Augmentative Communication News

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UPFRONT

The only prerequisite for augmentative communication (AC) intervention is "breathing,"[1] meaning communication, like breathing, is inherent to being alive. However, some people who are alive and need to communicate, are not able to breathe normally. Mechanical ventilators and tracheostomies (trachs) are the augmentative and alternative breathing devices sustaining their lives.

- **Tracheotomies** are performed to provide an alternate airway. A tracheotomy involves insertion of a canula (tube) into the trachea.
- **Mechanical ventilators** are used to support respiration when neuromuscular failure causes weakness or paralysis of the intercostal muscles and diaphragm. A ventilator, which can be portable, gives a specific amount of air to the lungs through the nose, mouth or a trach which is coupled (attached) to the ventilator.

Dependency on a trach and/or ventilator may occur at any time in someone's life between birth and death, for brief or prolonged periods, due to a variety of causes.

While sustaining life, ventilators and tracheostomies often make it impossible for individuals to talk without special equipment. Also, the conditions causing breathing problems may be associated with other difficulties (e.g., quadriplegia) that preclude writing, gesturing, and facial expressions. As technology and medical practices become more sophisticated and accessible, professionals *(continued on page 2)*

For Consumers

Living with trachs and ventilators

Imagine being ventilator-dependent with a tracheostomy, unable to speak or write, and in the midst of a life-threatening medical crises. While the incidence and prevalence of people who are maintained on mechanical ventilators and those with tracheostomies is not well documented by diagnosis or setting,[2] those interviewed concur the numbers are increasing. Causes include difficulties originating in the:

- **Central nervous system**: head trauma, brain stem tumor or infarction, high cervical spinal cord injury, prematurity.
- **Peripheral nervous system**: poliomyelitis, amyotrophic lateral sclerosis, Guillain-Barre syndrome, Werdnigs Hoffmans syndrome.
- **Neuromuscular junction**: botulism, myasthenia gravis.
- **Muscle**: muscular dystrophy.
- **Respiratory system**: congenital conditions (laryngeal web, hemangiomas; cystic hygroma) and acquired conditions (subglottic stenosis, respiratory distress syndrome, cancer, bronchopulmonary dysplasia, sleep apnea, acute upper airway infections, upper airway obstruction.)

The literature contains descriptions and follow up information about people with Guillian Barre syndrome, botulism, brain-stem strokes, spinal cord injuries, and other conditions resulting in ventilator and/or trach dependency for periods from weeks to years.[3-9] In an attempt to capture some of the issues confronting people who require ventilators and are dependent on trachs, 2 adults and 2 children are introduced below. Their stories illustrate *why* and *how* AC approaches can help.

First, let's meet the adults. Both sustained traumatic injuries at the C1 level of the spinal cord, causing them to be ventilator dependent and quadriplegic. Unlike most people seen by AC teams, they were capable of articulating, but could not generate sound for speech. *(continued on page 2)*

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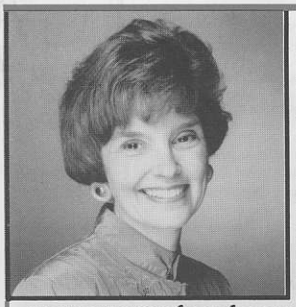

(continued from Upfront) on page 1)
specializing in the area of augmentative communication (AC) need to be informed about available communication options. My very special thanks to those interviewed *(see page 8)* for sharing their time, knowledge and experiences. **For Consumers** gives a snapshot of four people who have required alternative methods of breathing and talking for years. **Clinical News** has suggestions for intervention. The **Equipment** section displays a chart of devices used to augment speech and communication. In **Governmental** Carolyn Watkins gives us a glimpse of current practices in Eastern Europe. **University and Research** highlights two projects at Stanford's Rehabilitation Engineering Center. **ATTENTION Subscribers earning 1992 ASHA CEU's.** Your exam is included with this issue along with instructions for completing it. Finally, ACN staff wishes each of you a very happy and safe holiday season. Til '93!

Sarah W. Blackstone, Ph.D.

For Consumers *(cont. from page 1)*

Adult #1

Mark, a 29 year old male, was shot during an attempt to steal his car near the university he attended. After 3 months in an acute care hospital, he was transferred to a rehabilitation center. At that time, he had a Portex #8 speaking tube with the cuff inflated. This allowed him to talk; however, he rarely used it as he found the air flow drying. Instead, he relied on others to read his lips. Reportedly, no other ways to augment communication had been introduced.

