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Upfront

Hearing you have a terminal illness has been likened to crash landing in a foreign country. Suddenly you find yourself in a place you don't want to be. You don't know the culture, can't recognize the terrain and haven't got a clue what's in store for you. You don't speak or understand the language and can't imagine how to get your most basic needs met.

Gradually, perhaps even surprisingly, you, and those who have survived with you, begin to learn. Little by little you develop the expertise you need to go on with your lives. Perhaps ultimately, you find moments of humor in the situation, some resolution and peace. Along the way, you become familiar with a new vocabulary (e.g., augmentative communication, eye gaze techniques, mechanical ventilation). You meet, and get to know, nice people who can help you.

Receiving a diagnosis of Amyotrophic Lateral Sclerosis (ALS) and learning about this motor neuron disease (MND) is, in a word, devastating. For individuals with ALS/MND and their family members, the journey that ensues is extraordinarily difficult and different for each person involved. No one can forecast how the physical deterioration will occur, or predict the concomitant psychological, emotional and social impacts of the disease process. Ultimately, most individuals with ALS and their families learn to tolerate and integrate the experience of living with the disease. Because nearly everyone with ALS/MND has difficulty speaking and writing, addressing their communication needs is crucial. AAC strategies and devices play a major role. If professionals, family members and individuals with ALS understand the course of the disease and the options they have to maintain communication, then the journey can be easier.

As many AAC professionals have discovered, intervention with people who have ALS/MND is different from intervention with most other populations. While AAC

Continued on page 2

inside this issue

For Consumers

Amyotrophic Lateral Sclerosis

ALS is a progressive disease of motor neurons in the human cortex, brain stem and spinal cord. Motor neurons are cells that initiate and control movement by sending messages to the muscles of the body. In ALS, muscles gradually become weak and spastic. Ultimately, they atrophy. Initial symptoms (weakness) may occur in the upper extremities (1/3 of those with the disease), lower extremities (1/3), or with difficulty in speaking and/or swallowing (1/4).[1] Paralysis eventuates and can take away one's ability to walk, eat, speak, play, work and even breathe. The cause of ALS is unknown and there is no cure or known medical intervention to arrest the disease. Sporadic ALS is the most common form; familial ALS occurs in 5-10 percent of cases. Loss of sensory and cognitive functions has not typically been associated with ALS.[2] However, recent studies have found frontal lobe deterioration substantiated on neuropsychological testing and at autopsy.[3,4] When present, new learning is affected, which has implications for AAC intervention. Also, emotional lability (inappropriate laughing and crying) may be noted. Current estimates of cognitive changes vary from 2 to 36 percent in

Continued on page 2

For Consumers, Continued from page 1

sporadic disease and they are more common in familial ALS. If cognitive deterioration is suspected, other factors should first be ruled out: (1) depression, which can be treated, and (2) difficulties with pulmonary function, *i.e.*, carbon dioxide retention, which also can be treated.

Currently, the life expectancy of someone diagnosed with ALS is two to five years. Half of those affected live longer than three years; 20 percent live five years; and 10 percent survive more than ten years. More men than women (about 2 to 1) between the ages of 40 and 70 develop ALS; however, people in their 20s and 30s also are diagnosed. Although hereditary factors are not firmly established, families with a genetic dominant inheritance appear to have a 50 percent chance their offspring will develop ALS.[2] (Other variants of MND include spinal muscular atrophy, progressive bulbar palsy, lateral sclerosis, juvenile muscular atrophy and benign facial amyotrophy.)

The incidence and prevalence of ALS has not changed much. The incidence is estimated at 2 per 100,000 people. In the United States, the prevalence is approximately 30,000 individuals, and an additional 5000 more individuals are diagnosed each year.[2] There is no apparent relationship between motor neuron diseases (ALS included) and race. Geographically, ALS is evenly distributed throughout the world, except for three areas of high incidence: (1) the Kii Peninsula in Japan, (2) the Mariana Islands in the West Pacific and (3) West New Guinea. In these areas, motor neuron diseases are often associated with other neurological disorders, especially Parkinson's disease. In recent years, the annual incidence in these areas has declined, while the age of onset has increased.[5]

Treatment approaches

After an initial diagnosis, families often are anxious to participate in drug trials or research projects aimed at slowing the progression of the disease. Many say it gives them hope, and they feel they are doing something meaningful for themselves and others in the fight against ALS.[6] Only riluzole, however, seems to slow the progression of the disease if given in early stages.[7]

Medical treatment of ALS typically is the purview of neurologists who focus on symptomatic relief and prevention of complications. Effective medical management of a degenerative disease requires education, planning and an integrated approach to care. Patients and their family members need: (a) information about the disease process; (b) information about options they can consider as the disease progresses; (c) ways to maintain independence and daily function; (d) consideration of quality of life; and (e) the time and space to prepare for death. Trained professionals, including speech-language pathologists, occupational and physical therapists, dieticians, respiratory therapists, otolaryngologists, psychologists, social workers and assistive technology specialists

Upfront, Continued from page 1

professionals are familiar with how to teach someone to use devices and strategies to support communication, they do not automatically have an understanding of the journey people with ALS face, or how it impacts intervention. Moreover, most AAC professionals eventually will be asked to help a neighbor, colleague or friend who has ALS. Thus, this issue is relevant to all subscribers, not just those now working with ALS patients.

Ten years ago, I wrote an issue on ALS (July 1988, v.1, n.3). This is an update. It reflects changes that have occurred and identifies realities that have not changed. ***For Consumers*** *provides information about ALS and considers AAC service delivery issues for individuals with the disease.* ***University & Research*** *summarizes the results of an outcomes study on the use of AAC devices and techniques with ALS patients.* ***Clinical News*** *considers the changing communication needs for individuals with ALS and highlights "no tech" and "low tech" approaches.* ***Equipment*** *focuses on electronic devices that augment speech, writing and communication. (Iris Fishman developed the Tables in this section. Bless her!)* ***Governmental*** *highlights CINI, an organization that advocates for the communication needs of individuals with ALS/MND.* ***On the Web,*** *a new department, lists relevant websites. Many, many thanks to Susan Carroll-Thomas, Frima Christopher, Delva Culp, Iris Fishman, Marta Kazandjian, Pam Mathy and Kathryn Yorkston for their insightful contributions.*

After ten years of publishing, ***Augmentative Communication News*** *has a new look and color. Let me know what you think.*

Sarah Blackstone, Ph.D., Author

can contribute. Examples of clinics that address communication problems in ALS include:

1. The Neuromuscular Clinic for Speech and Swallowing Disorders (University of Washington in Seattle) sees individuals with ALS as early as possible post-diagnosis. The team follows the person and family for management of communication and swallowing at intervals ranging from two weeks to four months, depending on their needs.[8] They use the ALS Severity Scale (ALSSS) that separately measures speech, swallowing, and upper and lower extremity function, using a ten point ordinal scale.[9]

Severity ratings in each area enable staff to predict when and what AAC interventions will be needed. For example, a decrease in the rate of speech forecasts speech deterioration. Also, the initial presentation (bulbar or spinal) generally forecasts which areas will be most affected throughout the course of the disease.[10]

2. The ALS Clinic (Rehabilitation Centre in Ottawa) sees individuals from around the province on a regular basis during the course of the disease. Staff give specific information about the disease and individual management of breathing, communication, swallowing, self-care, psychosocial issues and mobility.[11] In addition to the ALSSS, the speech-language pathologists use two ordinal scales to rate the degree of communication disability and handicap.

