

Upfront



An increasing number are learning how to use a speech-generating device (SGD) and other AAC technologies.

In a new book entitled

Augmentative Communication Strategies for Adults with Acute or Chronic Medical Conditions,¹ edited by David Beukelman, Kathryn Garrett and Kathryn Yorkson, 12 chapters by 23 well-known AAC clinicians and researchers offer practical “how to” information based on solid clinical experience and current research. There is also an accompanying CD with clinical forms and strategies.

The editors and authors point out that no single healthcare or social system is charged with addressing the needs of people with acquired conditions who can benefit from AAC services and technologies. Instead,

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This issue focuses on the use of augmentative and alternative (AAC) approaches and related assistive technologies (AT) by people who acquire severe communication impairments as a result of diseases or injuries during adolescence or adulthood. It's a diverse group, widely varied in age, stage of life, communication needs, life experiences and preferences. These individuals do, however, have similarities that influence the AAC assessment and treatment process. For example, as children they developed natural speech, relied on it for many years and established ways of expressing their needs, exchanging information and maintaining social connections. Most are literate. All have carried out specific social roles, *e.g.*, student, employer, employee, parent, spouse, breadwinner, educator, housekeeper, *etc.*

When adults suddenly or gradually begin to experience difficulty speaking, not only their ability to communicate is affected. Much of what they do, and how they do it, changes. Severe communication impairments often influence self-image and how one is perceived and treated by others. Whether the condition is acute or chronic, improving, unchanging or deteriorating, most individuals will try to use their difficult-to-understand speech if at all possible. Many will also choose to use low-tech displays with family members and long-term caregivers.

AAC in the ICU

Based on chapter two by Kathryn Garrett, Mary Beth Happ, John Costello and Melanie Fried-Oken²

Speech-language pathologists (SLPs) are consulted on a routine basis in very few ICUs in the United States. Most units are not familiar enough with the communication possibilities of AAC to request services.³

Each year, millions of individuals are admitted to medical and surgical intensive care units (ICUs). Being unable to speak is a common condition in ICUs, because more than one-third of those admitted require mechanical ventilation. Some may

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Based on chapter ten by Yorkston & Beukelman⁴³



also have pre-existing or acquired cognitive-linguistic disabilities that interfere with functional communication.⁴

The efficacy of introducing AAC in ICUs and acute care settings is not yet well documented. However, while a patient's communication needs are obviously secondary to the life-sustaining medical treatments underway in an ICU, an ability to communicate during a critical illness can increase the patient's participation in the assessment of pain and other symptoms and in making important decisions.^{5,6}

The ICU is a noisy, crowded, often frightening environment and one in which patients may be

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unaware, or only slightly aware, of what is going on. Thus, the anxiety of patients (and their family members) is often palpable. Being able to communicate with family members, physicians and nurses in the ICU can help lessen that highly stressful situation.

Descriptive studies clearly support the provision of AAC services in acute care settings, including ICUs, and have demonstrated the benefits of using a variety of AAC intervention approaches (*i.e.*, gestures, writing, partner-assisted scanning, *Yes-No* and other signals, communication boards, digitized and synthesized speech generat-

ing devices) to support communication.^{6,7,8,9} While in the ICU, relatively few people with complex communication needs (CCN) are referred to SLPs for an AAC assessment. Instead, everyone tries to “make do” with nonvocal communication techniques, such as mouthing words, using gestures, writing and head nods. This often limits patient-medical team interactions in ICUs to nurse-initiated, informative comments related to physical care, occasional yes/no questions and commands.

To further investigate the use of AAC in the ICU, the National Institutes of Health (NIH) in the United States have funded a five-

Table I. AAC materials for the ICU

AAC assessment materials	<ol style="list-style-type: none"> 1. ICU communication needs and constraints checklist. 2. ICU communication skills screening form.. 3. Preroperative vocabulary checklist. 4. Vision skills screening form..
AAC communication materials	<ol style="list-style-type: none"> 1. ICU communication board: needs/feelings. 2. Hospital communication board: needs/feelings. 3. Simple alphabet board. 4. Complex alphabet board. 5. Chart for natural and <i>Yes-No</i> signals. 6. Augmented comprehension instruction card. 7. Instructions: Electrolarynx users. 8. Instructions: Partner-assisted scanning.

year clinical trial that is testing the effectiveness of two AAC treatment conditions.¹⁰ In the first, nurses are instructed in the use of low-tech AAC (Phase II), and in the second, an SLP provides assessment, consultation and high-tech AAC as appropriate (Phase III). Nurse-patient interactions are compared against baseline (no treatment interactions).

Chapter two

Chapter two, *AAC in Intensive Care Units*,² builds upon the clinical experiences and research of the co-authors, Kathryn Garrett, Mary Beth Happ, John Costello and Melanie Fried-Oken, as well as others. It reviews communication needs and cognitive and sensori-motor factors that can influence AAC interventions in the ICU, and it describes a continuum of AAC aids and strategies that provide support to individuals with varying cognitive and motoric abilities. The chapter also references the use of AAC in palliative care for individuals who are dying.^{11,12}

Table I lists assessment tools and communication strategies that are included in the book and the CD. The authors recommend that AAC treatment approaches be considered across four major areas:

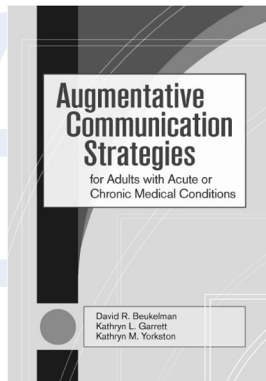
Natural communication signals and gestures. Identify signals for getting attention, making requests and giving

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these individuals transition from one setting to another (intensive care unit, hospital, nursing home, rehabilitation center, doctor’s office, clinic, family home, extended care facility, *etc.*). Too often AAC referrals come only after an individual’s speech is significantly compromised, making AAC interventions more difficult. Most individual’s don’t have access to the continuity of care they require to support communication over time.

Despite the proven efficacy of AAC as a treatment approach for individuals with complex communication needs, an individual’s access to AAC services typically depends upon (1) where they happen to live, (2) what their doctor already knows about AAC and (3) how aggressively they, or their family members, seek help from professionals who provide AAC services. Even today there are speech-language pathologists in hospitals, healthcare agencies and private practices who actually turn people away, saying, “We don’t do AAC.”

This book and CD take a giant



step toward solving this problem by offering a plethora of tools and strategies that delineate “how to” deliver AAC services to adults with acute or chronic

medical conditions.

I highlight six of the 12 chapters here although I highly recommend them all. Accolades to the editors, authors and publisher for providing this excellent resource. Finally, a very special thanks to those listed as Resources on page 15 for their help in preparing this issue.

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responses. Post these signals/gestures in the room and write them in the patient's chart. *Yes-No* signals are a priority. Try using a thumb up/down gesture, a head nod/shake, an exaggerated smile for *Yes*, pucker for *No*, or eye movements (eyes up for *Yes*, down for *No*).

Use of pre-existing sensory aids.

Because many people rely on glasses and hearing aids, ensure that whenever possible ICU patients have access to equipment they typically use.

Strategies to support attention and comprehension.

Due to variable levels of consciousness, noise factors, visual issues and medication effects, getting a patient's attention in the ICU can be difficult. Say the person's name aloud and perhaps lightly touch him/her on the shoulder. Try to establish and maintain eye gaze during all interactions.

If comprehension is questioned, try using augmented input (*e.g.*, provide written choices) so the individual can not only hear, but also see the message. Reduce speech rate and the complexity of spoken messages. Finally, "chunk" information and leave plenty of time for the person to respond.