At the rehabilitation hospital, cuff deflation became a major focus. His trach tube was downsized to a #6 Shiley, and ventilator settings were adjusted for speech. He was also taught to use a switch to control a computer and the environment. At discharge, he tolerated cuff deflation for up to 8 hours and was an oral communicator. His comments follow.

- Conveying messages 1 on 1 is very important to me. I feel more normal, less trapped in my body because I can project my personality out of my body.
- Most people I know are glad I can talk no matter how it comes about. When I feel good, I keep the cuff down the entire day. Cuff deflation allows me to be in control of speech as much as the respirator will allow rather than depend on another person to activate the speech modes as in the case of the talking trach. It's clearer, a more natural voice and certainly not as high-pitched or nasal.

Adult #2

Married with young children, Janet was 27 when she suffered a spinal cord injury at the C1 level in a weather related car accident 5 years ago. Unlike Mark, AC techniques were introduced in the intensive care unit (ICU).

- Three days post injury, she indicated *yes* and *no* reliably with eye blinks.
- The next day, she began using an Etran message board with 6 topics (Family/friends; Medical; Feelings; Needs; Miscellaneous; Questions).
- On day 5, she was taught to use alphabet scanning. This allowed her to generate novel messages.
- On day 7 a two part communication board was introduced, and she began to encode messages using the alphabet and numbers.

Janet gradually learned to talk on a ventilator with cuff deflation. Initially she tolerated 1 hour, 3 times per day. By discharge, she was able to use a one-way speaking valve throughout the day. For writing, she learned to operate a pneumatic switch to do word processing. Janet continued to do well after she went home using an IBM computer, a one-way valve to talk, and operating an environmental control unit and electric wheelchair.

Comment: Janet's and Mark's communication intervention focused on learning to produce audible speech using devices and techniques that direct airflow from a ventilator, or an external air source, up through the larynx. Balancing medical concerns with talking can take several months to accomplish. During the time she was unable to speak or write, Janet benefited from AC approaches. Mark did not. Their stories illustrate the value of approaching communication intervention using both speech and non-speech techniques.

Now, let's meet two 9 year old children. Because growth and development are factors, the medical management and communication issues surrounding these young children are far more complex.

Child #1

David's birth was one of those medical miracles that are the result of a lot of hard work and expert medical care. Both David and his parents are achondroplasic dwarfs. Despite being born six weeks prematurely, his health seemed fine and he went home at 6 days of age. However, he was admitted to the ICU at 9 months because of failure to thrive and chronic restrictive lung disease. Six weeks later he suffered congestive heart failure and was placed on a ventilator, receiving a tracheostomy shortly thereafter. Prone to infections, including pneumonia and ear infections, he remained hospitalized for the next two years.

During that prolonged hospitalization, his hearing status was questioned. He was later found to have a mild, bilateral sensorineural hearing loss. There were several unsuccessful efforts to wean him from the ventilator and reduce the size of the trach tube, but this was not accomplished until just before he went home at age 2 years 10 months. Communication intervention included language stimulation and sign language training. His mom, a preschool teacher, was his primary instructor. When he was discharged, he:

- was using approximately 500 signs although intelligibility was compromised by motor and structural difficulties in his hands.
- had discovered how to make an audible "raspberry" to get attention.
- had started to mouthe words, which were very difficult to understand due to immature articulation and tongue protrusion.

Getting David home depended on obtaining the necessary home care be-

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cause he still required oxygen which was delivered to his trach, and had to be suctioned every 10 to 20 minutes around the clock. Although manual signs were working as a means of communication with his mother, there were other people David wanted to talk to. Communication intervention began to focus on improving oral motor control and articulation when mouthing. Over a period of 6 months several kinds of electro-laryges were tried with minimal success. David hated having anything else around his neck and face and didn't like the vibration. A communication device (Touch Talker) was introduced when he was 4 years old. He caught on quickly, learning to use multiple icon sequences. With his family, David used the device to clarify messages and repair miscommunications. Sign language and mouthing words continued to be his preferred modes of communication. He used the communication aid more extensively with less familiar partners to participate in social routines at preschool and Sunday school. He was also learning to walk with support, pushing his oxygen tank and communication device on a cart.

