

Upfront



This issue of ACN focuses on people with amyotrophic lateral sclerosis (ALS) and their closest communication partners and highlights the tremendous difference that effective communication supports can have on their lives. It is no accident that much of the newest information emphasizes both sides of the communication exchange, because when individuals with ALS experience difficulty using natural speech, their communication problems won't be solved unless they and their interactants are able to work through the barriers that can derail successful exchanges. Thus, it makes sense for treatment to focus on ways to support the interaction, rather than placing the onus on "fixing" one or both interactants.

Each person's choice of communication modes and strategies will depend not only on the available alternatives, but also on the partners' skills with these alternatives. Thus, people who rely on AAC may use their difficult-to-understand speech or employ a low-tech display with a family member, but choose to use a speech generating device (SGD) with a new acquaintance. As decisions to use various combinations of signs, gestures, low-tech displays, SGDs, etc. are made, communication partners may need to gain new skills to co-construct messages, interpret impaired speech and support the effective use of an SGD.

As the work we report on in this issue suggests, there may be enormous differences between the state-of-the-art communication supports now available to people with ALS (as described on pages 1-7 and 11-12) and the kind of communication support most people with ALS around the globe are actually getting. Professionals who serve people with ALS need to take very seriously the challenges of closing this gap.

This issue contains updates on recent research that enables clinicians to predict more accurately when speech will become unintelligible, clarifies when AAC interventions should begin (**Fact Sheet**, page 8) and provides information about how to secure funding for the SGDs that more and more people with ALS are

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Social Networks

Interview: Living with ALS with Linda Rutz

Linda Rutz reflects on experiences she and her husband Tom had after he was diagnosed with amyotrophic lateral sclerosis (ALS) in 2003, at age 58. In an interview conducted by Miechelle McKelvey and David R. Beukelman, Linda provides a unique glimpse into a couple's journey through ALS. The interview captures Tom Rutz's determination to express his authentic self, and highlights how Linda and Tom were able to maintain an active lifestyle. Prior

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to his diagnosis, Tom was a middle-school teacher. He and Linda had raised three children, had two grandchildren

and were leaders in their community. After his diagnosis, Tom and his family found creative ways to preserve their social relationships. They worked closely with David Beukelman and his colleagues at the University of Nebraska to ensure that Tom had access to appropriate AAC strategies and technologies, until his death in October 2004.¹

Before Tom's diagnosis with ALS, you and Tom had a very

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active social life. Did that change?

We made a promise that ALS was not going to change our lifestyle. Our lifestyle was to be on the go—to go out.

Was Tom able to remain involved with his friends and participate in outside activities?

In November of 2003, we started a weekly gathering at a restaurant. We called it *Time Out with Tom*. We got the word out that it was a time to stop by and see Tom because, you know, even though many people will come by your house, some just don't feel comfortable doing that.

We did not miss a Monday. Some people would just stop by for a quick

refreshment, and others bought dinner, but all talked with Tom. We probably averaged 30 to 35 people every week. In April of 2004, we surprised Tom, because his birthday was on a Monday. We had over 125 people at the restaurant that night.

How was he able to communicate with such a large group?

When we started *Time Out with Tom*, he was still talking, using a small portable voice amplifier. After a few months, he began to use his communication device to talk. We developed pages for greetings and weekly news so he could tell people where he'd been, what he'd been doing and what was happening in the family.

During football season, we also had a sports page about Nebraska football, which was a lot of fun. Of course, Tom could prepare unique messages anytime he wanted.

Did he talk about the same things each week? Within about a month we had developed a system. He started by sharing a "Thought for the Day"— something introspective or reflective that he had thought about that week.

One Monday he thought it might be fun to tell a joke, and in a few weeks people were emailing him jokes all the time. I would print them out and we would pick a couple to use. Well, oh my goodness, that was a hit! He loved it because he had quite the sense of humor. Some of his jokes were the lamest jokes ever, but everybody loved them.

Did Tom have other regular meeting times with friends? Yes.

This group of young guys from church would come to the house. They started picking him up for lunch every Wednesday. After he was in a wheelchair and it became harder for him to move around, they would come to our house for lunch. They became the joke selection committee.

What else did he do to maintain community involvement?

Tom decided that he was going to call each member of our church on his or her birthday. As the disease progressed, it was harder to understand him, so he made all the calls using his communication device. We programmed in messages for birthdays and anniversaries.

At church, in August of 2004, our pastor asked, "How many people in this room have had a birthday call from Tom?" Just about everybody stood up. There are four hundred people in our church. I think the numbers of people he touched were

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finding to be a crucial component of living a full life (*On the Web* and *Governmental*).

Social Networks contains an interview with Linda Rutz, whose husband Tom had ALS. Linda captures the day-to-day reality of relying on AAC and describes how Tom was able to use an SGD to maintain his relationships and his lifestyle. The *Equipment* section explains how Tom's speech generating device was organized and personalized to address both his intrapersonal and interpersonal needs. In *Case Example*, Lisa Bardach describes her treatment approach with Mr. G, first in his nursing home and then at hospice. These articles offer a unique glimpse into the potential that exists when highly-trained professionals provide support to individuals with ALS and their primary caregivers.

In addition to these more personal stories, the *AAC-RERC* and *University Research* sections report important new information about the roles of informal caregivers

who serve as primary communication facilitators and the kinds of supports they prefer.

Thanks to Linda Rutz, David Beukelman, Laura Ball, Melanie Fried-Oken, Lisa Bardach, Lewis Golinker and Lynn Fox, who helped prepare this issue.

I hope ACN readers will see the urgency of sharing this news with individuals who have ALS, their family members and those who work with them. Being able to communicate effectively throughout the progression of this disease is a crucial factor in navigating its shifting obstacles and difficulties. Helping people to do so is an essential component of effective treatment.

*Sarah W. Blackstone, Ph.D.
CCC-SLP*



pretty amazing. People could not believe that somebody who was as ill as he was would still reach out and make birthday calls to them.

When did Tom begin to use his AAC technology? AAC was introduced to us early on. Tom started to work with a device in December 2003, while he was still able to communicate using natural speech. I'm glad we started as early as we did because we had time to figure out what to do and what the next steps would be. The AAC specialists had us talk about our lifestyle, how we wanted to use the AAC device and where we wanted to go. I said, "Well, we're going to keep going out, so we had better figure out a way to take it with us."

Tom had different pages of messages. I think that came out of our saying, "The communication device has to grow with us, so let's make sections that we can easily update and change."

What advice can you give a family about developing AAC for someone with ALS? I think you need to emphasize to a family that the AAC device is not just a machine or a piece of equipment, like an oxygen machine. It becomes a part of the person's personality. I feel that a big part of what I did was to help people know what to expect

Thought for the Day

I want to share a special message about my ALS journey that you have shared with me. First, I want to thank you for all of the sacrifices that you made coming to "Time Out with Tom" every Monday. Your love and concern have been the wind beneath my wings for the last year.

Tom Rutz, June 2004

so they could interact with Tom, and also help them be sensitive to where he was and how the disease was progressing.