Strategies to support expression. [See also Table II.] The authors discuss the importance of assessing the individual's cognitive and sensorimotor abilities before deciding how to augment expression. For example:

Table II. Supporting expression in the ICU: AAC strategies		
	Motor intact	Motor impaired
Cognition intact	Gestures, mouthing speech with first letter supplementation, alphabet board for spelling, writing supports, electrolarynx, complex and simple SGDs.	Alphabet board, whole message boards, partner dependent scanning, eye gaze techniques, complex and simple SGDs.
Cognition impaired	Simple communication boards, simple SGDs, written choice, mouthing with partner giving topic cues.	Signal/gesture dictionaries, tagged Yes/No questions, simplified partner-dependent scanning.

a. *Cognition and motor function are intact.* Consider using gestures, mouthing speech and pointing to an alphabet board for spelling. In addition, support writing. Some people may benefit from using an electrolarynx or a speech generating device (SGD) that is synthesized for novel messages and digitized for recorded messages.

b. *Cognition is intact and motor function is impaired.* Try alphabet and whole message communication boards with partner-dependent scanning and eye gaze communication. SGDs (synthesized or digitized) may also be useful.

c. *Cognition is impaired and motor function is intact.* Consider using gestures and other signals, communication boards that are simple, limited in content and intuitive to use. Consider also a digitized SGD. Written-choice conversations are often effective, so teach communication partners to ask questions and write possible answers using keywords and large print. Have partners provide topic cues using pictures or words.

d. *Cognition and motor function are impaired.* Use tagged *Yes-No* questions and simplified partner-dependent scanning. Try using a signal, gesture and/or vocalization dictionary to establish basic communication.

Finally, the authors strongly recommend developing "AAC kits" for ICUs and locating these in the ICU and in departments that provide speech and language services. See Figure 1 for a partial list.¹³

Comment


Can AAC make a difference? Sure seems so. Being able to communicate may increase a patient's sense of control and emotional health and may even have a positive impact on healthcare outcomes. 

Figure 1. Suggested ICU AAC equipment and supplies¹³

[Note: Everything should be well marked and conform to infection control and safety standards. Color code chargers to match devices. To prevent fires, the charging station should be away from the beds.]

Writing materials: Spiral bound notebooks OR brightly colored clipboards and tablets. Clipboards that hook over the bedrails. Felt-tip pens. Long strips of Velcro to attach pens (affix one end to clip, attach other to pen cap). Flexible pencil grips or orthotic writing aids. Universal elastic cuff.

Written Choice communication notebooks: Include a cover card. Outline of country map. Preprinted opinion scales.

Communication Boards: Yes/No boards. Needs/emotions boards. Alphabet boards (in various sizes). Symbol set(s) and posterboard for family-made communication boards.

Partner Dependent Scanning Notebooks: Include a cover sheet with instructions. Topic lists. Message pages. Alphabet page.

Eye Gaze Communication Board Set: Blank overlays. Alphanumeric overlays. Choice boards. Yes/No overlay. Clear plexiglas display board (optional). Erasable markers. Adhesive notes for novel choices. Metal rings to hold or store overlays. Poster board for encoded message chart.

Electrolarynx with oral adapter: With audible quality and volume control. Relatively moisture-proof housing. Disposable oral tubes.

Simple SGDs with digitized voice output: Preferred features are computer screens (rather than paper displays), bright screens, sealed housing. Purchase water-proof "skin" for device.

Complex, multi-level SGDs with visual and auditory scanning capability: Preferred features are bright screen display, light weight, durable, moisture-proof screen, easy to program.

Hand-held electronic spelling device or spelling-based AAC device.

Switches: Large, medium and small touch plate. Lever. Piezoelectric and/or infrared. Pillow. Squeeze. Sip-and-puff.

Switch and device mounting equipment: Weighted poles for hanging low-tech and lightweight high-tech devices, communication information posters, patient's signal chart and gesture dictionaries.

Miscellaneous Supplies: Velcro. Metal recloseable rings in various sizes. Plastic page sleeves for communication boards and overlays. Posterboard and markers. Clear plastic mailing tape for affixing labels. Ties for attaching items to IV poles, triangle pulls or bedrails.

Brainstem Impairment



Based on chapter three by Delva Culp, David Beukelman and Susan Fager¹⁴

When someone experiences brainstem impairment as a result of a stroke, injury, infection or tumor, the recovery process is often slow. Many individuals remain physically limited and medically fragile, although slight improvements can continue over many years. Some people return home, while others live out their lives in assisted living or skilled nursing facilities. In any case, AAC interventions often play a key role in the individual's short- and long-term quality of life, because AAC provides a way to connect to other people and to be productive.

Chapter three

*Brainstem Impairment*¹⁴ covers a spectrum of AAC interventions across multiple service delivery settings and describes four phases of treatment.

- **Phase I—Initial Assessment.** During the initial assessment, the speech-language pathologist (SLP) works with the individual, family and nursing staff to establish a *Yes-No* response and an effective call system. As the individual improves and stabilizes, the focus shifts to supporting more complex communication.
- **Phase II—Early Intervention.** The SLP helps determine which low-tech AAC techniques and strategies will establish functional communication and then supports the implementation of these. As the person's medical status becomes more stable, the focus can shift to selecting more

permanent AAC solutions.

- **Phase III—Formal Assessment.** Once the individual's residual capacities are better understood, the authors recommend identifying a communication advocate who will ensure that AAC and AT technologies are functioning and made available on a daily basis. The SLP can then work with the individual and his/her caregivers to set long-term communication goals, conduct an assessment for a speech generating device (SGD) and prepare a funding request.
- **Phase IV—Ongoing Assessment.** Supporting the use of AAC approaches over the long term often requires occasional modifications to AAC strategies and technologies to accommodate the person's shifting communication needs and medical status. Because medical crises continue to recur after brainstem injuries, someone needs to monitor status changes to make sure that communication modes the person can use are always available.

The role of communication partners and caregivers

For persons with brainstem impairment, the success of AAC inter-

ventions is nearly always dependent on caregivers who must maintain equipment and make it available each day. Caregivers also report any changes that affect communication status to AAC professionals, so modifications can be made, as needed. Thus, during each phase of treatment, individuals and their caregivers learn how to use current AAC approaches and identify unmet communication needs.

AAC assessment and treatment approaches

Table III provides examples of clinical tools that SLPs use to deliver AAC services to individuals with brainstem impairment.¹⁵ For example, in Phase I, introductory information is given to caregivers and family members about communication problems following a brainstem stroke or injury. Also provided are instructions on how to gather information about the individual's current levels of function and a protocol for teaching a simple *Yes-No* system. Phase II tools include examples of a range of low-tech communication boards and strategies to help re-establish functional communication. In Phases III and IV, the authors provide information about how to select a communication advocate and conduct an SGD

Table III. Clinical Tools and Strategies for Individuals with Brainstem Impairment¹⁵

Phases and Goals	Clinical Tools and strategies (available on the CD)
I. Initial Assessment Demonstrate a functional <i>Yes-No</i> response and ability to access a call system.	1. Introductory info about brainstem impairment and communication. 2. Daily communication log. 3. Motor-comprehension assessment. 4. Comprehension assessment. 5. <i>Yes-No</i> response options and <i>Yes-No</i> response practice.
II. Early Intervention Demonstrate ability to use a low-technology communication technique or techniques for functional communication.	1. Low-tech: direct selection alphabet communication boards; eye gaze communication boards; visual scanning boards & auditory scanning boards. 2. Strategies for using low-tech AAC. 3. Functional communication for basic needs, social closeness & information exchange.
III. Formal Assessment Secure a communication advocate and an appropriate AAC device.	1. Responsibilities of a communication advocate, <i>etc.</i> 2. Long-range communication planning.
IV. Ongoing Assessment	1. Guidelines for communication partners.

assessment. Finally, examples of long range plans and guidelines for communication partners are provided.

Four clinical profiles

Clinical profiles illustrate the range of communication outcomes for people who sustain brain stem strokes or injuries. The authors describe a continuum from complete locked-in syndrome to functional speech.

Locked-in syndrome (LIS). These individuals remain quadriplegic and unable to speak. Vertical eye movements often are their only reliable communication mode.

Joe sustained a brainstem stroke at the age of 51. At the time, he was divorced and employed as an accountant. His children were in their twenties. His stroke resulted in ventral pontine syndrome (locked-in syndrome). After a month in the ICU and acute care hospital, he was transferred to a long-term skilled nursing facility because of his extensive physical and medical needs. In the acute phase, except for vertical eye movements, Joe was completely quadriplegic. A *Yes-No* response was established early on, but he had limited success with other AAC approaches.