- The Disability Scale measures the extent of a person's restriction in oral communication [1= no restriction; 2= situational fatigue, effortful speech, occasional clarification required; 3= moderate impairment (<50 percent intelligible), frequent repairs required; 4= speech understood in a few contexts only; 5= speech nonfunctional].
- The Handicap Scale measures the person's disadvantage in communicative interactions [1= no limitation; 2= situational disadvantages (*e.g.*, talking on the telephone, meeting strangers, noise); 3= avoids phone communication/strangers/poor listeners, expects others to understand him/her; 4= interaction limited to primary caregivers, frequent breakdowns/frustration; 5= minimal/no interaction; facilitation required for interaction to occur.] [11]

Results of a recent study suggest that these scales may help predict the acceptance and rejection of AAC devices. Specifically, patients who had Disability Scale scores of 3,4 or 5 (*i.e.*, moderately to severely restricted in oral communication) and who rated themselves as not very disadvantaged (scores of 1 and 2 on the Handicap Scale) were far less likely to use AAC devices than those who perceived themselves as disadvantaged because of their disability.[12]

Making informed decisions

Over the past ten years, advances in technology have created new medical and rehabilitation alternatives for individuals with ALS:

- PEGs (Percutaneous Endoscopic Gastrostomies) and other feeding alternatives can provide nourishment when bulbar involvement and respiratory muscle weakness make it too dangerous for someone to eat or drink orally. Speech-language pathologists working with AAC often manage swallowing problems as well.
- Portable (and other mechanical) ventilators enable people to sustain life by breathing for them when their intercostal muscles and diaphragm become paralyzed. More individuals are now using ventilation options.
- Assistive technology provides a wide range of equipment, including AAC devices and access techniques, to augment communication when speech and/or writing are no longer options.

New technology is not without its costs, drawbacks and psychosocial implications. For example, while ventilation extends life, it also increases costs, care needs and the skill level of care required. Also, severe feeding and communication problems often develop at the same time. Patients and caregivers may find it too difficult to learn new approaches to communication and feeding simultaneously.[13,14]

Individuals with ALS and their families need to make informed decisions about interventions they wish to pursue. This requires education. To help patients make decisions about ventilation, for example, all patients from the ALS Clinic in Ottawa are referred for a pulmonary assessment to discuss possible respiratory complications (airway protection, airway clearance and hypoventilation). In a recent study of 87 ALS patients, 39 people (45%) said they were opposed to mechanical ventilation of any kind and were taught palliation and assisted coughing techniques (if capable). The 48 patients (55%) who wanted to consider ventilatory assistance attended three education sessions.[15]

- Education Session 1 lasted two hours. Small groups of two to three patients and their caregivers

Continued on page 4

For Consumers, Continued from page 3

learned about assisted coughing, volume augmentation, and the advantages and disadvantages of non-invasive and invasive positive pressure ventilation and bi-level ventilator systems. They also discussed informed consent, advance directives, family support and ways to direct personal care. After the session, 14 patients decided not to pursue ventilation. Seventeen decided to try ventilatory assistance and were invited to attend the next session, and 17 remained undecided.

- Education Session 2 was a three hour, one-on-one experience designed to help people become familiar with ventilation equipment and strategies. When patients experienced clinical respiratory failure or sleep disordered breathing, they received equipment through the Ontario Ventilator Equipment Pool, and went to a third session. [Note: This is a time when stress reduction approaches (relaxation, hypnosis) can address the emotional correlates of this intervention.][13]
- Education Session 3 taught caregivers/patients how to use ventilation equipment at home.

Results of the study showed that 17 of the 87 patients pursued mechanical ventilation; 17 remained undecided and 53 decided against it. Of the 48 patients who attended the Education Program, 31 (65%) were able to make an "informed decision." A satisfaction measure revealed that patients and caregivers felt the education sessions helped them to feel less anxious, as well as enabled them to make an informed decision about ventilation.[15]

When to introduce AAC?

To be optimally effective, education about AAC intervention should begin when speech and writing are still possible. Early education and ongoing monitoring enable individuals to develop familiarity with AAC strategies and equipment before they must play a substantial role in meeting their daily communication needs. When intervention is not offered, not available or is refused at early stages of the disease, it becomes more difficult to make good decisions and solve the communication problems that arise later on. For example, someone in late stages of the disease, who is alert but functionally quadriplegic, bedridden, locked-in and dealing with death, can find it exceedingly difficult to learn to use unfamiliar equipment to communicate in new ways. It is much, much better to have your options in place long before you need them.

Understanding resistance

What can an AAC professional do when someone with ALS rejects information about AAC? The answer is, "Just be there. Stand by." It happens all the time.

Not surprisingly, people in early stages of ALS do not see information about augmentative communication techniques as positive. Promises of being able to hit a switch, gaze at a board to select a word or use a computer to say something intimate to your spouse sound like very bad news to someone who can still talk and write. Clinicians should not take a patient's sharp, negative response or apparent lack of interest in AAC as a personal rejection or professional failure. Just stand by.

It is now clear from Carroll-Thomas's study that when individuals with ALS perceive their speech impairment differently from professionals and family members, they may not accept the recommendations of these individuals.[12]

I spoke with Frima Christopher, Ph.D., Director of Psychology at Coler-Goldwater Memorial Hospital in New York City, about psychosocial aspects that might play a role in a person's acceptance or rejection of AAC services.[13] Dr. Christopher pointed out that how an individual responds to a disease process is often a function of his or her: (a) personality, (b) psychological characteristics, (c) previous life experiences and (d) approach to solving problems. She added that cultural, social and familial contexts, as well as financial resources and support systems, will influence a person's response to treatment.