Just prior to entering kindergarten he got pneumonia and ended up in the ICU on a ventilator for two 6 week periods. His mother also had health problems, and communication intervention was put on the back burner. Despite these setbacks, David entered a regular kindergarten class in the fall. School staff concentrated on learning about the equipment and procedures needed to sustain David's life (i.e., portable oxygen supply, portable suctioner) and focused on adapting classroom activities. They felt unable to devote sufficient time to the communication device. Luckily, the intelligibility of his mouthing had improved. Several types of electrolarynx were evaluated, including an intraoral electrolarynx; however, he said, *"They are too long in my mouth, and the sound is too noisy."* A neck-type Romet electrolarynx was purchased and within a few months had replaced the voice output device.

David is now 9 years old. He is ambulatory, uses portable oxygen, has a trach, wears bilateral hearing aids, and uses a Jedcom electrolarynx. He uses multiple expressive communication techniques: mouthing words and signing with familiar partners, using an electrolarynx in groups, and writing notes to less familiar partners. Devices to augment communication, speech and breathing have played (and will continue to play) a critical role in his life. For now, however, as far as he is concerned, *"the less technology the better!"*

Child #4

Adam, who also is 9 years old, is diagnosed with congenital arthrogryposis multiplexia. His story is told by his mother, beginning with his birth.

- Adam's face was purple before he was fully delivered so I knew instantly that he was in trouble. The doctor's comment was "we've got a foot problem." I was in a total wash of fear that Adam would die. Feet and hands were nothing compared to not breathing. In a flash I knew I wanted that baby, no matter what; and there was a fool prattling about feet!
- "Doing therapy" was not helpful. For example, sniffing peppermint oil, arousing Adam with noise makers, and trying to "recreate" a home environment in the midst of an Infant Developmental Unit seemed ridiculous. "Early Interventionists" seemed to be ignoring the real experiences he was having.
- During those months in the hospital, I wish someone had put switches in bed with him. He had so much other stuff, one more thing couldn't have mattered and it would have allowed him to have fun or given him the equivalent of a voice...a way to scream, cry, get attention.
- Because he had poorly adducting vocal cords, someone (maybe a social worker) asked me if anybody had said anything about talking. I told her I guessed Adam would have to sign or use a little black box (I meant an electrolarynx). She asked how the "boxes" worked, and I told her. Maybe she really didn't know, but I hate "feigned ignorance."
- A doctor made a comment in passing that the only real consequence of a trach was kids couldn't talk. He told me kids can learn to talk later.

Frustrated and increasingly concerned about Adam's medical treatment and prognosis, the family sought help at another major medical center. A tracheotomy was performed.

- An otolaryngologist did point out that Adam had a highly arched palate and a submucous cleft so any speech would have a nasal sound. However, we both knew, at the time, it was only a theoretical discussion.
- At 8 months old, Adam had started to mouthe words.
- At 13 months, Adam started inventing signs. He pointed at his ear when we wound up the music box. He was really happy when I figured it out!

Adam and his family went through some tough times in the hospital that first year. Then, it got even worse! At 15 months, laryngeal cancer was discovered. Adam underwent a total laryngectomy. Now, he had a gastrostomy and a laryngectomy, not a simple tracheostomy.

- Holes in the throat are not easy, but it became easier over time. Suctioning used to be a big issue, but is rarely required now.
- Having a laryngectomy means
  * Having to explain that it's not a trach,
  * Running a suction machine off the vacuum hose in the car on trips,
  * Watching Adam put his face under water for 10 minutes in the bathtub and knowing he's okay as long as his neck doesn't get wet,
  * Knowing he can stick a whole hotdog down his throat and not choke to death even if it gets stuck
  * Getting scared to death at clogged mucous noises and then finding out that he's just having a wonderful time dropping his chin on his tube and making noise so he can watch his mother run like a gazelle.

Following the complete laryngectomy and over the years, communication issues have been handled in a number of different ways. The family reports that some recommendations were helpful---others were not.

- After the surgery, a prototype pediatric electrolarynx was tried; however, his oral motor and structural problems made it obvious it would never be a functional device.
- When he was about two years old, a speech-language pathologist said "when he reaches a cognitive level of 9 months we might have some suggestions." NINE months?! We already knew Adam's language understanding was better than that, and he was using many invented signs and gestures to communicate with us. After that, I mentally dug my heals in and said to myself, "If they can teach a gorilla to sign, I can teach Adam to sign."

Even though neuromotor problems in his hands made sign productions imprecise, Adam immediately used the signs he was taught. A little later, when he was 3 years old, professionals at the medical center suggested the family also look into AAC devices and computers.

- Adam wasn't interested in communication boards. And, as far as I was concerned, we already were using a "you have to be there" form of communication (i.e., signing). We wanted voice output and something portable.
- A speech-pathologist showed us a communication device, gave us a copy of the Wall Chart that lists device features, let Adam play with a computer program and told us to go to Closing the Gap.