After 15 years, Joe continues to live at a skilled nursing facility. He is still unable to move his head or extremities and communicates primarily through eye movements and some limited facial expressions. He relies on a *Yes-No* system and partner-dependent scanning with an alphabet board. Although these strategies may appear simple or limited, Joe uses them effectively to interact with staff and family members. From time to time, he has tried to use a switch to access a high-tech AAC device and computer, but without much success.¹⁶

Incomplete locked-in syndrome. These individuals recover some head movement but no functional speech.

Peggy, a registered nurse, wife and mother of three grown daughters, experienced a basilar artery stroke at the age of 60. The stroke resulted in severe brainstem impairment and a diagnosis of ventral pontine

syndrome (locked-in syndrome). For the first three weeks after her stroke, Peggy showed no apparent response to her environment. She was ventilated and fed through a naso-gastric tube. At four weeks post stroke, she was able to open her eyes and look up and down, but had no other volitional movement. A *Yes-No* response (eyes up-eyes down) was quickly established, and it was apparent that Peggy had good cognitive function. A stomach tube was inserted to facilitate nutrition. Due to recurring medical issues, Peggy remained in the hospital for two months. Attempts to establish use of a low-tech scanning alphabet board were confounded by variable blurring vision and other medical complications. Upon discharge to a long-term skilled nursing facility, Peggy remained dependent on a ventilator and feeding tube. Her volitional movements were limited to vertical eye movements and an intermittent ability to blink and slightly raise her eyebrows. Peggy continued to use her *Yes-No* response. Once her vision cleared, she also learned to rely on a partner-dependent visual scanning alphabet board.

Five years after her stroke, Peggy resides in a skilled nursing facility. She can breathe independently through her tracheostomy, but continues to be tube-fed. Medically, she has become more stable, but still requires hospitalization two to three times per year. Although volitional eye blinks and eyebrow movements have improved, fatigue remains a major issue and interferes with her efforts to use a switch for accessing an SGD. However, she is able to use an eye blink switch to control her TV and stereo and feels her quality of life has substantially improved as a result. She is able to move her head slightly and to better direct her gaze and give *Yes-No* responses. She has not, however, developed other volitional movements.

Peggy uses a partner-assisted scanning alphabet board to communicate long messages with a few select staff and with her husband and daughters, who visit regularly. With other staff and visitors, she relies primarily on her *Yes-No* response. Using alphabetical scanning, Peggy dictated her life story to her youngest daughter, which subsequently was published in a periodical for rehabilitation nurses.¹⁷

Return of limited functional speech. These individuals recover limited speech and writing abilities, and as a result, have many more communication options.

Nick was injured on a rugby field at the age of 23. Dissection of the vertebral arteries left him quadriplegic and without the ability to speak. In a published narrative, Nick portrays the confusion of the ICU during his hospital stay and his subsequent journey through the next four years.¹⁸

[Interspersed within Nick's narrative are comments from Grant Gillett, professor of medical ethics at the University of Otago Medical School in New Zealand, about clinical and ethical issues that arise in locked-in syndrome.]¹⁹

Nick writes,

It felt like I was in a really bad nightmare constantly for about the first three months. I could only just hear (I couldn't even open my eyes or breathe by myself). Without them even knowing that I still could hear, the doctors and specialists in front of me said to my mum that I would die. They even asked my mum if she wanted them to turn the life support machine off after a few days.

After my coma, it took a long time before I could even open only one eye. For a couple of months, when I could open both my eyes, I would see double and had to wear an eye patch sometimes. For about four months I couldn't use a call bell. So if something was wrong or I was in pain or I needed something, I had absolutely no way of attracting anyone's attention.¹⁸

Nick also reports the key importance of family members during his hospitalization and after he returned home. His comments about using eyegaze as a communication strategy follow.

I talk by using a transparent Perspex board (about A2 size) with the letters of the alphabet spaced out on it (identically on both sides). The person holds it up between our eyes (about 800 mm apart). I spell out each letter of my sentence using my eyes (similar to a typewriter), with the other person guessing each letter I'm staring at, until I've spelled out a whole sentence—extremely laborious! It's also very difficult (almost impossible) to express yourself or be sarcastic.¹⁸

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Brainstem Impairment, Cont. from page 5

Four years after his injury, Nick was living at home and had recovered some functional speech.

*I can say heaps of words, count, pronounce about four carers' names relatively clearly, sometimes stringing some words together when lying down and relaxed.*¹⁸

Recovery of functional speech. A few people fully recover functional speech after brainstem insults or injuries.


At age three, Ryan was diagnosed with a benign brainstem tumor. The tumor was resected (in part) at that time, but it continued to grow. At the age of twelve, Ryan underwent extensive surgery to remove the tumor, and his cranial nerves were damaged during the surgery. He was seen at a speech and hearing clinic approximately six weeks later and was unable to speak or swallow. Poor speech intelligibility was due to a severe dysarthria. Also, he lacked any movement of the soft palate and pharyngeal wall. Even so, he relied on 'speech' as his primary means of communication, supplemented by hand gestures and writing. Because he was primarily communicating with family members at that time, he was not interested in pursuing other options.

The focus of speech-language intervention was to restore functional speech and swallowing, as well as to support his communication. The staff determined at about seven months post surgery that Ryan was able to talk when his velopharyngeal problems were addressed. However, he was not fitted for a palatal lift until 17 months post surgery, after his swallowing and respiratory status had stabilized. The tracheostomy and gastrostomy tubes were removed 21 months post surgery. At 28 months, his speech intelligibility with the palatal lift was 97-98%.

Today (six years post surgery), Ryan is a freshman in college. Even though he still has essentially no soft palatal or pharyngeal wall movement, with a palatal lift in place, his speech is easy to understand.^{20,21}

Summary

After a brain stem insult or injury, individuals nearly always require AAC interventions to support communication. This chapter offers clinicians

a workable intervention framework and outlines key assessment and treatment strategies to address the daily communication needs of people with brainstem impairments throughout their lives. 

Traumatic Brain Injury



*Based on chapter five by Susan Fager, Molly Doyle & Renee Karantounis*²²

Traumatic brain injury (TBI) refers to both closed and open head injuries. Population-based studies in the United States suggest that the incidence of TBI is between 180 and 250 per 100,000 people per year. The incidence may even be higher in some other countries. Groups at highest risk for TBI are the very young, adolescents, young adults and the elderly. Males are more likely to sustain a TBI than females. Mortality rates vary by severity and are highest in those with severe injuries and in the elderly.²³

Communication difficulties associated with TBI are secondary to (1) motor-speech problems (mostly dysarthria), (2) specific language impairments and/or (3) cognitive disorders. While an inability to speak is common after a severe TBI, most people ultimately do recover their speech.²²

Chapter five

In *Traumatic Brain Injury*²² Susan Fager, Molly Doyle and Renee Karantounis systematically consider the types of communication support individuals may require after a severe TBI and suggest a framework for providing AAC interventions—beginning (for many) during the acute phase of recovery and continuing (for a few) throughout

their lives. The authors point out that a variety of factors influence the recovery process and that AAC interventions are multifaceted, multidimensional and ever-changing (at least initially). Factors influencing treatment include (1)

the extent and nature of brain damage sustained in the injury, (2) the nature of the individual's residual cognitive difficulties (e.g., memory, ability to learn new information, ability to initiate, emotional lability, etc.), (3) ongoing medical issues (e.g., seizures and medications) and (4) the presence and severity of visual and/or perceptual problems and motor impairments, as well as speech and language difficulties. In addition, the support of a communication advocate is often key to successful AAC outcomes.²⁴ In short, a dynamic set of variables can influence the effectiveness of AAC interventions over time.

AAC assessment and treatment approaches

The co-authors propose five principles to guide AAC treatment for people with TBI.²⁵

1. Assessment should be an ongoing and dynamic process, especially during the acute phase of recovery.
2. Natural motor responses should be used (at least initially) to minimize demands on new learning.
3. The individual's residual strengths should be taken into account, and old learning, familiar routines and previous interests should be utilized in treatment.
4. The individual's capabilities should be periodically reassessed. Even small changes can affect the use of AAC systems.
5. Family and caregivers should be included in AAC assessments and interventions because they will directly affect the acceptance and use of AAC systems.