Anger and sadness are common in ALS patients. In fact, it is "normal" to experience strong emotions, denial and depression in the face of this disease. Dr. Christopher emphasized the necessity of including the family and psychological components in the management of ALS. She urged professionals to treat patients in a more holistic way and meet the challenge of addressing resistance and depression while communication channels remain open. Continued access to communication is crucial. "If you can express yourself, then people are less able to reinvent you without your consent."[16]

How to introduce AAC

How should AAC professionals approach people with ALS? All the experts agreed. "Do so carefully!" Introducing AAC options is an art as well as a science. Successful intervention nearly always depends upon the establishment of an ongoing, trusting relationship with the

individual and his or her family. The importance of open, honest communication cannot be underestimated. Something people with ALS do have is time--time to take control and get educated.[17]

Susan Carroll-Thomas observes that some individuals want to "plan ahead," while others prefer to "take things as they come." An ALS clinic team works to help patients define their desired outcomes and achieve their goals. Successful AAC outcomes for someone with ALS will include maintaining an ability to function and preserving one's quality of life. In addition, "hope, comfort and a sense of belonging are important outcomes for someone with a terminal disease."[11] Underlying these outcomes is communication.

Summary

People affected by this disease need support from the AAC community. Ten years ago, most individuals, and the AAC professionals who served them, did not have access to an integrated approach to care. Communication issues were often ignored until later stages of the disease. Sadly, that continues to be true.

Several things have changed. We have research that better describes the communication needs and preferences of people with ALS. We also have a broader range of efficacious solutions. AAC professionals with years of experience are willing to share what they've learned. And, we have the Internet. Ten years ago it was difficult to get information about the communication needs and AAC solutions available to people with ALS. Today, when someone needs help, it is easier to find.

University & Research

Outcomes of AAC intervention in ALS

Pamela Mathy, Ph.D., Director of Clinical Services, Arizona State University, is investigating the outcomes of AAC intervention in adults with ALS.[18] In her first study, 24 individuals with ALS completed a questionnaire designed to elicit information about the types of AAC systems they used to accomplish communication activities.[19] Two groups participated: Group I (bulbar presentation group) was comprised of 12 individuals who had dysarthric speech and were ambulatory; Group II (spinal presentation group) had 12 people with dysarthric speech and upper and lower extremity involvement. All lived in their own homes. All had access to no tech, low tech and high tech AAC system components. Ten males and 14 females took part in the study. Technology was provided through a loan library of AAC devices and through an aggressive pursuit of third-party funding. Subjects used a combination of AAC strategies and devices:

- No tech: Twenty questions, gestures, facial expressions, partner-assisted scanning, eye pointing.
- Low tech: Some form of chart (*e.g.*, alphabet board) and some means to access it (*e.g.*, finger, light pointer, partner scan). Also includes handwriting (*e.g.*, paper, pencil, dry-erase boards, magic slate).
- High tech: Use of an electronic device, either dedicated (*e.g.*, LightWriter, Link) or multipurpose (software for computer access, as well as spoken, written and electronic communication).

Results of the survey showed that to accomplish different communication activities, individuals use a variety of AAC methods. See Table I for a list of these activities.[18]

Table I. Communication Activities
(Pam Mathy, 1998)

Face-to-face conversation. Rapid, informal, exchange of thoughts and feelings. Small talk between two or more partners.
Quick basic needs/wants. Quick communication of a need/want (*e.g.*, change position, change the channel, wipe mouth, *etc.*)
Detailed needs/wants. Conveying at least a few sentences about a need/want to be sure the partner understands (*e.g.*, indicate what you want to do on an outing, provide detailed information regarding medical needs).
Detailed information. Conveying considerable information (*e.g.*, tell someone how you feel about him/her, give your opinion on an issue or topic, give advice).
Personal stories/anecdotes. Telling a personal story or anecdote during a communicative interaction for purposes of illustrating a point, exchanging experiences, telling a joke, *etc.*.
Telephone. Using a voice output device or an interpreter to communicate over the phone.
Written communication. Producing "hard copy" for correspondence, work, creative writing.

Mathy reported that the two groups did not rely on the same methods:

1. Bulbar presentation group. All individuals said they relied on no tech and low tech approaches (handwriting, facial expression/meaningful gestures and "yes/no" questions). Eight used a multipurpose computer, five used a dedicated device and two used an alphabet board.

   When asked what they used "most of the time to accomplish specific communication activities," all reported using **handwriting** to express quick needs. Ten also used handwriting for conversation and six to tell stories, write, convey in-depth information and express detailed

Continued on page 6

University & Research, Cont. from page 5

needs. Seven people used a **multipurpose** or **dedicated device** to talk on the phone. [Note: Five said they didn't use the phone anymore.] Six used devices to tell stories, write, convey in-depth information and express detailed needs. Only two used devices for conversation. By report, this group relied on handwriting "most of the time," rather than other no and low tech methods.

2. Spinal presentation group. All said they relied on facial expressions, yes/no questions, call buzzers and multipurpose devices. Nine used an alphabet board (eight with scanning and one with an optical pointer), five used partner-assisted auditory scanning methods, three used a "yes/no" hierarchy and three used coded eye blinks.

   These individuals said they used a variety of **no tech approaches** "most of the time" to express quick basic needs. Five relied on no tech for conversation; one to talk on the phone and one to express detailed needs. [Note: Seven said they no longer used the phone.] They all relied on **high tech devices** "most of the time" to tell stories, write and convey in-depth information. Eleven also used devices to express detailed needs, four to talk on the phone and three to carry on conversations. Four said they used **low tech devices** during conversations.

To summarize, both groups relied on no tech, high tech and low tech systems, but for different purposes. The bulbar group relied heavily on handwriting (except over the phone), while the spinal group depended primarily on no tech and high tech approaches.

Individuals in both groups used high tech devices (mostly multipurpose) to tell stories, convey detailed information, talk on the phone and write. However, only a few people (two in the bulbar group and three in the spinal group) relied on high tech devices during conversation.[19]

In a second survey, Dr. Mathy asked six patients with ALS (5 with spinal and 1 with bulbar presentation) to respond to questions about: (a) the type of communication activities they engaged in; (b) the location of these activities--home, church, work, meetings, outdoors, stores/restaurants; (c) their "position" during communication (*e.g.,* wheelchair, bed, lounger, car); (d) what AAC methods they used with very familiar partners and with strangers and (e) their level of satisfaction with AAC methods.

Results lend support to previous findings that individuals with ALS rely on a variety of no, low and high tech strategies. Participants reported using no tech communication methods across all settings and high tech devices primarily at home. More specifically:

- In the community (church, restaurant, meetings), all relied on low tech and no tech strategies. (The subject with a bulbar presentation relied on handwriting.)
- In the car, they used no tech strategies. One person used a speech amplifier.
- At home, they used a combination of no, low and high tech devices. Half used their high tech devices in bed and two-thirds used them in their wheelchair and/or in a reclining position.