What role did the communication device play in maintaining Tom's social network? The communication device really became Tom, or rather an extension of him. For example, one time Tom received a Norwegian joke and wanted to get the machine to speak with a Norwegian accent. We were trying to spell phonetically and in the end, actually figured it out! All our friends adjusted to the device. People were great. During the last nine months, he used it all the time, and it really was an extension of him.

You mentioned that you had difficulty getting insurance to pay for the AAC device. I got a letter from our insurance company asking, "Does Tom really need this communication device?" I mean, it's so ridiculous!

Here's the deal, I went ahead and paid for the thing [AAC device] because we needed it. If I had waited until the insurance company agreed to pay, Tom would have been gone. Now how stupid is that! The month after he died, they finally reimbursed us for his equipment.

Did Tom's communication style and content change over time?

Before the ALS, Tom was basically a hands-on, doer person. He loved to make things better. Because of the disease, he had a lot more time to think about things. And he thought about stuff that had me wondering, "Why the heck is he thinking about that?" He would come out of the clear blue with something he wanted to do or something that was important to him.

He became more philosophical and thoughtful, thinking about ideas and thinking about things that he wanted to say or do for people. That was a dimension of him and his personality that I felt was always there and just really blossomed. He began communicating a lot more of his feelings.

How did Tom communicate his basic needs? As Tom's speech got worse, we used signals a lot. I had signal sheets in each bathroom, in the kitchen and all the rooms he spent time in. I would update the signal sheets periodically so whoever was there (a caregiver, volunteer or friend) could refer to them.

Tom communicated with his eyes and his head. He chose movements that were easy for him and made sense, like making different movements with his mouth and tongue to signal hunger or thirst. Sometimes, he'd have to type out the meaning of a signal on his communication device before we understood it.

How did his use of the AAC device impact your family life?



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The grandkids— I mean, he loved those boys— they thought that the AAC device was Tom’s voice. Sheila, our daughter, would bring Dylan (age 2) and Thomas (age 1) over every Monday morning to see Papa (Tom), and they’d watch *Sesame Street* together and play. We had programmed the messages, “Hi Dylan, I love you,” and “Hi Tommy, I love you.” When they walked in, Tom would play these messages and Tommy would just light up.

I still have the communication device in the kitchen. Recently, I had it say, “Hi Tommy, I love you.” Tommy said, “Papa, Papa.” So, they never missed a beat at all.

Tom had always taken care of the house and rented out the apartments you owned. As his ALS progressed, did you have to make more decisions in these areas?

Well, that’s interesting you should ask because that was one of our biggest issues. When we renovated our house so that he could have access, I had made some decisions that I basically didn’t think were a big deal. However, they weren’t minor to Tom because he felt that when I made decisions without him, I was saying that it didn’t matter what he thought, and that he didn’t bring any value to the decision. That wasn’t it at all.

I learned to make sure we really talked about things instead of saying, “I think we should do something, what do you think?” Like I was asking him, but had already made the decision.

How about your children?
Did they have similar issues communicating with their dad? I think Julie (daughter) had the same challenge that I did. For example, there were lots of little things that would happen at the apartments. Originally, she thought it would be



better not to tell Tom because he would get upset, but then he would find out anyway. I said to Julie, “I think what you need

to do is to come over and sit down with Dad and say, ‘Here’s what’s going on with the apartments,’ so he feels like he’s still part of it and it’s still a part of him.” That worked a lot better. Even at the end, Julie would ask him for advice about what she should do with the apartments.

What had to change was us learning to be sensitive, not Tom’s ability to provide input and make decisions.

Did the AAC device help him deal with ALS? One night when we got home after a *Time Out with Tom*, he was very, very angry with me about something. It was something that he had asked me to do, and I’d forgotten to do it. It wasn’t so much that I had forgotten, but rather it sent the message that he wasn’t important enough that I would remember to do it. I think caregivers have to struggle with this.

Our family would keep saying to each other, “You’re going to have bad days and you’re going to have good days.” When you just lose it

with each other, it may not be that particular situation, but rather the disease and all the feelings surrounding the disease.

Anyway, he was quite upset with me and he wanted his communication device, so I went and got it. I’m sitting there in the recliner, and it’s late, and he’s just written something. All of a sudden he says, “Don’t give up your day job, you suck as a caregiver.” And then he played it again and again...five times!

Scott, our son, was sitting across the room working on his computer, and he just looked at me and started laughing. Tom, however, was not laughing. He was quite upset—very upset—with me. After I heard it for the fifth time, I went over and said, “I get it! I get it! I get the message!” Then I told him, “I’m sorry,” and we had a talk, a good exchange. Still, it wasn’t until the next day that he could finally laugh about it.

Final thoughts

During the interview, Linda recalled that six months after Tom’s death they had a “Time Out with Tom Revisited” at the same restaurant where everyone used to meet when Tom was alive.

I took the communication device with me and played a couple of his jokes. My heart just kind of pounded because that was really Tom.

Linda and Tom Rutz clearly valued communication and were determined to live life to the fullest, no matter what. Working with a team of competent AAC professionals, Tom and Linda made sure he had the supports he needed to stay in touch with family, friends and acquaintances despite Tom’s loss of speech. We are all indebted to Linda for her willingness to share their experiences so openly.



Thought for the Day

I know in advance approximately when I will die. So I have been able to make a personal videotape for each member of my family. I have been able to say all of the things that are difficult to say or go unsaid many times. And each week at Time Out with Tom, I am able to see and share my thoughts with many of my friends. If there is one by-product of this disease, it is the time to say goodbye.

Tom Rutz, August 2004

Equipment



Tom's AAC system by David R. Beukelman, Ph.D.

Tom Rutz made it clear while he was still able to speak that he wished to maintain communication with a wide range of individuals in his social network; and throughout his illness, he continued to interact with people each week. As AAC professionals, we understood that Tom's AAC technology had to be efficient and support extensive message-based communication, letter-by-letter spelling and word prediction.

After an assessment at the Neuro-muscular Disorders Clinic at the University of Nebraska Medical Center, Tom selected Enkidu's Tablet XL Impact² speech generating device (SGD) because it (1) would enable him to store a large amount of novel information, (2) was relatively easy to program and (3) would allow him to easily retrieve messages. Tom accessed the device using Head-Mouse® technology.³

The content and organization of his SGD

AAC professionals worked with Tom and his family to customize his device so he could actively participate in his wide-ranging social network. Tom organized his social calendar by the week: church (Sunday), *Time Out with Tom* (Monday), lunch with the guys (Wednesday), phone calls for birthdays and anniversaries (whenever), sports events (whenever).

To interact with groups of people, Tom often relied on pre-programmed messages, but he also formulated novel messages. He made extensive use of both spell-

ing and message modes and occasionally used word prediction. Stored messages were updated each week.

As shown in Table I, Tom's speech generating device (SGD) had multiple pages and links. In addition, he could prepare special pages to support his participation in one-time events. Tom's upfront planning made him especially effective during radio and TV interviews. For example, Tom made a page for the Muscular Dystrophy Telethon, which included a statement about living with ALS, some news, a few jokes and a Thought for the Day. It also linked to his SGD description page.