Table IV provides an AAC treatment framework for TBI across three levels of recover: Stimulation, Structured and Compensation.²² Each also relates to the *Rancho Levels of Cognitive Function*.²⁶

Stimulation level. The speech-language pathologist (SLP) identifies a range of response modes and establishes a *Yes-No* response. Because family members are most familiar with the individual, they often provide important information. Worksheets to assist practitioners and family members include:

- *Creating a Quiet Environment*
- *Providing Information to the Team*
- *Sample AAC for Stimulation Level.*

Structured level. The goal is to provide sufficient structure so that individuals can convey basic needs and participate more actively in familiar routines. Treatment includes unaided and aided AAC strategies and technologies. Examples are the use of writing supports, *Yes-No* cards, communication boards and simple voice-output devices. Individuals often use communication boards to share personal information and to make choices. Some may use a speech generating device (SGD) with digitized speech and preprogrammed messages. Those who can generate text (even if it is far from “perfect” writing) can consider a text-to-speech device. Worksheets included are:

- *Communication Needs Assessment*
- *Visual Screening*
- *Motor Access Screening*
- *Writing and Symbol Use*
- *Sample AAC for Structured Level*
- *Strategies to Support Communication*

Compensation Level. As individuals become less confused and medically stable, AAC practitioners plan for longer-term communication solutions, taking into account the individual’s residual visual, percep-

Level	Characteristics	Purposes of AAC	Goals
Stimulation Rancho III	Recognizes family, Begins to follow one-step directions, May answer yes/no questions.	To stimulate consistent responses. Shape meaningful communication.	Elicit & track responses to stimuli. Identify response modes. Maximize consistency of responses. Shape responses into meaningful communication opportunities. Include caregiver/family in assessment and intervention process.
Structured Rancho IV & V	Confused and agitated. May have difficulty focusing. Cannot learn or generalize new information.	To convey wants and needs. Increase participation during familiar routines.	Assess specific communication needs and consider unaided and aided methods. Assess capabilities that affect AAC (visual/perceptual abilities, physical access, message representation and symbol use). Consider recommending SGD.
Compensation Rancho VI, VII & VIII	Socially appropriate and usually goal oriented. Communicates needs and ideas about familiar topics. Making transition into the community.	To convey needs and ideas. Increase efficiency of communication and participation across partners and settings.	Identify communication needs and methods. Assess visual acuity, perception, motor access. Assess symbol use and message generation. Provide trials for SGDs. Consider SGD options.

tual, motor, speech, language, communication and cognitive abilities. Communication needs associated with living at home or in an assisted living facility are assessed. Also factored into decisions are needs to interact with a broader variety of communication partners about multiple topics.

Because many individuals who require AAC will depend upon others to set up their AAC systems, the assessment process identifies *who will be responsible for what*. Treatment plans include training both individuals who provide natural supports and those who are paid to support the individual. Decisions are also made about which low- and high-tech approaches the person will rely on. When an SGD is recommended, a funding request is prepared and submitted. Also, communication boards and books are provided. Worksheets at this level include:

- *Cognitive Processes and AAC*
- *Encoding and Word Prediction*
- *Sample AAC for Compensation Level.*

The long haul

Ultimately, some individuals with TBI remain dependent on others to communicate (dependent communicators) and others continue to be dependent only in some contexts, with some partners (cued communicators).

Still others become independent communicators.²⁷ The authors describe different types of AAC approaches and levels of support for each group. For example, *dependent communicators* typically have significant cognitive and motor impairments and need partners to set up and support their use of AAC to make choices or convey needs. *Cued communicators* often have residual cognitive impairments that affect their choices and use of AAC systems. *Independent communicators* can initiate interactions with both familiar and unfamiliar partners and can use a variety of communication modalities effectively. Typically, those who require SGDs tend to rely on their spelling.

Case example

Roger sustained a severe TBI in a motor vehicle accident at the age of 29 years. During the acute phase of recovery, he transitioned through the ICU, acute inpatient rehabilitation, skilled nursing facility and his home. He now resides in an assisted living facility. Over the years, he has used a variety of AAC systems (eye gaze, head nods, scanning with a digitized SGD, direct selection on an alphabet board and direct selection on a spelling-based SGD).

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TBI, Continued from page 7

AAC treatment initially involved continually reassessing Roger's ability to produce intelligible speech, as well as monitoring his motor, visual, language and cognitive function and providing AAC approaches to support his daily communication needs. SLPs from the various agencies communicated with each other about his use of AAC, so services were well coordinated. Within a year, Roger functioned at the compensation level, but continued to be a cued communicator because his speech was not intelligible in many situations and he had to depend on others for support. He often used an alphabet board and was able to generate language. To expand his communication capacity, he learned to use a text-to-speech SGD. Funding was sought and obtained. Today, Roger is an independent communicator. He can interact with familiar and unfamiliar communication partners across settings.²⁸

Comment

A recent study reported the acceptance rates for low- and high-tech AAC systems after TBI. Participants with TBI initially accepted both low-tech (100%) and high-tech SGDs (94%).²⁹ After five years, 81% of the participants were still using their SGDs, and most (87%) relied primarily on spelling to generate messages. Sixty-three percent were also using low-tech approaches after three years. [The others had regained natural speech.] This study also found that individuals with TBI prefer to use high- and low-tech AAC systems for different purposes. For example, they prefer using high-tech devices to talk on the phone and write and low-tech alphabet and word boards to engage in conversations.



Spinal Cord Injury



Based on Chapter four by Deanna Britton and Ross Baarslag-Benson³⁰

*A spinal cord injury usually begins with a sudden, traumatic blow to the spine that fractures or dislocates vertebrae. Most injuries to the spinal cord don't completely sever it. Instead, injury causes fractures and compression of the vertebrae, which then crush and destroy the axons, extensions of nerve cells that carry signals up and down the spinal cord from the brain and the rest of the body. An injury to the spinal cord can damage a few, many, or almost all of these axons. Some injuries will allow almost complete recovery. Others will result in complete paralysis.*³¹

Advances in emergency medicine, aggressive treatment and improved rehabilitation strategies mean that more people with spinal cord injuries (SCI) now survive, including those with high (C1-C3) SCIs who are unable to breathe independently. SCIs occur most often in young males because of motor vehicle accidents, falls, gun shot wounds and recreational vehicles mishaps. SCIs are classified as complete (*i.e.*, the person lacks all sensory and motor function below the level of injury) or incomplete (*i.e.*, some motor or sensory function is present below

the level of the injury). Individuals with SCI also are likely to experience chronic pain and bladder and bowel dysfunction and are susceptible to respiratory and cardiac problems. Thus, successful rehabilitation depends on how well chronic conditions are handled, as well as how functional limitations (speaking, writing, computer access, mobility, *etc.*) are managed.³²

Chapter four

*Spinal Cord Injury*³⁰ underscores the need for speech-language pathologists (SLPs) and assistive technology (AT) teams to consider communication as an important component of the recovery and rehabilitation process after a SCI. Deanna Britton and Ross Baarslag-Benson review the anatomy of SCI, how SCIs are diagnosed, the prognosis after SCI and associated medical treatment. The focus is on how to support communication (speech, writing, phone and computer access for email, instant messaging, *etc.*) while acknowledging that other areas (*e.g.*, mobility and environmental control) are considered simultaneously.