The next year the family attended Closing the Gap (a large conference in Minnesota, U.S.A.) and began making decisions about assistive technology.

- It was wonderful. We had already figured out some of what Adam needed in a communication device: good direct access, portability and durability.

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When we were at Closing the Gap, we found out that the voice quality was important to him and that regular keys were easier than flat, membrane areas for access. Because we had heard rumors of a "better device" (smaller, improved speech quality) being released soon, we decided to wait. Besides, he wasn't going out much, and we were still taking sign language classes. In the end, we bought a computer and some educational software.

A year later the family purchased Adam a communication device. However, it was not portable enough for this active, ambulatory child, was not supported in his educational program, and soon "began gathering dust." Sadly, one of many reasons used to exclude Adam from attending his neighborhood school was his reliance on AC devices/techniques. For the past 3 years, he has been educated at home.

- Finding no chance for an education in our school was the hardest...harder than the medical stuff...harder than cancer. Maybe it's been the hardest to take because it should have been the easiest to do. We won the battle for Adam's life but we couldn't win the battle for fulfilling his capabilities. I will still have him but he won't have all of himself. I'm so angry that he's been cheated.

Today, at age 9 years, Adam communicates by using mime, signs and a computer with a word processing program.

- His written work looks a lot like his sign language, e.g., "I am happy Mom home."
- He can and does actively participate in most activities; however, he is lonely and misses the kids at school.

Comment: Solving the medical problems of people who can not breathe without assistance is being done. Solving their problems with communication also is being done, at least in some places. However, removing the social barriers individuals face who require special technologies to breathe, to speak, and to communicate is a far more elusive task. Preparing children to live in the real world, requires that adults pave the way toward opportunities. I believe AC professionals can play a very important role.

Clinical News

Service delivery issues in intensive care units (ICUs) & with young children

Primary team members who manage the care of people on mechanical ventilators and those with tracheostomies typically include physicians (pulmonology, otolaryngology, rehabilitation medicine), nurses, respiratory therapists, and speech-language pathologists working as a transdisciplinary team. However, to insure communication needs are met initially and over time, professionals who specialize in AC (speech-language pathologists, occupational therapist, rehabilitation engineers, etc.) also can help. This section highlights intervention approaches for adults in ICUs and then considers issues important to the care of children.

Communication intervention for ventilator dependent patients in intensive care units (ICUs)

People on ventilators often remain in the ICUs of acute care hospitals until they become medically stable, which can take from days to many months. This section gives suggestions for managing communication needs during that time.

What are the needs? It is a misconception that the communication needs of people in ICUs are limited. In fact, many people on ventilators and/or with trachs who can not speak are alert and have things to say that extend beyond basic needs. Important intervention principles are[5]:

1. Adequate communication is not a luxury but a medical necessity.
2. Patients need to communicate more than just medical needs.
3. Communication systems may change on a daily basis.
4. Oral communication should not be ruled out.
5. Training of staff and family is critical.
6. Communicating novel messages should not be overlooked when providing a patient with an initial communication system.

What are the realities? In acute care hospitals, time constraints are severe, the stresses of acute illness are high, and the patient's medical and emotional condition is likely to be constantly changing. Communication approaches must not compromise medical treatment and should be simple enough so patient, family, and staff can learn them quickly. A transdisciplinary approach is essential.

What can be done?

1. Determine if the patient is ready for communication.
2. Establish a way for the patient to indicate *yes* and *no*. Natural gestures are preferable, but other means can be taught (e.g., eye gaze up for "yes."). Excellent chapters by Culp and Ladtkow[4] and Mitsuda and Baarslag-Benson[5] outline procedures, e.g., see Assessment Protocol below:

COMMUNICATION ASSESSMENT PROTOCOL[5]	
Is patient alert?	If no, reassess later.
Does patient have 2 reliable movements to indicate yes/no?	If no, refer to OT and PT
Does patient have adequate cognitive skills	If no, reassess later.
Does patient already have a means to communicate yes/no effectively?	Document and train others.
Does patient need more than yes/no communication?	If yes, do a complete evaluation

3. Determine a person's capabilities, particularly their immediate potential for speech.[10-14] The team will assess oral, pharyngeal, and laryngeal function and develop a plan to insure optimal medical management while allowing communication to occur. The following guidelines may help:

- *When oral motor and laryngeal function are intact:* Cuff deflation of the tracheostomy canula or a cuffless tube is a simple yet effective means to preserve both oral communication and adequate ventilation.[14] For example,
  - Bach and Albad[15] report that of 104 unweanable ventilator-dependent patients with neuromuscular insufficiency, only 3 needed to continue with cuff inflation. Yet, despite reports of success with cuff deflation in allowing speech, Tippet found that in nearly 1/3 of articles she reviewed that claimed to address the comprehensive management, outcome and functional recovery of ventilator-dependent populations, no mention was made of oral communication. In fact, the only communication forms described were tongue clicking to draw attention and speaking on tracheostomy tubes.[2]

Cuff deflation requires a trained, transdisciplinary team who can assess a patient's tolerance for deflation and ability to achieve voicing. Ventilator settings are adjusted so there is sufficient air to the lungs and for phonation. Once deflation

is possible, patients may experience anxiety and a feeling of not being able to breathe. Alterations are made slowly. The fatigue in speaking with deflated cuffs can be ameliorated using one-way speaking valves. See the **Equipment** section for additional information.

- *When oral motor is intact, but laryngeal function is not.* A talking trach and/or an electrolarynx are considerations. With a talking trach, a separate air source is controlled by the patient or caregiver whereas an electrolarynx provides an external source for sound. Many learn to use these devices, even patients with quadriplegia because some products can be controlled by a remote switch. See **Equipment** section.
- *When oral motor function is not intact.* Aided and unaided augmentative techniques and devices are possible:
  - For those who can use their hands and are literate, handwriting often is preferable. Magic Slates (found in toy shops) are favorites, even for adults. Pointing to the alphabet, words, pictures on language boards to select messages and manual signs are also options.
  - For those unable to use their hands light pointers, eye gaze systems, listener assisted scanning techniques are available to select messages.
  - If cognition is limited or the person is unable to read or write, then vocabulary options can be presented using pictures, symbols, maps, or graphs.
  - Low tech approaches often are preferred because they are easier to learn, more readily available and do not introduce additional equipment. See the **Equipment** section.

What do patients prefer? Obviously, patients prefer to talk; however, when oral speech is not functional, non-oral techniques should be used. Fried-Oken, Howard, and Stewart[3] reported most patients in ICUs on ventilators expressed satisfaction with aided expression. The alphabet board was the aid of choice whether the patient used direct selection or scanning. Patients and families felt "phrase boards" and electronic devices were unsuccessful because messages on the boards were too limiting, and devices were too motorically and cognitively complex. Other problems with electronic communication devices noted were:[16]

1. **Volume.** Noise from the ventilators and the limited volume of most speech output devices compromise intelligibility.
2. **Positioning.** Many people on ventilators are bedridden, making the positioning of a device problematic.
3. **Nature of the injury.** Patient with combined injuries, i.e., head trauma, spinal cord and respiratory problems can be very complex to manage.
4. **Staff education.** ICU staff are used to guessing and reading lips. Even simple, low tech devices require training.
5. **Vision.** Vision problems must be ruled out prior to introducing AC techniques that require good visual skills, e.g., direct selection or visual scanning.)

What's the best approach: A combination of approaches works best, at any one time and over time because each patient's medical status and needs change. Mitsuda et al.[5] recommend the following equipment be available in all ICUs: 1) a light-weight neck-type electrolarynx; 2) an oral-type electrolarynx; 3) materials to construct alphabet boards, word boards, and picture boards; 4) several Magic Slates; 5) a portable mounting system on wheels to hold cardboard message boards or eye pointing displays. Finally, as with other communication interventions, ICU staff and families need inservice training, no matter how simple the augmentative technique or device being used.

Infants and young children:

Issues surrounding infants and young children on ventilators and those with trachs are more complex than those for people who have already acquired language.

- Oral structures (larynx, pharynx, jaw) are developing.
- Speech and language skills are developing,
- Social, emotional, cognitive, motoric, and communication patterns are being formed, and
- medical status is often fragile.