As in Study 1, subjects said they relied on **high tech devices** most of the time (80%) to tell stories and convey detailed information, and somewhat less often (50%) to express detailed needs. They generally (80%) used **no tech systems** to express basic needs. During conversation, these individuals used a combination of techniques: **High tech devices** 40% of the time, **no tech strategies** 50% of the time and **low tech aids** 10% of the time.

Participants said they used **no tech approaches** to express basic needs and carry on a conversation with very familiar partners. However, with strangers, they used **high tech devices** for conversation and to express basic needs. They also reported using **low tech strategies** more often with strangers than with familiar partners.

When asked to rate factors influencing their choice of AAC methods according to a six point scale (1=least important to 6=most important), they responded as follows:

- Speed. Rated as important (between 4 and 5) on all communication activities.
- Simplicity of use. Rated as very important (5.5) for quick needs and important (3.5 to 4.5) for other activities.
- Multiple positions. Rated 5 for quick needs; 4 for conversation and 1 to 2 for other activities
- Partner acceptance. Rated as not very important (2 to 3.5) across activities.
- Naturalness. Rated as not very important (2.5 to 3.25) across activities.
- Need for partner assistance. Rated as very important (4.5 to 5.5) for detailed needs, stories and detailed information. Rated between 2 and 3 for conversation and quick needs.

Individuals indicated that they were

Continued on page 9

Clinical News

Staying ahead of the curve

To compensate for increasing impairments, persons with ALS will use several techniques at any given point in time, as well as over time. Problems interfering with communication may be noted early in the disease, or later on in its progression. The goal of AAC teams is to stay ahead of the curve.

Over the course of the disease, the functional capabilities of individuals with ALS vary along a number of dimensions. Physical changes in upper and lower extremities, speaking, swallowing and breathing all influence AAC intervention decisions. To assist clinicians working with this population, Kathryn Yorkston and her colleagues at the University of Washington in Seattle conducted a study using the ALS Severity Scale (ALSSS).[9] One hundred and ten (110) patients (nearly half of whom had been diagnosed within the past six months) participated for a total of 303 visits. At the time of the study, 46.5% of the participants did not have communication difficulties (Group 1). However, 35% could no longer speak (Groups 3, 4, 5, 6) and 30% (Groups 2, 5, 6) could not use their hands to write or type. The researchers identified six groups of individuals and suggested each group would require a different approach to AAC intervention. For all groups, the AAC team monitored the patient's status and provided patients and family members with information.

- Group 1 had adequate speech and hand function.
- Group 2 had adequate speech and insufficient hand function. AAC intervention involved support for writing, typing and computer access.
- Group 3 had insufficient speech, adequate hand function and adequate mobility. AAC intervention taught ways to: (a) repair communication breakdowns, (b) express needs, (c) carry on conversations using low and high tech devices and (d) use the phone. This group often relied on handwriting and gestures. Depending upon their needs, some also used speech output devices and multipurpose computers. They were ambulatory, so portability was an important consideration.
- Group 4 had insufficient speech, adequate hand function and were non-ambulatory. These individuals were similar to Group 3 except they were no longer walking. They used handwriting, direct selection AAC devices (low and high tech), typewriters and computers. Equipment was mounted on wheelchairs and beds, or placed on tables.
- Group 5 had insufficient speech and hand function and adequate mobility. As with Groups 3 and 4, they required a range of low and high tech devices and strategies. However, this group needed to use alternate access techniques. Because they were ambulatory, portability was a concern.
- Group 6 had insufficient speech and hand function and were non-ambulatory. Like Group 5, they used a broad range of low and high tech devices and required alternate access techniques. As control decreased, they depended heavily on partner support. Finding a reliable control site often was difficult. Portability was generally not an issue.

Researchers also reported that changes in oral movement and speaking rates preceded changes in speech intelligibility, and that initial symptoms tended to remain the most severely affected throughout the disease.[10]

A moving target

A defining feature of ALS is change. While the six groupings described above are very useful, they do not reflect the dynamic and unpredictable nature of the disease, nor do they account for other variables that impact communication decisions. Readers are referred to the *Continuum of Disability*, which includes cognitive-linguistic and behavioral dimensions of communication management.[20] We know also that psychosocial and environmental factors influence decisions about AAC. According to Carroll-Thomas:

> The key management issue (in ALS) is frequently not device selection, access/interface or vocabulary selection, but forced adaptation to altered communication style, loss of spontaneity and potential loss of control.[21]

AAC professionals face the challenge of trying to stay up with, if not ahead of, this disease. In some cases the target is clear. In others, it is quite murky. Taking aim, shooting at and hitting a target that is constantly moving requires considerable professional skill.

Stages of AAC intervention

AAC professionals sometimes find it helpful to think about early, middle and late stages of AAC intervention in ALS. Marta Kazandjian suggests that:[22]

- **In early stages**, the focus is on maintaining a person's natural means of communication and normal lifestyle. At the same time, the team begins preparing for eventual losses of speech and/or hand function. Examples of intervention techniques include speech supplementation, use of vocal amplifiers and writing.

Continued on page 8

Clinical News, Continued from page 7

- **In middle stages,** motor impairments have an increasing impact on the person's ability to communicate. Lifestyle options are now affected. Some people remain very active and involved in family and community; others begin to become isolated. At this stage, individuals can use direct selection methods (even if they can't use their hands) to access low tech and high tech AAC devices and multipurpose computers. AAC enables them to be independent in most communication situations. Examples of AAC approaches are: Alphabet/word/phrase board, LINK, LightWriter, DynaMyte and laptop computers with communication software.
- **In late stages**, motor impairments significantly impair communication across modalities. People rely more and more on technology. They also depend increasingly upon assistance from their primary communication partners. Many people are now less active. Access methods may be restricted to eye gaze and scanning (electronic or partner assisted) and switches are often the key to access. Examples of AAC approaches are: Emergency signal, Eye-Link, E-Tran, Alphabet-phrase/word board, LightWriter, Dynavox, laptop computer with communication software and environmental control features.