AAC/AT assessment and treatment approaches

SCIs can affect both spoken and written communication, depending

Table V. The three phases of AAC treatment for Spinal Cord Injuries³⁰

Phases	Goals	Assessment	AAC/AT strategies
Early	Establish Yes-No response; communicate basic needs; call for help.	Evaluate oral mechanism, type of trach/ impact on speech, <i>etc.</i> Movements available for communication and switch access.	No-tech: Yes-No responses, <i>etc.</i> Low-tech: Alphabet/word board. High-tech: Electrolarynx, call light system.
Formal	Establish verbal communication using trach cuff deflation or AAC strategies; writing; computer access; phone; control aids for daily living.	Ventilator dependent: Assess oral mechanism; trach; switch access; ventilator and settings; tolerance of cuff deflation. Consider voice recognition technology. Ventilator independent: Assess upper extremity strength & dexterity. Consider ability to operate specific AAC/AT devices. Consider voice recognition technology, Concomitant TBI. See previous article.	Ventilator-supported verbal communication: Trach cuff deflation; coordination for speech with ventilator cycles; speaking valve with cuffless trach; glossopharyngeal breathing (GPB), ventilator options. Respiratory support for speech: Postural adjustments; abdominal binder; GPB. Basic communication access and aids for daily living: Call signals; telephone; audio/visual entertainment; lighting, heating and ventilation, <i>etc.</i>
AAC	Provide AT for functional communication; computer access; phone. Consider & integrate with other AT.	Identify person's abilities; current and future contexts; supports, <i>etc.</i> Identify and select AAC/AT devices. Develop long-term treatment plan and seek funding.	Speech recognition; typing aids; mouse control; keyboards; operating system accessibility features; integrated (versus distributed) control units.

upon the level of the injury. Some principles of AAC treatment are:

- Individuals adjust to their injuries and limitations at different rates and in different ways.
- Treatment goals and decisions are made in conjunction with the individual who needs to be able to make informed decisions.
- For people with high-level cervical SCIs, AAC intervention begins in the ICU.
- All AAC interventions are best carried out within the context of an interdisciplinary rehabilitation team.
- Identifying AAC facilitators and community resources is crucial to successful outcomes.
- Acceptance of assistive technology often occurs in stages: Pre-acquisition, early acquisition and late acquisition.³⁴
- When there is a concomitant TBI, assessments and treatment plans are affected.³³

The authors identify and discuss three phases of AAC intervention, which are summarized in Table V.³⁰ SLPs act as part of an AT team.

Early phase. Focuses on individuals who are ventilator dependent and seek to establish basic communication using no-, low- and high-tech options.

Formal phase. Establishes verbal communication for those who are ventilator dependent, working with trach cuff deflation and respiratory supports for speech. Also, seeks to establish writing, computer access and phone access, especially for those who are ventilator independent. Strategies begin to focus on computer access for writing, email, phone use, instant messaging, text messaging, and so on.

AAC phase. Identifies and provides long-term AAC/AT solutions. The team focuses on mobility, communication, computer access and control strategies to enhance independence throughout the day (turning lights off/on, etc.). Decisions are made about speech recognition programs, switches, devices and software to support speaking and writing for multiple purposes. Careful thought is given to how devices will work together, be managed and maintained.

Case Example

Paul sustained a C1-C2 spinal cord injury as a result of a roll-over motor vehicle accident when he was age 17. He transitioned to an acute care rehabilitation hospital at 2 months. Although he remains ventilator dependent, he gradually learned to speak

using a speaking valve with a cuffless trach. Early AAC/AT treatment helped him control his environment and use a speech generating device (SGD) during those times when he could not tolerate the speaking valve. Initially, he used a sip and puff switch to control his SGD, operate an infrared call system, change the channels on his TV and communicate messages. As his speech became clearer and he was able to use more words per ventilator breath group, he began to use voice recognition software.

At discharge he went home where he continues to reside with his parents and 24-hour support. He continues to use voice recognition to control his computer and a voice activated, free-standing environmental control unit to answer the phone, make phone calls, turn on lights, and control his TV. He re-entered high school, at first part-time and then full-time. He graduated and is now working with vocational rehabilitation to plan a career in computer

programming. Technology enables Paul to do online banking, set medical appointments, arrange transportation and shop online. Most importantly, he uses it to write, work and engage in social interactions with friends, using email and instant messaging.³⁵

Comment

AAC interventions for people with SCI vary depending on their associated motor and sensory impairments and stage of recovery. As recovery progresses, the focus of intervention shifts from no-tech or low-tech approaches to more sophisticated and/or high-tech options. Many kinds of assistive technology benefit individuals with SCI so designing and maintaining an integrated system of supports (equipment and human) is essential.



Dementia



problems associated with dementia.

Chapter eight

*Dementia*³⁶ by Michelle Bourgeois and

Ellen Hickey provides

information that can help speech-language pathologists (SLPs) offer a continuum of AAC-related services to support communication and participation. Dementia is a degenerative, neurological condition characterized by memory impairment and decline in other cognitive areas (*i.e.*, language, abstract thinking, judgment, executive functions) that affect social and occupational function.³⁸ The most common form of dementia is Alzheimer's disease (60-70%). Most dementias are caused by organic changes in the brain. Dementia also occurs as a primary feature of some progressive disorders and diseases, such as Huntington's disease, primary progressive aphasia, HIV/AIDS and Parkinson's disease. Depending upon the etiology of dementia,

*Based on chapter eight by Michelle Bourgeois and Ellen Hickey*³⁶

She was a daughter, student, actress, wife, mother, grandmother, great-grandmother, former president of the League of Women Voters and chair of its Overseas Education Fund. In her late 80s, a dreaded dementia took hold, and she reluctantly agreed to move out of her home to an assisted living facility near the family. Little by little, we lost who she'd been. Even so, her desire to participate, her need for social closeness and her stubborn dignity prevailed until her death at age 92.³⁷

As the human lifespan lengthens, the number of people who live longer with dementia increases. Even those who remain healthy and disease free are affected by aging. Bodies simply wear out, and sometimes the brain goes first. This article focuses on the role of AAC as a treatment for the communication

problems associated with dementia.

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Dementia, Continued from page 9

some people may initially exhibit language impairments, and others may demonstrate behavioral changes (depression, agitation, lack of inhibition, personality and mood swings). Ultimately, however, dementia always alters language and communication skills.

Stages of dementia

In the early stages of the disease, most individuals continue to reside at home and participate in community activities with support from family and friends. In middle stages, individuals require more care. Many move to an assisted living facility where their health, comfort, safety and social isolation can be monitored more closely. Later on, safety concerns and care needs often require that individuals move to facilities that offer supervision all day, every day. From time to time, an illness or injury may require hospitalization.

Most people with dementia transition from living independently to living in a long-term care facility. This journey can be very difficult, because people with dementia do better in familiar surroundings with caregivers they trust who can help them make sense of their world by building on their past experiences. Instead, as individuals become less able to deal with change, they are increasingly likely to find themselves in unfamiliar environments, cared for by strangers.

AAC assessment and treatment

The goals of AAC interventions in dementia are to maintain independence and quality of life. This benefits both individuals and their caregivers. At each stage, finding ways to help structure the day and support communication can make a difference in the quality of the lives of individuals with dementia.³⁹

Table VI. Some assessment tools

• Screening protocol to monitor residents with dementia (Rozsa & Bourgeois)
• Functional goals screening protocol: Community clients with dementia (Bourgeois & Rozsa)
• Bourgeois oral reading measure (Bourgeois)
• Spaced retrieval screen (Brush & Camp)
• Memory aid information form: Basic and nursing home versions (Bourgeois)
• Personal wants, needs and safety assessment form (Bourgeois)

- **Early stage.** Individuals are often aware of their difficulties. They may experience word retrieval problems, memory loss and some confusion. AAC interventions can support both memory and message content using a variety of approaches that include teaching caregivers compensatory strategies to enhance communication and participation within natural environments. Caregivers can also learn how to support conversations so that attention is not drawn to the individual’s memory or word retrieval problems or behavioral difficulties.
- **Middle stage.** Individuals gradually lose awareness of their cognitive and communication problems and become more ego-centric. Individuals also tend to lose touch with how their behavior impacts others. Conversations

become one-sided. SLPs can help caregivers facilitate interaction and participation using familiar family events and personal histories.

- **Late stage.** Individuals gradually lose their verbal abilities but may still demonstrate a desire to communicate. Caregivers can help by using simple language, tone of voice, familiar objects and touch to provide comfort and support communication.