Tom's AAC technology evolved over time in ways that reflected his changing needs, interests and preferences. Messages were often organized by

Main Page. The Main Page on the Tablet XL Impact is set up for spelling with the alphabet and word prediction. Tom's Main Page linked to his Quick Talk messages page and his Master Table of Contents (MTOC) page.

Quick Talk messages consisted primarily of conversation starters. *What have you been doing? How is your family? How are you doing? Great to see you again. Thanks for coming.* He often used these to get someone talking while he prepared to go further into a conversation.

Master Table of Contents (MTOC) enabled him to navigate to all other pages of stored messages. Tom created six additional categories of pages:

1. Jokes (organized by the week). Over time, he accrued about 25 Jokes pages. Each Jokes page contained six to eight jokes. He had

Table I. Configuration of Tom's AAC device

Pages	Content	Links
Main Page	Alphabet and word prediction page for spelling. The message window.	Quick Talk/Master Table of Contents (MTOC)
Quick Talk/Master Table of Contents (MTOC)	Quick Talk; Greetings/phrases that get people to talk. MTOC: Navigation page to stored messages.	Main Page, Jokes TOC, Thought for the Day TOC, News, Phone, AAC Device Description, Care
Jokes	Six to eight jokes per page. 25 pages of jokes. Organized with a Jokes TOC page.	Main Page, News
Thought for the Day	Six to ten thoughts per page. Organized with a Thought for the Day TOC page.	Main Page, News
News	Brief descriptions of news items organized by week. Retained for one month	Main Page, Jokes TOC
Phone	Messages for phone conversations.	Main Page, News
AAC Device Description	Messages that describe the device.	Main Page
Care	Messages about basic needs, medical issues and care	Main Page

both category and date to help him remember which messages he had used with a particular group or an individual. Links between pages specifically reflected Tom's conversational patterns. For example, he often went from the News page to the Jokes pages, but rarely went from the News page to his Thought for the Day pages.

a Jokes Table of Contents (TOC) page to help him access individual pages. Several pages contained jokes he had chosen for certain events, such as a class reunion or a special session at his church. Tom divided each joke into two or three separate messages so he could deliver them effectively.

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2. Thought for the Day (organized by week). Each Thought for the Day page contained six to ten thoughts. Some thoughts were brief (a few sentences), while others were quite long (about 500 words). A Thought for the Day Table of Contents (TOC) page gave him efficient access to individual thoughts.

3. News (organized by week). These pages contained brief descriptions of recent news items. Sometimes the items involved Tom and his wife, Linda, or were updates of their children's activities. Many individuals who came to *Time Out with Tom* had known the family for years. News items were things that had happened up to a month before. So, while the news pages were very important to his communication efforts, he did not retain them in his system.

4. Phone. Tom had two phone message pages with about 40 messages. He used these to interact during general phone conversations, make birthday and anniversary calls and deal with answering machines. Tom telephoned people at his church who did not regularly come to *Time Out with Tom* and who were not part of the lunch group. He also used the phone to develop relationships with children and young people at church. He would call them, wish them a happy birthday and then invite them to tell him what gifts they received when they saw him next. Not surprisingly, these kids would chat with him after church services. They were comfortable with him because he had already talked with them using his AAC device on the telephone.

5. AAC Device Description. Many people were interested in the AAC device, and it was not uncommon for strangers to approach him

at sporting events and concerts to ask about it. Tom had a single page with messages to describe his system. Typically, he would respond to the question and then tell them a joke or two, share a little news and ask how they were doing.

6. Care. Tom maintained several pages with messages that related to his physical and medical needs. These changed over time as his care needs increased.

Concluding remarks

Each individual with ALS wants to express his or her authentic self. Tom's device worked well to support his interpersonal and intrapersonal communication needs. He would have been pleased to know that a glimpse into how his system was designed might be helpful to others.

[For additional information about Tom's AAC system, including examples of stored messages, go to <http://aac.unl.edu>.]



AAC-RERC
SPREAD THE WORD

Primary communication facilitators by Laura Ball, Ph.D., Kim Schardt, M.S. & David R. Beukelman, Ph.D.

Most persons with amyotrophic lateral sclerosis experience severe communication disabilities at some point in the progression of the disease, and can benefit greatly from augmentative and alternative communication (AAC) strategies. To do so, they often require the active involvement of communication facilitators—people who support the use of specific AAC strategies and technologies.

This study surveyed the primary communication facilitators of 47

individuals with ALS. The goal was to investigate the technical backgrounds, learning mode preferences, training experiences and roles of those who support people who use AAC technology.

Persons with ALS. All 47 people with ALS relied on AAC technology to communicate. Eighteen (38%) were female and 29 (62%) were male. Twenty-five (53%) were diagnosed with bulbar ALS, eighteen (38%) with spinal ALS and four (9%) with mixed ALS. Ages at the time of diagnosis ranged from 33 to 80 years, with a mean of 57 years. Most (90%) were married, two were unmarried and four were widowers. All used complex speech generating devices (SGDs) from a range of manufacturers (Dynavox Inc., Enkidu, Words+ Inc., Assistive Technology Inc., Zygo Industries).⁴

Primary communication facilitators. Facilitators were defined as persons who had participated in AAC evaluations and training sessions with the person with ALS, made tech-support telephone calls and were engaged in ongoing interactions related to AAC technology use. Most primary facilitators were family members. Of the 47 individuals with ALS, spouses accounted for nearly half (N=23) of the facilitators. Ten facilitators were adult daughters; there were seven other family members (a daughter-in-law, a niece, a granddaughter, a mother, a grandson, a brother and a son) who acted as communication facilitators. In only five cases did paid staff (*i.e.*, 3 SLPs, 2 nurses) serve as primary facilitators. Finally, two individuals maintained and programmed their own SGDs.

[Note: Nearly all individuals with ALS relied on a single, primary facilitator throughout the disease, even after transitioning from home to a hospice or nursing care facility.]

Survey. The survey instrument was designed to examine a number of factors about people who act as primary communication facilitators. It was mailed to all 47 facilitators and completed by 19, representing a 43% return rate. Of those who responded, 16 (84%) were females and three (16%) were males. Fourteen were spouses (12 female, 2 male); two were daughters, one was a son and one was a niece. One respondent served as her own primary facilitator.

[Note: Researchers decided to exclude from the final data analysis all paid workers (N=5) who had served as primary facilitators.]

Preliminary results were as follows.

1. Technical background of facilitators. People who became facilitators of communication and AAC technologies for individuals with ALS did so because of their primary relationship with the person, rather than their level of technical expertise. No respondents were engineers, computer programmers or information system support personnel. However, many used computers for word processing and/or Internet access. One person was a student in computerized graphic design. A majority said learning about technology (with the exception of word processing) was “not at all like me.” Facilitators had learned to use AAC technology because of the needs of the individuals they supported.

2. Learning Mode Preference. All primary facilitators and individuals with ALS participated in training sessions provided by an AAC technology specialist (first author). The mean number of training sessions was 3 (range of 1 to 10) and the mean length of a session was 1.6 hours (range of 45-120 minutes). Three facilitators reported attending additional training sessions provided by an AAC manufacturer’s representative.

A majority (11) of the facilitators said they preferred learning about AAC devices through detailed, step-by-step instruction. One person commented,

I am a visual, hands-on learner. Workshop instruction works best, then allowing me to help the person with ALS.