Maintaining natural communication

This section highlights ways to maintain natural speech, handwriting and keyboarding using no tech and low tech methods. Table II gives 12 examples of strategies to help people maintain their speech.[23]

Maintaining natural speech. Yorkston reported that the average length of time between intelligibility scores of over 85 percent (intelligible under most circumstances) to scores of less than 30 percent (rarely intelligible) was only six months.[24]

Table II. Strategies for maintaining speech in patients with ALS

1	Explain how various muscles and organs work to produce speech. Most people do not understand that it takes the smooth coordination of more than 100 muscles related to respiration, phonation and articulation to talk.
2	Encourage people to discover strategies that work for them. Suggest they try (a) phrasing–one word per breath; (b) elongations--prolonging vowels and concentrating on production; (c) exaggerated articulatory patterns; and (d) positioning that gives adequate support for speech, particularly during long and/or stressful conversations.
3	Make sure people know that any exercise intended to strengthen weakening muscles may be counterproductive.
4	Point out that fatigue is a significant factor in ALS. Something that works in the morning may not be effective later in the day.
5	Use amplification when speech is not loud enough for others to hear (and before speech becomes unintelligible.) See **Equipment**.
6	Use an electrolarynx or respiratory tube as an alternate air source if someone is on a respirator with fully inflated cuffs. See **Equipment**.
7	Use one-way speaking valves if tracheostomy tube is fully deflated. See **Equipment**. Use talking trachs if the trach tube cannot be deflated. See **Equipment**.
8	Use first letter cueing when intelligibility problems are intermittent.The person points to the first letter of a word spoken that isn' t understood.
9	Teach people to establish the topic before speaking (either by writing, using an alphabet board or spelling out loud).
10	Teach conversational repair strategies, *e.g.*, "Please repeat out loud as I point." " Let's start again."
11	Encourage the use of verbal speech, even when it is limited to YES-NO and a few single word utterances.
12	Consider a palatal lift for patients who have lost velar control (without much swallowing difficulty) and can still articulate.

Maintaining handwriting. Many individuals who are unable to speak use handwriting to communicate whenever possible. To maintain this ability, clinicians suggest:

- Encasing pencils, pens in rubber grips to make them easier to grasp.
- Using Crayola markers.
- Using Magic Slates/Magna Doodles, which are erasable and provide some degree of privacy.
- Positioning equipment for use.
- Teaching people how to interact using writing as a conversational tool (*i.e.*, Be telegraphic. Use strategies to interrupt, initiate, change topics, ask questions).

Maintaining keyboarding. People who type, use a mouse or calculator want to continue to use these tools even when they have difficulty with the keyboard. Others may decide to learn to use a portable typewriter (particularly with message storage and retrieval features), a dedicated AAC device and/or a computer to help them communicate. Initially, low tech approaches like a splint or a keyguard can help people maintain their keyboarding skills. Later on, high tech solutions are required.

Maintaining access to language

This section gives examples of no tech and low tech methods that enable people with ALS to generate language when speech and handwriting are no longer possible. Most of these techniques require education and instruction.

Low tech solutions always include the use of charts/communication displays. Most people with ALS prefer using displays with letters, words and/or phrases arranged in a

way that facilitates efficient message transfer. To produce a message, for example, individuals select a letter, word or phrase using a finger, light pointer or their eyes. When direct selection is not possible or too slow, partner-assisted techniques work well. Two examples follow:

Partner-assisted visual scanning. Relevant vocabulary is available on the display, which is divided into halves or quadrants. The top half might have the alphabet and the bottom half important words. The partner establishes how the individual indicates yes/no. Then, the partner holds the board in front of the person and points to the quadrants, "Is it in the top half (point) or bottom half (point)?" When the person responds, the partner scans down the rows until the person selects a row. Then the partner moves across the row until the person selects the message. To speed up the process, partners can ask the person if it is okay to try to guess.[25]

E-Tran and Eye-Link. These charts enable people to generate messages with their eyes. Typically, they contain the alphabet or some words for basic needs or emergencies.[26]

No tech solutions do not use a chart or device. While important nonverbal communication requires a no tech approach, language expression typically requires speech, sign language or technology. However, with the assistance of a partner, individuals can be given choices and select what they want to say. Less familiar partners can use printed materials to aid efficient message transfer. Examples of partner-assisted auditory scanning are:

Twenty questions. Many people today don't really know how to play the game of Twenty Questions. To be successful, the "guesser" uses an organized hierarchy of questions (not a hit and miss approach). The goal is to find out what another person is thinking. As an AAC strategy, a 20 questions approach requires a reliable yes/no signal. The partner begins asking questions. For example, "Does it have to do with you? me?" Based on the response, the questioning proceeds until the message is known.

Yes/no hierarchy**.** This is a similar strategy. However, a familiar set of questions is generally written down and memorized over time. For example:

1. Do you want to tell me something? (partner reads a list of topics)
2. Is something wrong? (partner asks emergency? location?)
3. Do you want something? (partner reads a list)
4. Do you want to tell me how you are feeling? (partner asks . . in general?. . .about this activity? . . about something else?)
5. Do you want to ask a question? Who. . . what . . . where. . . when. . .why. . .how? (partner reads list for each)
6. *Do you want to discuss something? (partner reads list).*[25]

Summary

It is not easy to stay ahead of the curve so people with ALS have the tools they need to meet their communication needs. As Carroll-Thomas wrote, the challenge for the AAC professional is to:

- Understand as much as possible about the disease, its impact and prognosis.
- Approach the patient and family with honesty and dignity.
- Listen actively to what is said and what is not said.
- Having offered choices, respect the decisions made.
- Recognize when your skills are inadequate and seek advice or refer to others.
- Plan for change and thereby avoid crisis.[27]

University & Research, Cont. from page 6

"satisfied" to "very satisfied" with AAC intervention techniques for all communication activities, except conversation.[19]

Summary

Dr. Mathy's studies reflect the opinions and experiences of individuals with ALS who have benefited from AAC intervention. Each person had access to (and used) many AAC methods. They were generally satisfied, or very satisfied, with AAC intervention. However, all expressed less satisfaction about their ability to carry on a conversation. Data show that individuals with ALS use multiple approaches during conversation, although most rely on no tech or low tech strategies. They feel that high tech options are less effective at meeting communication needs during conversations than all other communication activities. Considering that these people rated speed and simplicity of use as important device features, this is not surprising.

Finally, the studies suggest that when individuals with ALS are provided with a range of AAC options and taught to use them effectively, they will strategically use what they feel is most effective. Their choices are likely to depend on their communication partners, where they are and the demands of the communication activity, as well as on their motoric abilities.

Equipment

High tech communication solutions

Ten years ago, clinicians reported that many individuals with ALS:

1. Were not inclined to select devices that required a great deal of new learning.
2. Preferred approaches that closely represented what they were already familiar with. [Note: Most continue to prefer orthographic systems.]
3. Were more likely to explore available computer-based technologies if they (or someone in their family) had used a computer before.
4. Were concerned about finances and reluctant to spend money on equipment. [Note: Funding continues to be a concern because funding agencies do not respond in a timely fashion, and most solutions are time-limited.]
5. Needed good information about what available technology could (and could not) do.[28]

The difference today is that decision makers, *i.e.*, people with ALS and their family members, are more familiar with technology. Also, technology is more available and user-friendly, and software caters to a wider range of interests. Perhaps the most important difference is the Internet. Electronic communication allows people with ALS to work, maintain their hobbies and even develop new interests, as well as e-mail family, friends and the broader community.