Assessment. AAC assessments for persons with dementia identify goals, select compensatory strategies and ascertain caregiver training needs. The assessment process garners basic information about sensorimotor, cognitive and linguistic function, as well as case history data about the individual’s interests, primary communication partners and important life experiences. Assessment measures, observational and interview protocols and AAC-related assessment tools are provided on the CD and in the book. (See Table VI).

Treatment approaches. The authors cite three principles for treating people with dementia: (1) maintaining communication and independent function; (2) maintaining participation and engagement and

Table VII. Examples of SLP goals for people with dementia⁴¹

Indicate meaningful information about pain and body function to staff using multi-modality communication with minimal cues 90% of the time.	Decrease occurrence of agitation and abusive verbal behavior through increased functional communication, using written and visual cues with less than two episodes of agitation per shift.
Make comprehensible requests for basic needs using written and visual cues with minimal staff cues 80% of the time.	Recall daily schedule using a written cue card with minimal to no verbal cues 80% of the time.
Increase ability to participate in conversation/activity programs using written cues and pictures with minimal staff cues 80% of the time.	Decrease repetitive questions using written cue cards with minimal to no verbal cues less than two times per hour (five times per day).
Produce comprehensible language in conversation related to basic, social and emotional needs using written cues 90% of the time.	Use memory logbook to increase recall of personal and facility information with minimal to no verbal cues 80% of the time.
Increase recall of hip precautions using a written cue card independently with 90% accuracy.	Using a personal Talking Photo Album, share personal stories/information from the past with family members, staff and volunteers no less than three times per day.

(3) emphasizing personal relevance and natural contexts.⁴⁰ Table VII lists measurable goals that SLPs can use to improve and maintain functional communication. These goals specify the use of communication books, boards, calendars, day timers, photo albums, *etc.*⁴¹

- *To enhance communication and support independent function.* The authors give examples of how to use external memory aids, such as daily planners, calendars, checklists, sticky note reminders, memo boards, reminder cards and memory wallets to support the individual's strengths and reduce demands placed on 'impaired systems,' by minimizing memory, language and organizational requirements. For example:

Memory wallets can support conversational interactions in early to middle stage dementia. Put one picture or photograph on each page. Design wallets so they can be worn or placed in a wheelchair/walker bag and remain accessible.⁴²

- *To maintain participation and engagement.* AAC professionals can help identify an individual's favorite activities and interests and then develop materials to support participation, involve individuals in desired activities and teach others to implement key strategies. For example, an illustrated step-by-step cookbook may support participation in cooking. External memory aids can remind people how to operate their TV or play a simple card game. Simplifying text and increasing print size can support reading. Even in late stages of dementia, many individuals can engage in simple tasks, such as sorting and folding, with support.
- *To ensure personal relevance and training in natural contexts.* Because involvement in preferred activities is often dependent on support from caregivers, onsite communication partner and

caregiver training are integral to AAC treatment approaches. Effective treatment always reflects the person's life-long interests, habits and lifestyle and is carried out in natural contexts.

Comment

These authors offer a framework for assessing communication and cognitive skills, designing AAC treatment programs and establishing compensatory strategies for people with dementia. They suggest goals for SLPs that insurance companies will cover and demonstrate how AAC treatment can significantly improve communication and quality of life. In addition, they describe many of the ways in which AAC interventions can support caregivers.



Multiple Sclerosis, Parkinson's Disease, Huntington's Disease



and (3) the impact AAC has on communication effectiveness.⁴⁵

Chapter ten

In *AAC Intervention for Progressive Conditions: Multiple Sclerosis, Parkinson's Disease and Huntington's Disease*,⁴³ Kathryn Yorkston and David Beukelman point out that MS, PD and HD share certain features. Each results in a slow deterioration of neurological function that affects motor and cognitive/linguistic areas and often causes severe dysarthria and difficulty understanding and using language. Because some people with these diseases lose their ability to speak and to understand language (especially in later stages of the disease), AAC treatment approaches can support them and their caregivers in ways that help main-

tain functional communication and participation.

Multiple Sclerosis⁴⁵

The usual onset of Multiple Sclerosis (MS) is between 18 and 40 years of age. It is the third leading cause of disability in young and middle-aged adults and occurs more frequently in women. The etiology is unknown. MS is a demyelinating disease characterized initially by a remitting-relapsing course that gradually results in a chronic degenerative pattern known as secondary progressive MS. Many individuals with MS develop dysarthria, which may become severe in later stages of the disease.

Currently, the incidence of individuals with MS who benefit from the use of AAC interventions

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Based on chapter ten by Kathryn Yorkston & David Beukelman⁴³

Three diseases that often result in severe speech and language impairments and complex communication needs are Huntington's disease (HD), Parkinson's disease (PD) and Multiple Sclerosis (MS). According to a survey of AAC clinicians in Scotland, individuals with these conditions represent a very small proportion of the total AAC clinical population in medical settings (from .8 to 3.7 percent).⁴⁴ Limited information is currently available about (1) the types of AAC services individuals with MS, PD and HD receive, (2) their acceptance of AAC

MS, PD, HD, Continued from page 11

is not well documented. MS causes a “complex constellation of other physical, cognitive and psychosocial changes,”⁴⁶ and its symptoms are unpredictable. This can make AAC interventions challenging.

AAC assessment and treatment. The AAC assessment process for MS begins by taking a medical history and determining the nature of the problems individuals and family members are experiencing. This means (1) identifying communication needs and preferences, (2) ascertaining the individual’s and family’s perceptions about the person’s communication difficulties and (3) being aware of changes in the individual’s condition and living situation.⁴⁷ There is a *Needs Assessment Form* in the book and on the CD. Because associated visual, motor, cognitive and behavioral problems affect decision-making and communication planning, the assessment includes consideration of hand function and vision, as well as the extent to which cognitive and behavioral difficulties may affect learning and the individual’s use of AAC approaches.

Early stage. Typically, speech is functional in the early stage of MS; however, some people benefit from using a portable speech amplification device to support respiratory weakness. If memory or organizational impairments are present, individuals may benefit from using low-tech memory boards, calendars and Personal Digital Assistants (PDAs). Other types of assistive technology (e.g., canes, wheelchairs, adapted keyboards) can also help.

Middle stage. Individuals sometimes use speech supplementation strategies at this stage, especially under noisy environmental conditions or with unfamiliar partners.

Some also rely on alphabet boards, pointing to the first letter of words while they speak; others may use topic boards with words or pictures. Research shows that speech intelligibility can improve by 25% with alphabet supplementation.⁴⁸

Late stage. Individuals often develop a severe dysarthria so that speech is no longer functional. Decisions about how to intervene will depend upon the residual capabilities and communication needs of the individual.

Case Example: MS

Kathy was diagnosed with MS in her late 30s. At the time, she was married and had four children who ranged in age from four to 15 years. As her disease progressed, she became more difficult to understand. She received speech therapy briefly, but the therapist worked on articulation and breath support and never mentioned AAC-related strategies as a way to support speech or to address current or future communication needs.

Ten years after her initial diagnosis, Kathy lived at home even though significant family problems and difficulties with her care were identified. She was regularly seen by a psychologist and social worker, but these professionals struggled to understand her speech. Finally, they referred her for an AAC assessment, even though Kathy felt her speech was not really a problem.

During the assessment, Kathy indicated she was bilingual and her primary caregiver spoke only Spanish. Speech intelligibility was less than 50%, secondary to a severe dysarthria. When queried, she identified two unmet communication needs: (1) using the telephone and (2) conversing with her youngest child’s teachers. At the time of the assessment, Kathy was quadriplegic. She had an electronic wheelchair, but was no longer able to operate it independently. Upper extremity involvement precluded her from writing. She could point, albeit slowly. Vision was functional with glasses.

During the assessment, she was able to use a low-tech, partner-assisted alphabet display to help clarify messages and identify topics. This strategy was somewhat effective during sessions with her psychologist. She expressed an interest

in exploring the use of an SGD. A follow-up SGD assessment was scheduled during which she demonstrated an ability to select messages using one finger (very slowly) and to scan. She generated simple messages using whole words and the alphabet and expressed excitement about using an SGD to talk on the phone and access her computer.