In all, six (32%) preferred to learn in a group situation. Only two said they liked to learn to use technology without help. One person said,

Taking the device home with all the booklets that came with it and trying to operate it on our own was extremely frustrating and confusing.

3. Facilitator Roles. These facilitators coached and mentored individuals with ALS to use SGDs. They (1) programmed pronunciation exceptions, (2) assigned prediction values or priorities for word prediction algorithms, (3) adjusted scanning and dwell values as physical abilities changed and (4) positioned switches to accommodate fine movement or strength changes. They also communicated with AAC interventionists and manufacturers about AAC technology issues.

Primary facilitators also said they routinely coached and instructed a range of communication partners, most often immediate family members, friends and caregivers, but also less familiar and even unfamiliar partners. They provided more or less support depending upon the participation patterns, living situation and health care needs of the individual with ALS. For example, one man habitually used his AAC technology at home, but typically “forgot” to bring it when he went out for a weekly get-together with friends. His facilitator (wife), thinking he might be fearful of a negative reaction from his buddies, decided to bring his SGD to a party and demonstrate it. She reported that it

took only a few minutes before her husband was “elbowing in” to show everyone how his device worked.

Primary facilitators also taught other caregivers to maintain SGDs and accessories. While they did not assume complex programming and troubleshooting activities, these caregivers did help by moving and positioning mounts and switches, charging equipment and setting up communication devices for daily use.

Summary

Facilitators play a key role in ensuring that individuals with ALS can access and use AAC technologies effectively to communicate with family, friends and others in their social network. Survey results suggest that primary communication facilitators of individuals with ALS are typically female family members with non-technical backgrounds. Facilitators reported mentoring and coaching a variety of people, mostly other family members and friends about how to communicate with the individual and care for equipment. Data also suggest that primary facilitators had strong preferences about how to learn to use SGDs (e.g., preferring hands-on, detailed, step-by-step instructions). In conclusion, it is vital for clinicians and developers of AAC technology to find ways to support the primary communication facilitators of persons with ALS.

For additional information about the AAC-RERC and its projects and activities, go to <http://www.aac-rerc.com>.

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AAC-RERC
SPREAD THE WORD

Communication Support for Persons with ALS: A Fact Sheet

Prepared by Laura J. Ball, Ph.D., David R. Beukelman, Ph.D. and Gary L. Pattee, M.D. 2005

- **ALS is a rapidly progressive, neurodegenerative disease often resulting in mixed dysarthria (spastic & flaccid) of speech.**⁴
- **As ALS progresses, the severity of dysarthria worsens so that a large percentage of persons with ALS (80 - 96%, depending on the report) are unable to meet their daily communication needs through speech alone. These persons require augmentative and alternative communication (AAC) in very timely interventions.**
- A recent study reported that following an evaluation and recommendation for AAC technology, **96% of persons with ALS accept AAC technology**² either immediately (90%) or after some delay (6%). Approximately 4% of individuals with ALS rejected AAC technology. Those who rejected AAC technology usually demonstrated complex medical or cognitive conditions in addition to ALS.
- Research shows that those who accept AAC recommendations and receive AAC systems **use AAC until within the last two weeks of their lives.**² Ongoing data collection suggests that on average, those with a spinal onset of ALS use their device approximately 27 months, those with bulbar onset approximately 19 months and those with mixed onset approximately 17 months.
- **The timeliness of the referral for an AAC assessment is an essential component in providing AAC devices to people with ALS.**^{1,4} It is necessary that a device be recommended and purchased with enough time to learn to use it prior to losing intelligible speech.
- **The Neuromuscular Disorders Clinic at the University of Nebraska Medical Center recommends an AAC assessment as soon as speaking rate slows to 125 words per minute, even if sentence intelligibility remains over 90%.**^{1,4} If intelligibility drops below 90%, the ability to use speech to communicate will be lost. For most, speaking rate decreases before loss of intelligibility (*Sentence Intelligibility Test*⁵) is observed. For all types of ALS (bulbar, spinal or mixed), a rapid deterioration of intelligibility often occurs when speaking rate reaches approximately 55%–70% of the habitual rate.
- **Speaking rate can be monitored adequately for change using a standard telephone.**³ Between visits, simply provide a standard series of sentences to be read. At regular intervals, time and record the sentences as they are spoken over the phone to obtain an overall average and monitor changes over time.

References

1. Ball, L., Beukelman, D., & Pattee, G. (2002). Timing of speech deterioration in people with amyotrophic lateral sclerosis. *Journal of Medical Speech-Language Pathology*, 231–235.
2. Ball, L., Beukelman, D., & Pattee, G. (2004). Augmentative and alternative communication acceptance by persons with amyotrophic lateral sclerosis. *Augmentative and Alternative Communication*, 20, 113–123.
3. Ball, L., Beukelman, D., Ullman, C., Maassen, M., & Pattee, G. (2004-submitted). Monitoring speaking rate at a distance for persons with amyotrophic lateral sclerosis. *Journal of Medical Speech Language Pathology*.
4. Ball, L., Willis, A., Beukelman, D., & Pattee, G. (2001). A protocol for identification of early bulbar signs in amyotrophic lateral sclerosis. *Journal of the Neurological Sciences*, 191, 43–53.
5. Yorkston, K., Beukelman, D., & Tice, R. (1996). *Sentence Intelligibility Test*. Lincoln, NE: Institute for Rehabilitation Science and Engineering at Madonna Rehabilitation Hospital.

The Rate-Intelligibility Relationship in ALS: Guidelines for Clinical Practice

- § When speaking rate has slowed to about 150 words per minute (wpm), a physician referral to a speech-language pathologist is recommended, and monthly monitoring via telephone should begin.
- § When speaking rate has slowed to about 125 wpm, an AAC evaluation is *imperative*.
- § If, at any time, intelligibility of speech decreases below 90%, an AAC evaluation is recommended.

University & Research



ALS caregiver research

Informal caregivers are defined as family members and close friends who provide unpaid assistance. The informal caregivers of individuals with amyotrophic lateral sclerosis (ALS) are known to play crucial and varied roles, and often act as primary communication facilitators. For example, if speech deteriorates and communication becomes difficult, informal caregivers often step in to support communication, including the individual's use of AAC devices, techniques and strategies. They help individuals acquire and use AAC devices, maintain communication equipment and program AAC devices. They often learn to support the use of partner-assisted communication techniques and strategies, such as eye-gaze and auditory scanning. Caregivers who support and facilitate communication also serve as interpreters, instructors and/or coaches for family members, friends, acquaintances and for unfamiliar partners. In other words, they help individuals with ALS converse with others (and vice versa), express feelings, wants and needs and stay connected and in control of their lives.

Despite the acknowledged importance of informal caregivers as communication facilitators, little is known about their attitudes regarding AAC technologies, their comfort levels with AAC devices and strategies, how they view their roles as facilitators or whether they consider AAC technology a burden, a strain or an advantage.

Melanie Fried-Oken, along with her colleagues in Portland, Oregon, and Joan Murphy in Stirling, Scotland have recently examined the roles informal caregivers of individuals with ALS play in supporting the use of AAC technologies. Results from their studies are briefly described below.