What then, is the impact on a child's development of being unable to cry, coo, babble and ultimately speak? What happens to children and families who spend months and even years in hospitals? Studies attempting to assess the impact on the speech, language, and communication development of children on long-term tracheostomy/ventilation are inconclusive, at best.[17-19]

- Some researchers report differences in verbal comprehension and expressive language between normal children and those who have undergone tracheostomy in infancy. Note: IQ was taken into account.
- Others report differences at the time of decannulation (removal of the trach) that resolve over time.
- Other data suggest long-term tracheostomy in infancy may adversely affect expressive language in school aged children of normal intelligence. Overall measures of language at follow-up were within normal limits and commensurate with cognitive abilities, but 61% of all cases had impaired articulation skills, and a clear pattern of expressive language disability was noted in the older group of children.[19]

Bleile, Stark, and McGowen[17] report that once a child is decannulated, speech proceeds to develop, but at a slower pace. Further, the rate of development is directly related to the oral/verbal practice a child has had. Additional observations made by those interviewed are:

- Handling issues are important considerations as they can cause changes in respiratory rate and blood pressure
- Parents often do not want to talk about communication development-- no surprise given what they must deal with!
- Children are rarely decannulated[19] (i.e., removing the trach) successfully before age 2 years.
- Children can occlude a trach by lowering their chin and slowly releasing it.
- *Donald Duck* speech is useful for getting attention.
- Teaching signs, using picture boards, playing gesture games, using switches is important. Note: language boards have been observed to increase a child's attempt to talk.

McGowan[20] suggests considering the following when making decisions about communication intervention: Communication partners, parental support/knowledge, physical ability of child, vocabulary needs of child, and portability. She recommends using an electrolarynx to stimulate oral language development as early as 9 months developmentally. This can also help diagnose apraxia and dysarthria. To desensitize the infant, first vibrate the child's arms and legs; and then work on oral imitation activities with the device near the neck. Initially, the clinician holds the device. She also suggests making a *disguise* for the electrolarynx, with a face and hat. Then you can say, "he's going to tickle you." One last thought. Don't do away with any component of a child's system until he or she is totally able to depend on speech. Even then, let the child decide when he or she is ready.

Equipment

Communication options with trachs & ventilators

Communication aids, by definition, should include devices allowing speech to occur (e.g., *speaking valves, electrolarynx*), as well as those that permit other means of expression (i.e,. *Etrans, language boards, computers, voice output devices*). When people who use trachs or ventilators have intact oropharyngeal motor control, intervention will focus on ways to enable them to speak by using their own larynx as a source of sound or if their vocal folds are paralyzed or removed, using an external sound source. When a person does not have sufficient oral motor control for intelligible speech because of cranial nerve damage, vocal cord paralysis, respiratory problems, structural problems involving the speech mechanism or cognitive deficits, augmentative communication (AC) techniques offer many options. Over time, people may use multiple approaches to meet their communication needs. The purpose of the chart is to raise awareness so professionals and caregivers make choices that insure access to communication, over time.

