Pittendrigh, Optimal Speech Pathology and Speech Pathologist for the Multidisciplinary MND Service at Macquarie Neurology, Sydney NSW.

**Bibliography**