Caregiver attitudes about AAC technology skills, mutuality and role strain (Northwestern USA).

Fried-Oken and colleagues investigated the relationship among (1) attitudes about AAC technology, (2) computer and AAC technology skills and (3) role strain.⁶ Participants in the study included 34 caregivers of 27 individuals with ALS who reside in the northwestern part of the United States. The 34 caregivers included: 20 spouses, 5 adult children, 5 friends, 1 sibling and 3 others. Their mean age was 54 years with a range of 23 to 88 years. Most (79%) were female.

The individuals with ALS included 22 males and 5 females with a mean age of 60 years. Their mean score on the ALS Severity Rating Scale was 10.44 with a range of 0 (no function) to 32 and a standard deviation of 10. They relied on a variety of AAC technologies, including dedicated text-to-speech devices such as the LightWRITER™ (7), computer based systems with specialized software such as EZ Keys (16), symbol/word-based dynamic display devices (7), computers with adapted software (3) and voice recognition (1). Some individuals used more than one device.

Research associates interviewed caregivers and individuals with ALS in their homes, by email or over the telephone. All participants completed a demographic survey, the AAC Scales and checklist and the

Table II. Caregiver Assessment of Communication Support (CACS)

The CACS includes the following scales and checklists that measure caregivers' subjective experiences of supporting individuals with ALS to use AAC technologies:

- (1) Communication Device Skills Checklist;
- (2) Computer Use Skills Checklist; (3) Communication Device(s) scale and (4) Attitude Scale.

Developed by Melanie Fried-Oken, Lynn Fox, Judy Rau and Jill Tullman (2002).

AAC Caregiver Assessment of Communication Support (CACS). [See Table II].

Caregivers in this sample described very positive attitudes toward AAC technology (4.29 on a 5 point scale, with 5 being very positive). Researchers found no relationships between caregivers' role strain and their attitudes toward AAC technology. Results showed no correlation between role strain and general computer use. The researchers concluded that, because computers are widely used in our culture, caregivers were therefore comfortable with computer-based AAC technology. Thus, it did not affect their level of role strain.

With regard to AAC device skills and domains of role strain (rewards, mutuality and other caregiving tasks), caregivers who had greater AAC device skills reported greater rewards associated with caregiving. They also indicated an increased perception of closeness with their partners and less difficulty with caregiving tasks.

Perceptions about AAC technologies and services (Stirling, Scotland). During a three-year, longitudinal project in Scotland, Joan Murphy investigated the perceptions of individuals with motor neuron disease and their caregivers about issues related to AAC.⁷ [ALS is one of several motor neuron

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diseases.] Fifteen individuals with motor neuron disease (8 men and 7 women) participated. Most participants (13) had a bulbar onset, while two had a spinal onset of ALS. Each participant with ALS chose a communication partner to participate in the study. Ten asked their spouse, two a close relative and one a friend. Two had no one available, so the researcher served as their interactant.

Data were collected using video recordings of dyads in open conversation, and through interviews and field notes. Although the researcher planned to visit each dyad seven times at approximately six-week intervals, this was possible with only nine dyads. During the final visits, one person had no speech impairment; eight had severe to profound impairments, and four had mild to moderate speech impairments. [Two individuals died before the end of the study.] Participants relied on speech, gestures, paper and pen and alphabet boards to communicate. Ten had high-tech AAC devices (LightWRITER™).⁸ Some individuals also used computers to search the Internet, send emails and write.

Over the course of her three-year study (about ten months for each participant), Murphy analyzed the data using qualitative methodologies, which involved coding conversational control, communication modes, topics and strategies that helped or hindered communication. An inductive analysis revealed three common themes in relation to AAC.

(1) Results relating to the individual with motor neuron disease and caregivers. Participants (caregivers and individuals with motor neuron disease) preferred to interact using speech (despite existing impairments) and other body-based

modes. Topics were often predictable with familiar partners and emphasized social closeness. The dyads reported that more formal modes were often not required.

(2) Results relating to AAC devices. Participants said they did not like the quality of the speech output on their AAC devices. The researcher noted that most of the devices (7) either had no speech output or were earlier versions of the LightWRITER™. [Note: the LightWRITER™ began shipping with DECTalk in the mid-1990s.]

Participants also said they had technical difficulties with their AAC device and had found learning to use it challenging. For many, physical access was problematic, but only two dyads were aware that their device had an available scanning module. Murphy noted that no dyads used a speech output device during her visits.

(3) Results relating to professional input. The LightWRITER™ was the only high-tech device professionals had suggested, and participants in the study said they had received very little training in the use of their device. No one had offered them information about other AAC devices, made suggestions about future vocabulary requirements or recommended any kind of symbol board, picture communication book, memory book or personal communication passport. Even so, five dyads used low-tech communication successfully (alphabet board, board with key words and phrases, paper and pen, or a combination).

Based on her study, Murphy emphasized the need for speech-language pathologists to support close communications with familiar partners. Among the recommendations she made for professionals who support people with ALS were:

1. Focus on supporting communication, even if you are also providing assistance with swallowing. Speech-language pathologists should have sufficient expertise, and should spend time introducing, supporting and updating low-tech and high-tech AAC approaches so the capacity to communicate is maintained throughout the course of the disease.

2. Support the use of speech strategies for as long as possible.

3. Be aware of each client's communication purposes. Address ways for the person with ALS and their caregivers to maintain social closeness. Take care to do nothing that might make it more difficult.

4. Provide information about vocabulary that might be needed in the future. Show caregivers and individuals with ALS how to update vocabulary in ways that maintain small talk and nurture social relationships.

5. Make sure appropriate AAC devices are available in a timely manner and that sufficient training is provided to individuals with ALS and to their caregivers.

6. Recommend devices that the person with ALS and caregivers can easily learn, that are reliable and have good quality voice output.

7. Consider the need to recommend devices that are easily adaptable to accommodate changes in physical status.

Communicative purposes

(Northwestern USA) In a study that specifically investigated communication purposes, Melanie Fried-Oken and her colleagues surveyed caregivers to ask why and when individuals with ALS use AAC technologies.⁹ Participants included 27 caregivers of 22 individuals with ALS who relied on a variety of AAC technologies. The caregiver group was comprised of 16 spouses, 4 adult children, 3 friends, a sibling and 3 others. The ALS group were 22 males and 4 females, with a mean age of 60 years and a mean ALS severity rating score of 11.

Using Janice Light's four social purposes for communication (*i.e.*, basic wants/needs, information exchange, social closeness and social etiquette), the researchers asked caregivers (1) how the individuals they support use their AAC technology to communicate and (2) how caregivers perceive the importance of AAC technologies in expressing different communicative functions. Not surprisingly, results showed an overall increase in the use of AAC technology as the severity of speech impairment increased. In addition, as speech worsened, caregivers reported AAC technology was used more frequently. Caregivers felt that using technology to communicate about basic wants and needs was significantly more important than communicating for other purposes. There were no significant differences between ratings for communicating other social purposes (new information, social closeness or social etiquette.)