AAC professionals can educate families about available technology and facilitate the decision-making process. Some devices work well in the early stages of communication impairment, while others are designed for middle and/or later stages. A few, like the multipurpose computer, can be used throughout the course of the disease. This section covers speech amplifiers, one-way speaking valves, electrolarynxes, multipurpose computers, dedicated devices and some special access technologies.

Table III. Speech Amplifiers (CINI,1998)

SYSTEM	MANUFACTURER	PRICE	WIRELESS	MICROPHONE	PORTABILITY
Voicette	Luminaud	$195	No	Collar or Head mounted Hand-held	Can be carried on shoulder strap
Speech Maker	William Sound	$335	No	Head mounted Hand-held	Can be worn around waist or neck
Park speech amplifier	Park Surgical Brooklyn	$270-$320	No	Head mounted, Throat mounted, Hand-held	Can be carried
Personal Talker	Luminaud	$99	No	Mike & amplifiers in one piece, Hand-held	Can be held in hand
Minivox	Luminaud	$240	An option	Collar mounted, Head mounted, Hand-held	Mounted to wheelchair or stationary
Voice Amplificaider	Crestwood	$294.95	Yes	Lapel mike	Can be carried in a bag or stationary
Camcord Mike	Radio Shack	$100-125	Yes	Lapel mike	Can be carried in a bag or stationary
Speech Enhancer	Electronic Speech Enhancer, Inc	$2495-$4950	No	Head set Over-the-ear	Wheelchair model/ belt-pack model

For more specific information about any of the products mentioned, contact the manufacturers listed on the outside cover.

Speech amplifiers

In the early stages of communication impairment, when muscles involved with respiration and phonation are weakening, speech amplifiers can augment the volume of speech. This also minimizes the strain and fatigue associated with speaking. Amplifiers are not effective, however, when a person has intelligibility problems related to articulation. Issues in selecting amplifiers include the: (a) quality of the amplifier, (b) portability, (c) whether the device will be cost effective as a temporary solution and (d) how and where to mount/ carry the microphone.[29] Table III lists available amplifiers and some of their features.[30]

One-way speaking valve, talking trach, electrolarynx

While sustaining life, ventilators and trachs often make it impossible for individuals to talk without special equipment. Most patients who require ventilators are in late stages of the disease and are severely dysarthric. Therefore, they use dedicated devices or multipurpose computers to communicate. However, a few individuals require mechanical ventilation while they still have adequate oral motor (and laryngeal) control for speech. If provided with one of the following options, speech may be possible:[29]

- **One-way speaking valves.** If the tracheostomy tube has a fully deflated cuff, air can travel around the sides of the tube, allowing airflow through the vocal folds to produce speech. Examples are the Olympic Trach-Talk, Montgomery Speaking

Valve, Hood, Kizner, Passy-Muir Trach Valve. Some valves like the Passy-Muir are approved for ventilator use as well as for a tracheostomy.[29]

- **Talking Trachs**. If the trach tube cuff cannot be deflated, a conduit can be attached to a source of compressed air for speaking, which is separate from the ventilator. When the patient wants to speak, the conduit or port is occluded, which directs the airflow through the larynx. Examples are the Portex Talking Tubes, Bivona Talking Trach Tube and Communi-trach.[29]
- **Electrolarynx**. For those who have adequate oral motor control, but difficulty voicing, an electrolarynx provides an external source for sound that the individual uses to speak. Individuals with quadriplegia can use a remote switch electrolarynx.[29] Examples are: Romet, Western Electric, Copper Rand.

Multipurpose computers

While most high tech options are more or less temporary solutions for people with ALS, the multipurpose computer is flexible enough to be useful in early, middle and late stages of the disease and can support a range of communication activities.

Some people use computers to write, others to manage their finances, play games, "surf" the net, give speeches, e-mail friends, talk to people in their community and keep up on information about their disease. As needs and interests change, a multipurpose computer allows for the addition of communication software and access technologies. This enables individuals to keep doing what they want to do. Table IV lists communication software products available for Windows and DOS platforms.[31] Clinicians also mentioned three programs for the Macintosh: (1) Speaking Dynamically Pro (Mayer Johnson, $349), a communication program; (2) the CoWriter/Write Out Loud Bundle (Don Johnston, $350) as described in Table IV and (3) Companion (Assistive Technology, $399), a communication program. All said that most of their clients select EZ Keys because of its features and the company's policy of software upgrades.

Dedicated AAC devices

Although a large number of dedicated AAC devices exist,

Continued on page 12

Table IV. Communication software for PC Computers (CINI, 1998)

SOFTWARE	MFR/PRICE	PLATFORM	SEL. TECHNIQUE	RATE ENHANCEMENT	SPEECH SYNTHESIZER
EZ Keys	Words+ $1395	Windows 95	Direct selection (keyboard/onscreen; Scan; Morse code	Word prediction Abbreviation expansion	DECtalk (with Micro Communication Pac to increase volume)
Gus	Gus Communications $795	Windows 95	Direct selection (keyboard, onscreen) Scan	Word prediction Abbreviation expansion	DECtalk $195 (4 languages) ProVoice (4 languages) Digitized speech
CoWriter/Write Out Loud bundle	Don Johnston $350	Windows 95	Direct selection Alternative keyboard Onscreen keyboard Scan (rwith Discover)	Word prediction Abbreviation expansion	Pro Voice (Write Out Loud) True Voice (CoWriter and Discover)
WiViK2 with WIVOX **WiViK2 Scan with WWIVOX**	Prentke Romich Co $415 $520	Windows 95	Direct selection Keyboard and Onscreen Scan	Word prediction Abbreviation expansion	DECTalk (Sound Blaster card) Lernaut & Hauspie (Sound Blaster compatible card)
Aurora for Windows 2.0	Aurora Systems, Inc $205 - $490	Windows	Direct selection	Word Prediction	Real Voice
Aurora for Dos 2.0	Aurora Systems, Inc. $745 -$895	DOS	Direct selection, Scan Morse Code	Word Prediction	
HandiCHAT; HandiCHAT Deluxe	The Learning Co./ Internet Solutions Gp. $149 and $295	Windows 3.1 and 95	Direct selection from keyboard	Word Prediction Abbreviation expansion	External synthesizer or Sound Blaster card with Text Assist
HandiKEY/HandiKEY Deluxe (includes HandiCHAT software)	The Learning Co. Internet Solutions Gp. $395/$495	DOS 3.1	Onscreen keyboard Direct selection Scan	Word Prediction Abbreviation expansion	External synthesizer or Sound Blaster card with Text Assist
KeyWi **KeyWi2**	Consultants for Communication (CCT) $495 $995	Windows	Keyboard on screen Direct selection Scan	Word Prediction Abbreviation expansion	MultiVoice or CCT synthesizer DECtalk
Windbag	Zygo $275	Windows 95	Direct selection Scan		DECtalk (Eng) (syntheizer or sound card) Infovox (other languages) (sound card) Digitized

Equipment, Continued from page 11

individuals with ALS seem to prefer ones that are portable, use traditional orthography, are easy to learn to use and have intelligible speech. Those interviewed said their clients preferred synthesized speech devices listed in Table V.[31] In early and middle stages of the disease, individuals often select from the LightWriter family. These devices have a dual display, are portable and the user can store simple messages. Later on, if desired, a scanning module can be added. The Link is another portable, direct selection device with speech output. Several clinicians said their patients select the DynaMyte or DynaVox because of their dynamic displays and their quick access to vocabulary categories. Also, these devices can serve as keyboard emulators to a computer.