Goals were set, an SGD device with synthesized and digitized speech was recommended, funding was sought and obtained. Unfortunately, her use of the SGD, while helpful in structured therapy environments, was not optimized at home because she was dependent upon others for set up. The team agreed that if AAC approaches were introduced earlier, Kathy not only might have more easily addressed her unmet communication needs but also might have participated more actively in decisions influencing her care.⁴⁹

Parkinson’s Disease⁵⁰

Parkinson’s Disease (PD) affects the basal ganglia and results in a slow deterioration of motor function. While its etiology is often unknown, PD is sometimes caused by head trauma or by drugs. Symptoms of PD include tremor, bradykinesia (difficulty initiating movement) and rigidity, as well as depression and cognitive/linguistic changes. Visual-spatial deficits and problems with executive function are also reported. Dementia is six times higher in PD than in the general population.⁵¹ When tremor is the predominant motor deficit, cognition is usually normal or near normal; however, when bradykinesia and rigidity are the dominant symptoms, cognition is more likely to be impaired.⁵²

Many people with PD have dysarthria affecting laryngeal function and voice (89%), articulation (45%) and prosody (20%).⁵³ Speech impairments increase as the disease progresses.

AAC assessment and treatment approaches. AAC assessments take into account the identification of current communication needs,

functional levels and contextual and partner-related variables.

Early stage. While speech is typically functional in early stages of PD, a mild dysarthria may require the use of conversational supports, *e.g.*, a voice amplifier or alphabet supplementation. Some individuals also need support for writing and computer access in order to maintain employment and continue to engage in preferred leisure activities.

Middle stage. Some individuals with PD try DAF (delayed auditory feedback) techniques, alphabet supplementation and pacing boards to maintain functional speech. In certain situations, they may also choose to use a portable AAC device to type messages.

Late stage. Communication can be very limited and partner support is often required. AAC strategies include the use of written choice conversation and rate-control techniques (*e.g.*, pacing boards).

Case Example: PD

V.A. is a 72-year-old man with PD and increasing rigidity, who lives at home with his wife and receives in-home nursing care. He was admitted to an intensive care unit with a diagnosis of respiratory failure secondary to recurrent pneumonias and aspiration associated with eating food. He was referred for an SLP consult to improve communication. During the assessment, he was intubated.

A cursory evaluation revealed an alert, visually attentive individual who had limited volitional movements of his upper extremities and oral motor mechanism. However, serial counting in unison elicited a greater range and accuracy of oral movements. Both his nurses and family members had significant difficulties communicating with him. Several nurses felt he did not have the cognitive skills to support much communication.

During the assessment, V.A. demonstrated that he could use a Written Choice Conversation Strategy (*i.e.*, the clinician generates a series of written choices about a topic of interest.) With physical support to enhance pointing,

he was also able to answer questions such as, “What part of Italy are you from?” He also could tell the clinician and attending nurse that his favorite foods were chocolate and pastrami and that he had emigrated from southeastern Italy to the U.S. as a child.⁵⁴

Huntington’s Disease⁵⁵

HD is a hereditary, autosomal dominant degenerative neurologic disease that affects both men and women. Symptoms typically appear during the fourth decade with death following 15 to 20 years later. HD results in motor, emotional and cognitive disturbances and always affects communication. Dysarthria (changes in respiratory, laryngeal and articulatory movements) affects speech intelligibility. Upper extremity problems also affect handwriting.⁵⁶

AAC assessment and treatment. The goal of AAC interventions is to capitalize on the person’s preserved abilities and provide the necessary supports and compensatory strategies to maintain communication. To do so requires that communication partners provide external supports during structured conversations.

Early stage. Memory loss, cognitive impairments and depression, as well as speech and language impairments occur during this stage. Thus, sorting out the kinds of AAC approaches to recommend is difficult. Some individuals benefit from conversational supports (*e.g.*, alphabet supplementation).

Middle and late stage. The increasing cognitive deterioration associated with HD often makes effective communication very difficult. Caregivers learn to support interaction during familiar routines. The authors suggest⁵⁷

1. Selecting simple systems that take advantage of previously overlearned skills.
2. Initiating training in alternative communication approaches early.

3. Avoiding techniques that require new learning.

4. Appreciating that there are potential discrepancies between what the person with HD understands and what he or she is able to produce.

5. Using strategies that provide opportunities to make choices and that employ memory aids.

6. Teaching *Yes-No* systems and providing communication notebooks.

7. Relying on well-instructed communication partners.

Case Example: HD

When W.R. was 44, he had an AAC assessment. During the interview he indicated, “I want to talk about things I am doing, not my disease all of the time.” Thus, before attending a family gathering, he and his wife learned to create a list of key words and scripts that he might talk about. They made a set of index cards, keywords on one side and utterances on the other. For example, the keyword *Northbend* might trigger utterances about a recent hike. When he had difficulty at the family gathering, he would simply read the card.⁵⁸

Comment

The authors note that doctors, family members and other professionals often don’t make AAC until middle and late stages of MS, PD and HD. This makes it difficult to introduce AAC approaches and substantially decreases their potential effectiveness. When early referrals are made, individuals can learn to use AAC strategies, and family members and caregivers can learn how to support communication as the disease progress and interactions become more difficult. Systematically involving families and caregivers “at every step along the way” is essential to effective treatment.⁵⁹



Augmentative Communication Strategies for Adults with Acute or Chronic Medical Conditions¹
 edited by Beukelman, Garrett & Yorkston
A list of Chapters and their Authors

1	An introduction to AAC services for adults with chronic medical conditions: Who, what, when, where and why	David Beukelman, Kathryn Yorkston & Kathryn Garrett
2	AAC in the Intensive Care Unit	Kathryn Garrett, Mary Beth Happ, John Costello & Melanie Fried-Oken
3	Brainstem Impairment	Delva Culp, David Beukelman & Susan Fager
4	Spinal Cord Injury	Deanna Britton & Ross Baarslag-Benson
5	Traumatic Brain Injury	Susan Fager, Molly Doyle & Renee Karantounis
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9	Amyotrophic lateral sclerosis	Laura Ball, David Beukelman & Lisa Bardach
10	AAC Intervention for Progressive Conditions: Multiple Sclerosis, Parkinson's Disease and Huntington's Disease	Kathryn Yorkston & David Beukelman
11	AAC for Persons with Head and Neck Cancer	Marsha Sullivan, Carol Gaebler & Laura Ball
12	AAC Decision-Making Teams: Achieving Change and Maintaining Social Support	David Beukelman, Kathryn Yorkston & Kathryn Garrett

References

¹ Beukelman, D., Garrett, K. & Yorkston, K. (Eds.). (2007). *Augmentative Communication Strategies for Adults with Acute or Chronic Medical Conditions*. Baltimore: Paul H. Brookes Publishing Co.

² Garrett, K. L., Happ, M.G., Costello, J. & Fried-Oken, M. (2007). AAC in the intensive care unit. In D. Beukelman, K. Yorkston and K. Garrett (Eds.). *Augmentative Communication Strategies for Adults with Acute or Chronic Medical Conditions*. Baltimore: Paul H. Brookes Publishing Co. 17-57.

³ *Ibid.*, 47.

⁴ Fowler, S. (1997). Impaired verbal communication during short-term oral intubation. *Nursing Diagnosis*. 8: 93-98.

⁵ Happ, M. (2001). Communicating with mechanically ventilated patients in the ICU: State of the science. *AACN Clinical Issues*. 12: 247-258.

⁶ Fried-Oken, M., Howard, J. & Stewart, S. (1991). Feedback on AAC intervention from adults who are temporarily unable to speak. *Augmentative and Alternative Communication*. 7: 43-50.

⁷ Dowden, P., Beukelman, D. & Lossing, C. (1986). Serving nonspeaking patients in acute care settings: Intervention outcomes. *Augmentative and Alternative Communication*. 2: 38-44.

⁸ Costello, J. (2000). AAC intervention in the intensive care unit: The Children's Hospital Boston Model. *Augmentative and Alternative Communication*. 16: 137-153.