Caregivers said AAC technology was used most frequently (85%) for communicating face-to-face about basic needs. While caregivers considered "calling for help" mandatory, individuals with ALS used other signaling systems to call for help. Caregivers also felt that AAC devices were "mandatory" for communicating many forms of new information and social closeness (*e.g.*, expressing feelings, giving instructions and clarifying needs, conversing about work, talking about health care, discussing important issues). Caregivers said individuals with ALS also used AAC technology to have casual conversations, talk about religion, flirt, be funny and tell stories. While caregivers did not feel it was important for individuals to use AAC technology to be polite, AAC devices were reportedly used


to express social etiquette. Finally, one-third said that individuals with ALS used devices to converse and stay connected over on email.

Based on these data, Fried-Oken and her colleagues recommended clinicians address the following:

1. Developing communication strategies (including AAC technologies) that foster social closeness between caregivers and persons with ALS.
2. Providing adequate training in maintaining and managing AAC technology.
3. Providing AAC technology that is less, not more, complex.
4. Considering caregivers' comfort level with complex AAC devices before recommending the purchase of a device.

Summary

The results of these studies provide insight into the supports caregivers require acting when they serve as primary communication facilitators. The research-

ers' recommendations suggest that when caregivers receive the proper support and feel comfortable about AAC technology, they experience very positive outcomes and feel enthusiastic about its use. Some samples of caregivers report a decrease in their levels of stress and an increase in their feelings of connectedness as a result of AAC technologies and communication support. Others, however, did not receive much support. They tended to feel that recommended AAC technologies were unreliable, unintelligible and inappropriate. In that sample, individuals with ALS did not use recommended AAC devices and caregivers did not support their use of technology. 

Case Examples

Mr. G: A man with ALS by Lisa Bardach, M.S., CCC-SP

I first met Mr. G in October 2001. He had ALS and was living at the time in a skilled nursing facility. Because of his physical needs, his wife no longer could care for him at home. He used a wheelchair a few hours a day, but was unable to propel it himself. I conducted a speech and language assessment and found that his speech was at Stage 4 (unintelligible) and that he required a speech generating device (SGD) to meet his daily communication needs. His communication partners included his wife, adult children, grandchildren, the



nursing staff, doctors and patient services aides. Very few friends were able to visit him; and due to his diagnosis, he did not receive much therapy. Mr. G indicated he felt socially isolated.

During the assessment, Mr. G demonstrated an ability to generate text and store messages on a speech generating device (SGD). His range of motion was limited, but he could access a keyboard using the eraser end of a pencil held in his hand. Anticipating further deterioration in his physical condition, Mr. G selected a LightWRITER™ SL35 with a detachable scan module and click switch.¹⁰ His family purchased the equipment with assistance from ALS of Michigan.

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Initial trainings took place in December 2001 and January 2002. Mr. G learned to generate messages of sentence length or more using his SGD. He and his wife agreed that the device would assist him in getting his needs met at the nursing facility.

The next time I saw Mr. G, it was at the request of the social work manager of the hospice facility where he had been transferred. He was no longer able to use his hands to access the LightWRITER™ and could no longer point to the letters on the alphabet board he had used at the skilled nursing facility. [See Figure 1.] Once again, he was frustrated at being unable to communicate. During that session, we set up the scanning module with the click switch for access and reviewed how to use various menu features of the device and how to change settings. I also introduced a variety of advanced procedures, such as programming pronunciation exceptions, using the song features and changing pitch and feedback options to give Mr. G more control over his communication. Since he was an engineer by background, he appreciated the underlying assumption that he was cognitively capable of understanding the processes involved in programming his device.

His social network had expanded at the hospice, and he needed to communicate with more people about a broader range of subjects. Volunteers had begun to visit him, and he was attending art, music and recreational therapy classes. In addition to using his device to speak, Mr. G now wanted to print out written descriptions for some of his photographs. For example,

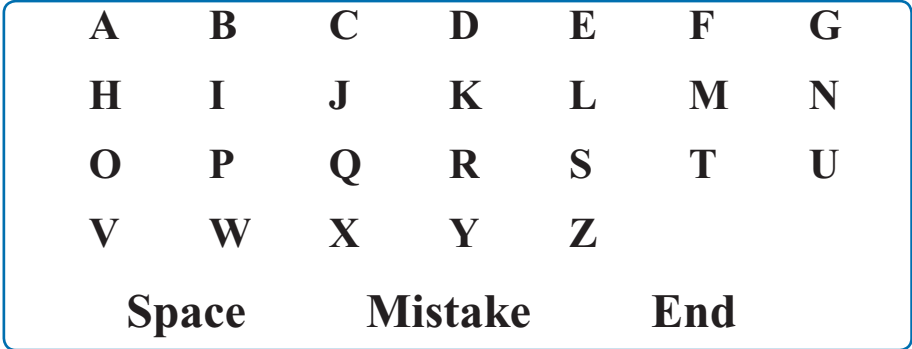


Figure 1. Configuration of Mr. G's alphabet and partner assisted scanning board.

he had photos of machines he had invented in the past and wanted to print descriptions to go with them. A mini-printer was recommended. Once again, the family purchased his new equipment. Mr. G subsequently used the mini-printer to create posters in his room with jokes for his grandchildren and to write captions for the photos from his daughter's wedding.

In addition, the family, volunteers and hospice staff learned to use his alphabet board with partner-assisted scanning, and everyone quickly discovered when it was more expedient to use partner-assisted scanning and when Mr. G preferred to use the LightWRITER™.

Mr. G's family and the hospice staff felt his ability to communicate had influenced his desire to continue living. While at the skilled nursing facility, Mr. G had stated repeatedly that he was not interested in any efforts to prolong his life. However, after he transferred to the hospice, he changed his mind and had a feeding tube inserted.

As Mr. G's physical condition deteriorated even further, he began having difficulty using the click switch. After further evaluation, I recommended an infrared SCATIR switch¹¹ and, after only two training sessions, he learned to use it. Although non-volitional eye blinks tended to cause unwanted activations of the SCATIR switch, Mr. G

was so familiar with his device that he was able to direct his attention to making the switch work, without having to think a lot about the scanning layout or where desired items were located. In addition, he continued to spell using his alphabet board with partner-assisted scanning.

Mr. G passed away in December 2002. His family said they highly valued the assistance they had received in maintaining his communication. The staff at the hospice said their experience of communicating with Mr. G had made them more comfortable working with him, and consequently, with other individuals with ALS. They now realize that other methods of communication can be established.

Final comments

Like others with ALS, Mr. G and his primary communication partners learned to use multiple methods of communication and to adapt over time. As a result he could continue to participate in the lives of his family members and maintain a quality of life he found satisfying. The challenge for me, as a speech-language pathologist, was to keep up with Mr. G's changing communication needs and support him, his family and primary caregivers so he could sustain the ability to communicate.



On the Web



SGD funding for people with ALS by Lewis Golinker, Esq.

Funding for speech and language pathology services and speech generating devices (SGDs) is a concern of people with amyotrophic lateral sclerosis (ALS) with dysarthric speech. However, it is sometimes difficult to learn about funding opportunities and to take advantage of them. This article provides funding information and tips for people with ALS who reside in the United States and highlights existing resources on the Internet, some of which may also prove quite useful to clinicians in other countries.