Digitized speech devices (*e.g.*, Message Mate, Easy Talk, Walker Talker), although limited to prerecorded messages, can help in specific situations. For example, one man used a digitized device in the car to give his wife directions. "Turn left." "Turn right." "Slow down." *etc.* [She must have loved that!] It is even possible for individuals to program a digitized device before they lose their speech. Researchers are currently investigating these possibilities.

Accessing Equipment

In middle and late stages of communication impairment, individuals who can no longer use their hands to select messages/targets need to find a reliable movement as a control site. Direct selection options include the head (in early and middle stages, but rarely later on) and eyegaze. Head controlled mice are listed in Table VI.[31]

One concern expressed about selecting a good control site is that efficient control necessitates the establishment of an automatic motor pattern. The constant need to change the site of control can interfere with efficient switch use.

In later stages of communication impairment, scanning often becomes the best or only option. Some people try Morse code, but many do not want to learn it. Because scanning requires a reliable movement to activate a switch, the type of switch and how it is mounted is key to the person's control. In later stages, when pressure switches become too difficult, people can use movement switches. Mounting switches on a person's body (eyebrow switch) or for use in bed, in the community, in loungers and in wheelchairs can be challenging.

Eyegaze systems sometimes seem like the only option in very late stages of the disease. Clinicians report that this technology is still not easy to use and many people find it frustrating. However, for some, it works. As with all technology, it is important to try before you buy. Table VII lists available eyegaze systems.[31]

Table V. Dedicated Communication Devices (CINI, 1998)

Device	Manufacturer/ Price	Selection Technique	# of message areas	Symbol system	Rate enhancement	Synthesizer	Portability	Printer options
LightWriter	Zygo $3,995 - $5,325	Direct Selection Scan	Fixed	Traditional orthography (TO)	Word Prediction Abbreviation expansion	DECTalk-English	Hand/ Notebook	External printer 1 line display
Link	Assistive Technology, Inc. $1,395	Direct Selection	Fixed	TO	Abbrev. expansion	DECTalk/-English	Notebook	External printer 4 line display
Dynamyte 3100 **DynaVox 3100**	Sentient Systems, Inc. $5,995 $6,495	Direct Selection Scan	Variable	TO DynaSyms Other symbols can be imported	Word prediction Abbrev. expansion	DECTalk - English/ Spanish)	Hand/Notebook (DynaMyte) Laptop (DynaVox)	External printer Multi-line display
Crestpeaker	Crestwood $299.95	Direct Selection	Fixed	TO	-----	English/ Spanish	Hand	1 line
Say It ALL **Scan It All**	Innocomp $1,995 - 3,995 $3,495 - 3,495	Direct Selection Scan	Fixed	TO	Levels Abbrev. expansion	DECtalk-Eng/Span Clarity -English	Notebook	External printer 2 line display

Table VI. Head controlled mice (CINI, 1998)

Device	Manufacturer/Cost	Platform
HeadMaster Plus	Prentke Romich Co. $1195	Mac, PC
Head Mouse for Desktops	Origin Instruments $1795	Apple II GS, Mac, PC
HeadMouse for Portables	Origin Instruments $1695	Apple II GS, Mac, PC
Tracker	Madenta Communications, Inc. $1695	Mac, PC

Table VII. Eyegaze systems (CINI, 1998)		
Device	**Manufacturer/Cost**	**Platform**
The Eyegaze System	LC Technologies $17,500 (plus)	DOS
Vision Key Series	H.K. EyeCan Ltd. $2,950 - $3450	Mac; IBM PC
Quick Glance	EyeTech Digital Systems $2,500	Windows 95
Eye Ware	Assistive Technology, Inc. $14,999 (pre-release)	Windows

Emergency signals

Dealing with emergency situations is another important area. Technology can make a difference between life and death. Some buzzers, alerting mechanisms, alarms, and other devices can enable people to remain independent and live at home. They offer peace of mind. Professionals working with individuals with ALS can use adapted switches to activate this technology.

Summary

High tech AAC approaches can sustain access to language and communication from early in the disease until its end stage. Individuals with ALS and their families deserve to have what they want and need. The technology now exists and the professional expertise is available. However, the service delivery system and the sources for funding services and equipment often present a quagmire of obstacles. Advocacy is needed.

Governmental

Communication Independence for the Neurologically Impaired (CINI)

CINI is a not-for-profit organization whose mission is to advance communication solutions for person's with ALS/MND and other neurological diseases. Founded in 1993 by Marta Kazandjian, a speech-language pathologist, and Peter Strugatz, whose mother had ALS, this organization's programs include:

- Information and referral service via e-mail, Internet and phone (1000 inquiries in 1997)
- Patient and professional education
- Advocacy
- Research and development
- Publications:
  (1) Communication and swallowing solutions for the ALS/MND Community: A CINI Manual. Available from CINI. $7.95 plus $1.70 for shipping and handling.

  (2) Communication and swallowing management of tracheostomized and ventilator-dependent adults. Available from Singular Publishing. $57.95.

CINI is a member of the International Alliance of ALS/MND Associations. Its scientific advisory board is comprised of such notables in the medical community as Dr. Edward Anthony Oppenheimer, Associate Clinical Professor of Medicine at UCLA and Dr. Michael Swash, Consultant Neurologist at the Department of Neurology at the Royal London Hospital. Involved members of the AAC community include Dr. Howard Shane, Director of Speech and Language Services at the Communication Enhancement Center at Children's Hospital in Boston. Lewis Golinker, Esq., Director of the Assistive Technology Law Center and Dr. Frima Christopher are on the Board of Directors. CINI's corporate and other sponsors include the NEC Foundation, MCI Corporation Foundation, the New York Community Trust, the Chai Foundation and Saks Fifth Avenue Corporation.

Iris Fishman, an AAC specialist, is CINI's Executive Director. The CINI office handles specific requests for information such as: *What kind of communication software can help me write? How can I talk with my grandchildren over the phone? I just got a denial from Medicare for funding. What do I do next? When should I begin introducing the idea of using an AAC device to my client?* CINI also responds to questions at its e-mail address.