⁹ Menzel, L. (1998). Factors related to the emotional responses of intubated patients being unable to speak. *Heart and Lung*. 27: 245-52.

¹⁰ Happ, M., Garrett, K., Sereika, S., George, E. & Donahoe, M. *Improving communication with nonspeaking ICU patients*. National Institute of Child Health and Human Development grant 5R01HD043988. (2003-2008).

¹¹ Fried-Oken, M. & Bardach, L. (2005). Augmentative communication and end-of-life. *Perspectives on Augmentative and Alternative Communication*. 14(4). 15-19.

¹² Garrett & Happ (2007). Based on case example from John Costello. 52.

¹³ Garrett *et al.* (2007). 48.

¹⁴ Culp, D., Beukelman, D. & Fager, S. (2007). Brainstem impairment. In D. Beukelman, K. Yorkston & K. Garrett (Eds.). *Augmentative Communication Strategies for Adults with Acute or Chronic Medical Conditions*. Baltimore: Paul H. Brookes Publishing Co., 52-90.

¹⁵ *Ibid.* 71.

¹⁶ *Ibid.* Based (loosely) on William. 65.

¹⁷ Delva Culp. (January 2007). Personal communication.

¹⁸ Chisholm, N. & Gillett, G. (2005). The patient's journey: Living with locked-in syndrome. *BMJ Journal*. 331:94-97. <http://www.bmj.com/cgi/content/full/331/7508/94>. Accessed 2/25/07.

¹⁹ *Ibid.*

²⁰ Hakel, M., Garcia, J., Beukelman, D. & Marshall, J. (2002). The influence of perceptual and instrumental measures of dysarthria treatment intervention including palatal lift fitting. *Journal of Medical Speech-Language Pathology*. 10:4, 257-263.

²¹ David Beukelman. (January 2007). Personal communication.

²² Fager, S., Doyle, M. & Karantounis, R. (2007). Traumatic brain injury. In D. Beukelman, K. Yorkston & K. Garrett (Eds.). *Augmentative Communication Strategies for Adults with Acute or Chronic Medical Conditions*. Baltimore: Paul H. Brookes Publishing Co., 131-162.

²³ Bruns J. & Hauser W. (2003). The epidemiology of traumatic brain injury: A review. *Epilepsia*. 44: Supplement 10, 2-10.

²⁴ Fager, *et al.* (2007). 136.

²⁵ *Ibid.*, 145.

²⁶ Hagan, C., Malkamus, D. & Durham, P. (1979). *Rehabilitation of the Head Injured Adult: Comprehensive Physical Management*. Downey, CA: Professional Staff Association of Rancho Los Amigos Medical Center.

²⁷ Fager, *et al.* (2007). 135-136.

²⁸ Fager, *et al.* (2007). Based on Roger, 160-161.

²⁹ Fager, S., Hux, K., Beukelman, D. & Karantounis, R. (2006). Augmentative and alternative communication use and acceptance by adults with traumatic brain injury. *Augmentative and Alternative Communication*. 22:37-47.

³⁰ Britton, D. & Baarslag-Benson, R. (2007). Spinal cord injury. In D. Beukelman, K. Yorkston & K. Garrett (Eds.). *Augmentative Communication Strategies for Adults with Acute or Chronic Medical Conditions*. Baltimore: Paul H. Brookes Publishing Co., 91-130.

³¹ <http://www.ninds.nih.gov/disorders/sci/sci.htm>. Accessed on 2/24/07.

³² <http://www.spinalcord.uab.edu/> Facts and figures at a glance. Accessed on 2/24/07.

³³ Britton & Baarslag-Benson. (2007). 106-107.

³⁴ Ripat, J. & Strock, A. (2004). Users' perceptions of the impact of electronic aids to daily living throughout the acquisition process. *Assistive Technology*. 16: 63-72.

³⁵ Susan Fager. (February 2007). Personal communication.

³⁶ Bourgeois, M. & Hickey, E. (2007). Dementia. In D. Beukelman, K. Yorkston & K. Garrett (Eds.). *Augmentative Communication Strategies for Adults with Acute or Chronic Medical Conditions*. Baltimore: Paul H. Brookes Publishing Co., 243-285.

³⁷ Based on author's (SB) personal experience.

³⁸ American Psychiatric Association (1994). *Diagnostic and statistical manual of mental disorders (4th Edition)*. Washington, DC: American Psychiatric Association.

- ³⁹ Bourgeois, M. & Hickey, E. (2007). 240.
- ⁴⁰ *Ibid.*, 251-252.
- ⁴¹ *Ibid.*, 279-280.
- ⁴² Bourgeois, M. (1992a). Evaluating memory wallets in conversations with patients with dementia. *Journal of Speech and Hearing Research*. 35:1344-1357.
- ⁴³ Yorkston, K. & Beukelman, D. (2007). AAC Intervention for Progressive Conditions: Multiple Sclerosis, Parkinson's Disease and Huntington's Disease. In D. Beukelman, K. Yorkston & K. Garrett (Eds.), *Augmentative Communication Strategies for Adults with Acute or Chronic Medical Conditions*. Baltimore: Paul H. Brookes Publishing Co., 317-345.
- ⁴⁴ McCall, F. & Moodle, E. (1998). Training staff to support AAC users in Scotland: Current status and needs. *Augmentative and Alternative Communication*. 14:4, 228-238.
- ⁴⁵ Yorkston & Beukelman (2007). 318-326.
- ⁴⁶ *Ibid.*, 321.
- ⁴⁷ Yorkston, K., Miller, R. M., & Strand, E. A. (2004). *Management of Speech and Swallowing Disorders in Degenerative Disease*. (2nd ed.). Austin, TX: Pro-Ed.
- ⁴⁸ Hanson, E., Yorkston, K. & Beukelman, D. (2004). Speech supplementation techniques for dysarthria: A systematic review. *Journal of Medical Speech-Language Pathology*, 12(2): ix-xxix.
- ⁴⁹ Based on author's (SB) personal experience.
- ⁵⁰ Yorkston & Beukelman (2007). 326-334.
- ⁵¹ Aarsland, D., Andersen, K., Larsen, J. P., Lolk, A., Nielsen, H. & Kragh-Sorensen, P. (2001). Risk of dementia in Parkinson's disease. *Neurology*. 56:730-736.
- ⁵² Levin, B. E., Tomer, R. & Rey, G. J. (1992). Cognitive impairments in Parkinson's disease. *Neurologic Clinics*, 10:2, 471-481.
- ⁵³ Logemann, J. A., Fisher, H. B., Boshes, B. & Blonsky, E. (1978). Frequency and co-occurrence of vocal tract dysfunction in the speech of a large sample of Parkinson patients. *Journal of Speech and Hearing Disorders*. 43:47-57.
- ⁵⁴ Yorkston & Beukelman (2007). Based on case example from Kathryn Garrett. 334.
- ⁵⁵ Yorkston & Beukelman (2007). 335-340.
- ⁵⁶ Klasner, E. R. & Yorkston, K. M. (2000). Augmentative communication for Huntington and Parkinson's disease: Planning for change. In D. R. Beukelman, K. M. Yorkston & J. Reichle (Eds.), *Augmentative and alternative communication for adults with acquired neurologic disabilities* (241-279). Baltimore: Paul H. Brookes Publishing.
- ⁵⁷ Yorkston & Beukelman (2007). 339.
- ⁵⁸ Yorkston & Beukelman (2007). Based on case example from *Klasner & Yorkston (2001)*. 338-339.
- **Ibid.* 340.

Resources

I communicated with six of the 23 authors in preparing this issue and wish to recognize those individuals.

Due to page limitations, I (sadly) was unable to write about all twelve chapters. Please note that I recently published a 16-page newsletter on amyotrophic lateral sclerosis, and I am planning an upcoming issue on aphasia.

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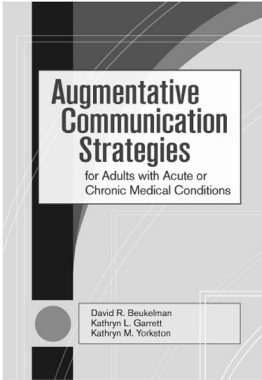
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