Medicare eligibility

For most people with ALS in the U.S., Medicare will be the funding source of choice for a wide array of SLP assessment and treatment services, including speech generating devices (SGDs). This is because special Medicare eligibility rules apply to individuals with ALS. These special rules allow those with

ALS who are younger than age 65 to obtain both Social Security Disability Insurance (SSDI, a cash benefit) and Medicare benefits as soon as they are diagnosed with the disease. Under Medicare, individuals with ALS can receive the comprehensive SLP services they may need.

[Two other requirements for access to these benefits are that: (1) prior to diagnosis the person must have worked and contributed to the Social Security trust fund, and (2) the person must stop working.]

[Additional information about Medicare eligibility rules for people with ALS is available at www.aac-lerc.com/pages/medicare/MCFAQs.htm#faq3]

SGD funding sources

Medicare Part B, Medicaid, Tricare, health insurance programs, self-funded health benefits plans and the Department of Veterans Affairs now cover and provide SGDs for individuals with ALS who live at home. However, most health insurance and self-funded health benefits plans, including Medicare, exclude all coverage of SGDs to people who reside in skilled nursing facilities or in hospice.

[Note: Some telecommunications equipment distribution programs also cover SGDs. See next article.]

The above-mentioned programs cover and provide SGDs for individuals with ALS based on their present or anticipated future communication needs. This means an individual with ALS should see a speech-language pathologist (SLP) as soon as possible after diagnosis, to develop a plan for monitoring changes in speech function. If an SGD will be needed to meet daily communication needs in the foreseeable future, a funding request for an SGD should be immediately prepared by an SLP.

[For more information about the role of the SLP, go to www.aac-lerc.com/news/pathway_info.htm.]

SGD funding process

All funding programs follow a three-step, decision-making procedure for SGD coverage and funding. All require an SLP assessment and a report, a physician's prescription and processing by an SGD supplier:

1. SLP assessment and report.

All programs require an SLP assessment and a report. Some, such as Medicare, offer payment to the SLP for the assessment. An SLP makes an initial determination that an SGD is needed, prepares a report that recommends a specific model and accessories for an SGD and develops a treatment plan. If an SLP needs support during this process, a wide range of assistance is available. [See Table III.]

2. *Physician's prescription.* The completed SLP report is sent to the individual's physician who prepares a prescription to be included in the funding request. All funding programs, except some telecommunications equipment distribution programs, require a physician's prescription as part of the SGD request.

3. *SGD supplier.* The SLP forwards the SLP report and the

Table III. Speech-language pathology supports for SGD funding process

MEDICARE GUIDANCE FOR SLP ASSESSMENT	Medicare has issued guidance that lists the elements of an SLP assessment. In addition to its use for Medicare, this guidance is a model for funding requests for SGDs by other third-party payers.	Go to Medicare Regional Medical Review Policy (RMRP) for Speech Generating Devices, posted at www.aac-lerc.com/pages/medicare/RMRP.htm
SAMPLE REPORTS	A group of experienced AAC professionals developed a protocol and sample reports that explain the assessment and data gathering process and are consistent with the Medicare RMRP. The protocol lists the types of data an SLP needs to gather and the content required in an SLP report to ensure that proper documentation of the need for an SGD and necessary accessories is provided.	The SGD assessment protocol is posted at: www.aac-lerc.com/pages/medicare/MCApp-Protocol.htm
REPORT COACH	A "Report Coach," developed by Pamela Mathy, Ph.D., is available to help SLPs quickly and easily transform the data they gather during the SGD assessment into a written SLP report that meets the expectations of Medicare and other funding programs.	The "Report Coach" will soon be posted at www.aac-lerc.com . In the meantime, it is available from Lewis Golinker, lgolinker@aol.com

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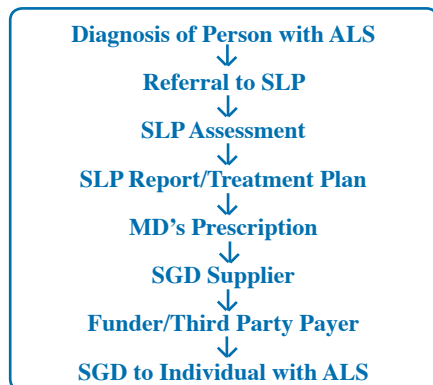


Figure 2. The SGD funding process

supplier, which in most cases is the SGD manufacturer. Most AAC manufacturers have staff that assemble and submit requests to funding programs. If additional information is sought by the funder, the SGD supplier or manufacturer typically serves as a conduit. [See Figure 2.]

Expect “Yes!”

Individuals with ALS should expect a “yes” in response to an SGD funding request. SGDs are recognized as a covered item of equipment, either as durable medical equipment or as a prosthetic device. Regardless of the benefit category used for coverage, SGDs are increasingly considered part of a standard benefits package.

While exceptions will arise, funding barriers for SGDs are the exception, not the rule. Thus, when a complete SLP report is prepared and submitted with a physician’s prescription, it is reasonable for individuals with ALS and family members to expect funding requests to be approved promptly. If a denial is issued or delivery of an SGD is delayed, the individual, family and/or SLP should seek assistance by contacting Lewis Golinker at lgolinker@aol.com



Governmental



Telephone equipment distribution programs (EDPs)

Laura Ball, Ph.D., Lewis Golinker, Esq. & Elizabeth Anderson, M.S.

Lack of access to the telephone can be a significant hardship or even life-threatening. The telephone has become an essential tool for most people, and is an excellent way to provide, seek and exchange information with others anywhere in the world and to establish and sustain social closeness, make appointments and ensure ones safety. In many countries, access to telecommunications is considered a civil rights issue.

Equipment distribution programs (EDPs) in the United States now give people with disabilities greater access to the telephone.¹² These programs provide a variety of equipment (e.g., TTYs, telebrailles, voice activated telephones, amplification, large-button telephones and automatic dialer telephones with picture symbols). Presently, programs in a dozen states also cover speech generating devices (SGDs) so that people with unintelligible speech can use the telephone.¹³ Efforts are under way to expand the number of states that offer coverage for SGDs.

Phone usage patterns

Despite consensus about the importance of telecommunications, little is known about the telephone usage patterns of individuals with severe speech impairments. Voice output and TTYs work at home with phones, but nonelectronic letterphrase or picture-symbol boards do not, because the letters, phrases or

pictures a user selects cannot be converted to an electrical signal and sent over the telephone network. While some individuals with severe

speech impairments can use TTYs, relays or interpreters, only an SGD is voiced by the caller and thus enables people to have private conversations with anyone they choose.

Telephone connectivity is now a standard feature on a wide range of SGDs. A few, such as the Link-PLUS™,¹⁴ have a telephone built-in. Others can connect to a telephone through an external speaker port or modem in the SGD, by use of a speakerphone or through an infrared signal with a compatible phone.