COMMUNICATION OPTIONS FOR PERSONS DEPENDENT ON A TRACHEOSTOMY OR VENTILATOR*

	METHOD	BRIEF DESCRIPTION	EQUIPMENT **	SOME BENEFITS	POTENTIAL PROBLEMS
LARYNX AS A SOUND SOURCE FOR SPEECH	**Continuous or intermittent occlusion of trach.** Must not occlude airway.	1. Caregiver or patient put finger or chin over trach during exhalation to cause air to move through vocal cords	Nonfenestrated trach (cuffless or deflated)	Speech. "Cough" for clearing upper airway. Make noise to get attention.	Hygiene/infection. Someone must occlude trach. Must synchronize occlusion with exhalation.
		2. Caregiver or patient put finger over trach during exhalation to allow speech	Fenestrated trach (trach can be inflated)		
		3.Plug the trach. Often used prior to weaning from trach	Tracheostomy button		May require close monitoring.
	One-way speaking valve. Trach must not occlude airway.	Valve attached to trach allows air to flow in, but instead of going out trach during expiration, the air goes through the patient's nose and mouth making speech possible. Contraindicated for patients with laryngeal or tracheal stenosis.	Examples are Olympic Trach-Talk, Montgomery Speaking Valve, Hood, Kistner, Passy-Muir Trach Valve (available in pediatric size)	Speech. Upper airway clearance. Useful when patient a) is not ready for plugging and may require oxygen; b) cannot use fingers; c) wants to use both hands and talk. d) is ventilator dependent	Patient may not be able to apply/remove valve independently. Valves can pop off with cough. Valve may not be easily cleaned and may require replacement every 3 months
	Talking Trachs	*Primarily for patients on ventilators.* A conduit is attached to a source of compressed air which is separate from the ventilator. Patient/caregiver occludes the conduit to direct airflow through larynx.	Examples are Portex Talking Tubes, Bivona Talking Trach Tube, Communi-trach	Speech. Useful because it a) allows speech throughout respiratory cycle. b) permits maintenance and monitoring of ventilator and tidal volumes. c) allows cuff deflation	Interference by secretions. Difficulty positioning tube. Altered voice quality. Airflow can be uncomfortable
EXTERNAL SOUND SOURCES FOR SPEECH	**Neck-type Electro-larynx**	For patients unable to use vocal cords because of laryngeal injury or cuff inflation but who can articulate well. Need hand function, upper extremity strength	Examples are Western Electric, Romet, Jedcom, Servox	Speech, Portability and ready accessibility. Can personalize sound to some extent.	Requires learning new skills. Placement problems.
	Oral type electro-larynx	Tone generator with a plastic tube which is placed in mouth. For patients who can not use neck type.	Examples are Copper Rand	Speech. Has pitch and volume controls	Requires learning new skills. Placement problems.
	Remote switch electolarynx	A modification of oral type. Has remote switch so person with quadriplegia can operate. Tube mounted on headband.	Examples are Copper Rand	Speech. For patients who can not hold electrolarynx	Placement is a problem. Requires learning new skills
WHEN SPEECH IS NOT AN OPTION	**Hand-writing**	For patients who can print or write. Allows them to respond, initiate, etc. and prepare messages in advance	Magic Slate; Notepad and pen/pencil	Natural and familiar form of communication. Unlimited access to language	Cognitive/linguistic requirments; lack of privacy
	Signs and gestures	Natural gestures for everyone. Signs used with children learning language who have good upper extremity skills	None, but need upper extremity strength and function	Natural gestures easily understood. Signs provide access to language. Portable.	Sign language- new learning for user and partners
	Direct Seclection	For patients, even those with no literacy skill who can point using finger, eyes, hand, head stick, etc. to select desired messages from a display	Alphabet boards, Symbol boards, ETRANs, Charts, Communication devices	Access to language (words, symbols). Use of encoding to expand access to vocabulary. Provide options for speech output, rate enhancement.	Limited access to vocabulary. Slow. Requires new learning for user and partners,
	Scanning (Auditory and Visual)	For patients unable to use direct selection because of visual and/or motor problems. Either a person or a device scans vocabulary/letters. When the desired message is reached, the user indicates, stopping the scan.	Alphabet boards, Symbol boards, Listener assisted scanning charts, Communication devices	Access to language. Listener assisted scanning can be very efficient. Can use encoding to expand access to vocabulary, Options for speech output, rate enhancement	Limited access to vocabulary. Slow. Requires new learning for user and partners,

* This chart was developed by Sarah Blackstone, Donna Tippett, and Carolyn Watkins.
** See page 8 for addresses and phone numbers

University & Research

Rehabilitation Engineering Center at Standford

The Rehabilitation Engineering Center (REC) at the Lucile Salter Packard Children's Hospital at Stanford (LPCH) was founded 18 years ago. Over the years, many successful projects have been completed. Two are highlighted below:

1. *Transitional Powered Mobility Aid (TPMA)*. Peggy Barker, rehabilitation engineer, and Christine Wright, occupational therapist, are working with John Wadsworth, an engineer specializing in product design, to develop an exploratory mobility device that enables physically disabled children (ages 12 months to 5 years) to move independently. Funded by the OSER, the TPMA is conceptualized as a precursor to functional use of a power wheelchair. It consists of a power base and an adjustable positioning frame, allowing children to sit or stand. Controls (switches or a joystick) can be easily mounted and positioned in any location. Because of its small size, the TPMA can be used indoors and is transportable from clinic or school to the home. Project staff are looking carefully at development issues inherent to providing children with early mobility during mobilty camps and in schools. Preliminary observations? Children are:

- vocalizing more
- initiating interactions with toys around room.
- manipulating things from this device. Both hands are free and they can get close to tables, counters, etc.

Hopes are for the TPMA to become a commercially available product. Among other products developed at Stanford are three in the area of AC:

- *Step-by-Step* (Software to introduce beginning scanning);
- *Communication Interaction Software Series* (Software)
- *The Preschool AAC Checklist* and *Getting ready for ABC's with AAC*." A manual and videotape. Well-designed, practical tools by Judy Henderson.