Current CINI projects include:

- *Medicare AACtion*. Spearheading an initiative to have Medicare, the largest healthcare funding program in the United States, fund AAC devices, CINI sponsors a monthly teleconference of nationally recognized leaders in the field. This group is developing strategies to compel or negotiate policy reform, as well as to assist professionals in successfully pursuing Medicare appeals.
- *Communication Technology Symposium*, International Alliance of ALS/MND Association in Vancouver, 1999. At this international conference, which will bring together leaders in the

Continued on page 14

Governmental, Continued from page 13

field of ALS research and treatment, CINI plans to sponsor a program on communication options featuring presentations by experts in AAC, rehabilitation technology and medicine.

In addition, CINI is seeking funding to complete several other projects. These include:

- *ALS Communication software bundle*. CINI's team of experts is working with Marilyn Buzolich, Susan Fridie and Assistive Technology, Inc. to develop a software package specifically designed for adults with neurological impairments. The goal is to provide easy access to communication, word processing, the Internet, environmental control and other functions.
- Project *EyeLink*. Made out of a thin sheet of mylar with letters of the alphabet printed on it, the EyeLink provides a low-cost yet rapid means of communication for individuals who are unable to point or to write. CINI plans to design, manufacture and distribute EyeLinks internationally through ALSA chapters, clinics and professionals involved in AAC.
- *CINI Website* (www.cini.org). The site is being designed to provide resource and referral information on communication technology, ALS/MND and other neurological impairments, as well as to link to related sites.
- *Environmental Control Guide.* CINI will publish and distribute a comprehensive brochure that will describe the range of technology options for individuals with communication impairments who, due to severe physical disability, are unable to control electrical appliances and devices such as television, lights and radio.

CINI is committed to fostering collaborative relationships among organizations, companies, foundations and manufacturers who share a common mission. CINI is working hard to assist all those interested in addressing the communication needs of individuals with ALS/MND.

For more information about CINI and its projects contact: Iris Fishman, Executive Director, CINI, 250 Mercer Street, Suite B 1608, New York, NY 10012. 516-874-8354 (phone); 516-878-8412 (fax); (e-mail) 73523.151@compuserve.com

On the Web

Examples of Web pages with information about ALS and/or AAC are listed below. If you can add any, please e-mail me at sarahblack@aol.com and I'll pass it along to others.

ALS Digest. This is an ALS Interest Group's weekly newsletter with over 3050 subscribers. Bob Broedel is the editor. E-mail bro@huey.met.fsu.edu to subscribe.

ALSA. The ALS Society Web site has general information about the disease, research activities and a variety of other information. It does not have much about communication issues. www.alsa.org

Muscular Dystrophy Association. This site has an information brochure online called Facts about ALS. www.mdausa.org

ISAAC. The International Society for Augmentative and Alternative Communication Web site has information about the organization, national chapters, *AAC* (the Journal), conferences, direct links to manufacturers and an interactive section. www.isaac-online.org

Applied Science Engineering Laboratory. I didn't find anything specific on ALS at the ASEL Web site at the University of Delaware www.asel.udel.edu/rerc-aac but they have lots of good information and links.

University of Nebraska-Lincoln. The Barkley Center website is rich with resources. Check out the Case Study of Mr. Scott, a man with ALS who uses Vision Key. Tom Jakobs did a nice job describing the process of equipment selection and its impact. www@aac.unl.edu

In addition to information, the Web offers individuals with ALS opportunities to learn and share experiences. Some folks even have their own Web sites. Check out **Stephen Hawking's** site www.damtp.cam.ac.uk/user/hawking/home.html as an example.

Having access to the Internet can make a significant difference in the lives of individuals with ALS. The following quote gives one perspective.

> As for comments about experiences using online services, I really enjoy E-mail. I feel on par with others as long as I can compose off-line and then send. It's a good felling. For a time, when writing and reading e-mail I've received, it's as though I don't have this terrible disease.[32]

Your Resources

Frima Christopher, Ph.D., Dir. of Psychology, Dept. of Psychiatry, Coler-Goldwater Memorial Hospital S-210, 1 Main Street, Roosevelt, NY 10044. Phone: 212-318-4613; Fax: 212-318-4349.

Delva Culp, Coordinator, AC Team, Callier Center for Communication Disorders, The University of Texas at Dallas, 1966 Inwood Road, Dallas, TX 75235. Phone: 214-905-3137; Fax: 214-905-3022.

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Marta Kazandjian, Exec. V.P., CINI/Director, Dept. of Speech Pathology, Silvercrest Extended Care Facility, New York Hospital Medical Center-Queens, 144-45 87th Avenue, Briarwood, NY 11435. Phone: 718-670-2736; Fax: 718-670-1924. 74514.1633@compuserve. com

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Manufacturers

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Aurora Systems, Inc., 2647 Kingsway, Vancouver, BC V5R 5H4. Phone: 604-291-6310/888-290-1133; Fax: 604-291-6310; E-mail: aurora sw@direct.ca Web site: www.djtech.com/Aurora

Consultants for Communication Technology, 508 Bellevue Terrace, Pittsburgh, PA 15202. Phone: 412-761-6062; Fax: 412-761-7336; E-mail: 70272.1034@compuserve.com

Crestwood Company, 6625 North Sidney Place, Milwaukee, WI 53209-3259. Phone: 414-352-5678; Fax: 414-352-5679; E-mail: crestcomm@ aol.com Web site: www.communicationaids.com

Electronic Speech Enhancement, Inc., 1115 Ridge Road, St. Louis, MO 63021-5932. Phone: 800-600-9819/314-731-1000; Fax: 314-731-1130; E-mail: service@SpeechEnhancer.com Web site: www.SpeechEnhancer.com

EyeTech Digital Systems, 1755 E. McLellan Road, Mesa, AZ 85203. Phone: 602-386-6303; E-mail: etsbus@aol.com Web site: www.members.aol.com/etsbus/eyetech-home.html

Gus Communications, Inc., 1006 Lonetree Court, Bellingham, WA 98226-3167. Phone: 360-715-8580; Fax: 360-715-9633; E-mail: gus@gusinc. com Web site: www.gusinc.com

HK Eyecan, Ltd., 36 Burland Street, Ottawa, ON, K2B 6J8. Phone: 800-356-3362; E-mail: eyecan @cyberus.ca Web site: www.cyberus. ca/eyecan

Innocomp, 26210 Emery Road, Suite 302, Warrensville Heights, OH 44128-5771. Phone: 800-382-8622/216-464-3636; Fax: 216-464-3638; E-mail: Innocomp@sayitall.com Web Site: www.sayitall.com

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