Recently, the authors conducted a survey to determine the extent to which persons with severe speech impairments use the telephone and how successful and satisfied they are when making and receiving telephone calls using an SGD. The survey was completed by 24 individuals who rely on AAC technologies (12 males and 12 females) ages 16 to 75 years, representing a 71% survey return rate. Participants reside in ten states and reported living in their own home (75%), a residential facility (17%) or their family home (8%). Most respondents indicated they are engaged in a range of daily activities (e.g., school, full-time employment, part-time employment and adult educational/day programs). They use a variety of SGDs from five different manufacturers. All of their SGDs had DECTalk® synthesized voice output. Most (58%) have used their SGD for more than 5 years. All use their SGDs to communicate over the telephone.

Table IV illustrates the frequency with which participants reported

Table IV. Frequency of calls

Call Frequency	Placed calls	Answered calls
More than 3 per day	28.6%	26.3%
2-3 per day	9.5%	10.5%
1 per day	19%	5.3%
4-6 per week	19%	10.5%
2-3 per week	4.8%	21.1%
1 per week	19%	26.3%

placing and answering telephone calls. Most (57%) placed calls at least once per day, and 29% placed calls more than three times per day. Although fewer individuals received calls on a daily basis, almost 42% reported that someone called them at least once per day. In short, all respondents both received and placed calls on a regular basis using an SGD.

Participants reported that they were more successful communicating by telephone with an SGD than without one. Their satisfaction ratings were significantly greater using an SGD.

As shown in Table V, participants reported speaking on the telephone

"If I don't have a device, I don't have a telephone."

with both familiar and unfamiliar communication partners. They were more likely to engage in shorter calls with unfamiliar partners and longer calls with familiar ones. Participants noted that telephone access helped them to respond to emergencies and to maintain connections with family and friends who lived outside their immediate geographic area. One participant stated, "I can answer (vocalize), but can't speak to anyone without my device." Another wrote, "If I don't have a device, I don't have a telephone."

Table V. Length of calls

Call Length	With familiar partners	With unfamiliar partners
Less than 1 minute	0	26.3%
2-5 minutes	28.6%	31.6%
6-15 minutes	28.6%	26.3%
16-30 minutes	19%	10.5%
31-45 minutes	9.5%	5.3%
45+ minutes	14.3%	0%

The results of this survey illustrate the functional utility of SGDs for telephone communication. Respondents reported using the telephone daily to receive and initiate calls, and they used an SGD to do so. Without SGDs, many individuals with severe speech impairments are simply unable to use the telephone successfully. Because a specific goal of the EDPs is to provide telephone access, funding support by EDPs for SGDs is both a legitimate and urgent concern.

Conclusion

Telephone use represents a crucial daily communication need for citizens around the world. This survey supports current advocacy efforts to persuade telecommunications equipment distribution programs (EDPs) to cover and provide SGDs to individuals with severe speech impairments so that they can communicate over the telephone.

[Note: Go to <http://www.aac-lerc.com/news/SGD%20and%20Telephone%20Use.pdf> to read more about the survey.]

References available upon request from
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Address Service Requested.

References

- ¹ Neuromuscular Disorders Clinic at the University of Nebraska Medical Center (sponsored by the Muscular Dystrophy Association)
- ² Available from Dynavox Systems, Pittsburgh, PA [www.dynavoxsys.com]. Go to www.enkidu.net/enkidu_tablet_xl_text.html for more information.
- ³ Available from Origin Instruments Corporation, Grand Prairie, TX [<http://orin.com/access/head-mouse/index.htm>]. Also some AAC device manufacturers.
- ⁴ Assistive Technology Inc., Dedham, MA. www.assistivetech.com
Dynavox Systems. Pittsburgh, PA. www.dynavoxsys.com
Enkidu. Pittsburgh, PA. www.enkidu.net
Words+, Inc. Lancaster, CA. www.words-plus.com
Zygo Industries. Portland, OR. www.zygo-usa.com
- ⁵ Fried-Oken, M., Fox, L., Rau, M.T., Tullman, J., Baker, G., Hindal, M., Wile, N., & Lou, J. (in press). Purposes of AAC device use for persons with ALS as reported by caregivers. *AAC*.
- ⁶ Rau, M.T., Fried-Oken, M., Fox, L.E., Hindal, M., Baker, G. & Wile, N. (2004, November). ALS, AAC technology, and caregivers: Attitudes, skills, and role strain. Poster presented at the American Speech Language Hearing Association Convention, Philadelphia, PA

- ⁷ Murphy, J. (2004). "I prefer contact this close"; Perceptions of AAC by people with motor neuron disease and their communication partners. *Augmentative and Alternative Communication (AAC)*. 20 (4), 259-271.
- ⁸ Available from Toby Churchill, Ltd. Cambridge, UK. www.toby-churchill.com
- ⁹ Fried-Oken, M., Murphy, J., Fox, L.E., Rau, M.T., Baker, G., Hindal, G., Lou, J.S., Tullman, J., & Wile, N. (2004, October). Caregiving and AAC systems in ALS: Quantitative and qualitative analyses. Biennial Conference of the International Society of Augmentative and Alternative Communication, Natal, Brazil.
- ¹⁰ Available from Zygo Industries, Portland, OR. www.zygo-usa.com
- ¹¹ Available from TASH, Inc., Ontario, Canada & Richmond, VA. www.tashinc.com/catalog/s_scatir.html
- ¹² Ball, L., Golinker, L. & Anderson, E. (June 2005). Speech generating devices & telephone use. *The Networker*, Newsletter of the Nebraska Speech-Language-Hearing Association (NSLHA). 13-15.
- ¹³ Current support in Arizona, Georgia, Louisiana, Maryland, Nebraska, New Jersey, North Carolina, North Dakota, Pennsylvania, South Carolina, Texas, Washington, Wisconsin. Past support in Minnesota and Rhode Island.
- ¹⁴ Available from Assistive Technology Inc., Dedham, MA. www.assistivetech.com

Related References

- Ball, L., Beukelman, D., & Pattee, G. (2002). Timing of speech deterioration in people with amyotrophic lateral sclerosis. *Journal of Medical Speech-Language Pathology*. 231-235.
- Ball, L., Beukelman, D., & Pattee, G. (2004). Augmentative and alternative communication acceptance by persons with amyotrophic lateral sclerosis. *Augmentative and Alternative Communication*, 20, 113-123.
- Ball, L., Beukelman, D., Ullman, C., Maassen, M., & Pattee, G. (2004-submitted). Monitoring speaking rate at a distance for persons with amyotrophic lateral sclerosis. *Journal of Medical Speech Language Pathology*.
- Ball, L., Willis, A., Beukelman, D., & Pattee, G. (2001). A protocol for identification of early bulbar signs in amyotrophic lateral sclerosis. *Journal of the Neurological Sciences*, 191, 43-53.
- Mathy, P., Yorkston, L.M. & Gutmann, M.L. (2000). AAC for individuals with amyotrophic lateral sclerosis. In D.R. Beukelman, K.M. Yorkston & J. Reichle (Eds.). *Augmentative and alternative communication for adults with acquired neurological disorders* (pp. 183-229). Baltimore: Paul H. Brookes Publishing.
- Yorkston, K., Beukelman, D., & Tice, R. (1996). *Sentence Intelligibility Test*. Lincoln, NE: Institute for Rehabilitation Science and Engineering at Madonna Rehabilitation Hospital.