For information write, REC, Children's Hosptial at Stanford, 520 Sand Hill Road, Palo Alto, CA 94304. FAX (415) 497-8153

2. *Technology Transfer.* Paul Mortola, Jean Kohn, and Maurice LeBlanc conducted a client follow-up and consumer satisfaction with technology study focusing on orthopedic seating systems (OSS). Specifically, clients compared their old and new OSS after 12 months of use. Subjects were able to sit erect, for longer periods, more comfortably. Also clients (96%) were pleased with the appearance and safety of their new systems. Project staff feel the importance of follow-up includes improving the quality of life of clients served as well as:

- verifying device performance in relation to objectives
- documenting client satisfaction
- solving performance problems
- evaluating clinician and facility performance
- preparing for review for funding agencies; and
- iinforming manufacturers about mechanical failures, redesign needs and unmet needs.

Note: This study was part of the Technology Transfer REC awarded to Los Amigos Research and Education Institute Inc. with a subcontract to the Stanford REC. Funding is from NIDRR.

Governmental

Perspective from Eastern Europe: Patients on trachs or ventilators

Recently Carolyn Watkins was part of a professional delegation to Eastern Europe and Russia (Prague, Budapest, Moscow and St. Petersburg). The delegates, with expertise in brain injury and rehabilitation, shared information and assessed the treatment of individuals with brain and/or spinal cord injuries in rehabilitation facilities (polyclinics), acute care facilities (traumatological clinics), pediatric hospitals, psychiatric facilities, medical schools, research institutes and long term care facilities. Her thoughtful observations below highlight problems and needs related to patients using ventilators and tracheostomies.

1. **Emergency care.** Restricted to emergency units in local hospitals, it is feasible that a patient could be deprived of oxygen and other life support needs until arrival at the facility. For example, there is only one emergency ambulance service in Prague, a city of 1.5 million people. The trauma center concept has not developed although medical personnel understand the need. Money, facilities, and trained personnel, as well as a lack of governmental support to date, prohibit this.
2. **Management of patients.** There is an increased number of patients on mechanical ventilation but a lack of pulmonology, otolaryngology and respiratory team members. Metal trachs are still used because they can be used long term and can be sterilized. "Disposable" tubes are reused through cold sterilization techniques, which increases dramatically the risk of infection. People die because of secondary factors related to their injuries, such as respiratory complications and infections.
3. **Communication options.** Functional gestures and signs tend to be the only means of communication for patients with a tracheostomy or ventilator. These patients frequently return home, often to manage the best they can. Some return to work or school but many are unable to continue any productive life.
4. **Medical equipment and expertise.** I was able to participate in neurosurgery in the operating theatre and obtain a first hand view of equipment and procedures. Some have some excellent modern equipment (e.g., mechanical ventilators, surgical tools, and monitoring equipment). These are combined with equipment that would be considered old and outdated in the West. However, the expertise of the medical and rehabilitation teams, given equipment and supplies limitations is remarkable.
5. **Funding for rehabilitation.** This is a new and nagging problem. But, the Cortex Foundation in Budapest is collecting funds and grants to build a rehabilitation hospital for pediatrics and adults in Budapest.
6. **Access to information.** Scholarly journals and "trade" magazines are very limited. Printed information with translations is difficult to obtain.

She concludes, "the level of professional exchange was stimulating and insightful. The important point to note is that these areas of medicine and rehabilitation are being addressed through the best means possible, under conditions that many would find difficult, by professionals with whom any of us would be proud to work side by side, and with a limited amount of equipment and printed resources."

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RESOURCES

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Thanks also to David Beukelman, Sidney Hook, Ces Manno, and Lisa Fornataro

Addresses for some equipment manufacturers

TALKING TRACHS

Portex, Inc., 42 Industrial Way, Wilmington, MA 01887 (800) 258-5361

Communi-trach, Implant Technology, 7800 Metro Parkway, Minneapolis, MN 55420. (800) 328-0925.

Bivona, Inc., 5700 West 23rd Avenue, Gary, IN 46406. (800) 348-6064.

ELECTROLARYNGES

Romet, Inc., Hawaii Kai Corporate Plaza, 6600 Kalanianeole #221, Honolulu, HI (808) 396-2855.

Cooper Rand oral type electrolarynx with remote switch, Luminaud, Inc., 8688 Tyler Blvd, Mentor, OH 44060

VALVES

Olympic Trach Talk, Olympic Medical Corp., 4400 Seventh South, Seattle, WA 98108 (800) 426-0353.

Passy-Muir Tracheostomy Speaking Valve, Passy & Passy, Inc., 4521 Campus Drive, Suite 273, Irvine, CA 92715 (714) 856-2634.

Montgomery Speaking Valve, Boston Medical Products, 87 Rumford Avenue, Waltham, MA 02154, (800) 433-2674.

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