ALTERNATIVELY SPEAKING

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IN THE SPOTLIGHT

Choking & AAC

This spotlight focuses on an unpleasant topic that tends to get set aside until a colleague, friend or neighbor who uses augmentative and alternative communication (AAC) dies from choking or aspiration pneumonia. Recently, two more tragically unnecessary deaths launched a discussion on the AAC listserv, ACOLUG,[1] which provides the foundation for this issue of *Alternatively Speaking*.

Let's be perfectly clear. I believe individuals with complex communication needs should take responsibility for their own lives to the extent they can. The accompanying article, "Individuals Take Charge," is in that spirit. However, when a problem repeatedly occurs to individuals within a group, it is no longer about each individual's unique personal situation; this is evidence of a need for systems change. Let's take charge of our own lives as we work together for change.

Training

ACOLUGers discussed how training people who assist with eating can decrease the chance of choking or aspirating on food. Many points of view were presented. Some ACOLUGers feel individuals should take responsibility for training anyone who may be involved in their care.

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Others feel there is an institutional responsibility to train their workers. "We were wondering if what is really needed is a lot stronger state monitoring—similar to what nursing homes go through. …Maybe it needs to be regulated more strongly."[2]

More regulation might increase safety but it also would decrease the control individuals have over who assists them with eating. This presents a double-edged sword: needing help from someone who may be inadequately trained versus having to comply with institutionalized restrictions about who is adequately trained to do a job. Individuals who rely on AAC must participate in social policy decisions about these issues.

Experience counts

Another example of the importance of real-life experience in social policy is feeding tubes. While a feeding tube is quite easy to use, it is a medical device and some governmental and institutional entities demand that only medically trained persons or immediate family members manage the feeding tube. Some

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Message from the editor

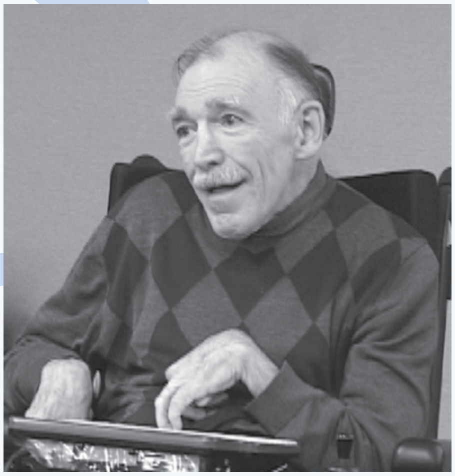
This issue of *Alternatively Speaking* is a call for action. It was prompted by the death of a young augmented communicator in my hometown. She choked to death while eating dinner. Even though I live a few blocks from her apartment, I learned of this on ACOLUG, an AAC listserv.

In the days following this tragic incident, we used ACOLUG as a sounding board for our sadness, anger and fear. Over the course of a week our emotions morphed into a serious discussion of what we can do to lower the chances of choking while we go about the daily business of living. The pages that follow attempt to summarize, synthesize and amplify these discussions while offering suggestions on how to reduce the risk of choking.

I've had some choking incidents during my life; none of them have been fun. When I look back at the events immediately preceding these incidents, I realize I often was doing something foolhardy or stupid at the time, like shoving more food in my mouth in the hope that it would dislodge the food that was already stuck in my throat. I assure you that's a theory worthy of the great scientific team of Curly, Larry and Moe—the Three Stooges.

Taking personal responsibility for mealtime safety is only a small part of this complex puzzle. We must enlist researchers, governmental agencies, AAC clinicians and independent living groups to join us in this battle. You can read more about this in the article "Working Together for Change."

I realize reading about the issue of choking may make some of you uncomfortable. I remind you that knowledge is power and knowledge about choking may save a life.



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personal care assistants (PCAs) are not allowed by their agencies to help with feeding tubes. According to Colin Portnuff, "Personal care assistants should be trained in using feeding tubes. I cannot stress this enough—it is a straightforward and simple matter. If they can put food into your stomach through your mouth, they can put food into your stomach through a PEG tube."[3] These feeding tube policies can lead to unwanted and unneeded placement in a nursing home. On ACOLUG, for example, Claire Rosenbaum shared her frustration with Rhode Island's regulations. "I was just working this morning to help plan a full life for a young lady who has a feeding tube and was confronted with the bureaucratic restriction of her always needing a nurse available to do her feedings. … This young lady's life (and others like her) will be severely limited if she must always have access to a nurse when she has to eat."[4]

Feeding tubes do not require a nurse; bad public policy does. Living with a disability always requires balancing freedom and safety, but having to give up independent living in order to eat is a Hobson's choice.

Mealtime reviews

There is now a field of practice in speech-language pathology called "mealtime management." The emphasis of this practice is institutional—to assure the administrators and owners of hospitals, schools, day programs and living facilities that they are doing everything they can to make mealtimes at their facility safe. While the effort to run a safe program is commendable, it is worrisome that the point of view of the individual client may not be the primary concern. What is best for the program may not be what any one individual needs or desires. Additionally, most mealtime management specialists are not familiar with people who use AAC and may make unwarranted assumptions about functional abilities. “There are many people with CP who have a dreadful looking swallow but who never aspirate so a good health history is important.”[5] A complete, accurate, regularly updated health history can serve as a personal norm for individuals who eat or swallow in nonstandard ways and can highlight any changes over time.

Aging and CP

An individual who has cerebral palsy and complex communica-

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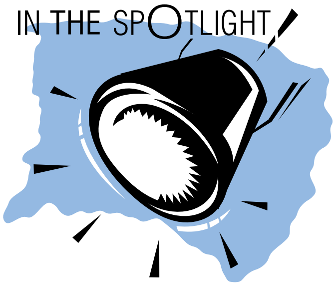

Fast Facts

Let’s define our terms. The entries on choking and aspiration pneumonia in Wikipedia and Answers.com explain the mechanics of swallowing and choking.[7] Choking occurs when food or liquid blocks the airway to the lungs, making breathing difficult. Food and liquid can get into the airway because the top part of the airway, called the pharynx, has the dual functions of transporting air to the lungs and food to the stomach.

Air enters the nose and/or mouth and goes through the pharynx to the larynx (voicebox). The larynx is made of cartilage and muscle and has folds known as the vocal chords. Air then travels down the trachea or windpipe, a tube of cartilage and soft tissue, and into the lungs.

Food, on the other hand, goes from the mouth through the pharynx to the esophagus. Muscles on the wall of the esophagus contract to propel food down to the stomach.

When everything goes right, food and liquids go directly down the esophagus and into the stomach. A lid-like flap in the voicebox called the epiglottis automatically folds down to cover the path to the windpipe and protect the airway during swallowing.

Hang-ups

There are a few potential problems: 1) Both food and air go through the pharynx; 2) The epiglottis has to close before any swallowed food or liquid gets there; 3) The epiglottis must close completely; and 4) Muscles in the mouth, throat, pharynx and esophagus need to coordinate in successful swallowing. It’s easy to see how choking could occur, especially for someone who doesn’t have good control of the physical structures involved in speaking since many of the muscles involved in speech are also involved in breathing and swallowing.

Aspiration pneumonia occurs when food or liquid (including saliva and vomit) enters the lungs causing an infection. It is sometimes called bronchopneumonia. According to Wikipedia “Whether aspiration pneumonia represents a true bacterial infection or a chemical, inflammatory process remains the subject of significant controversy.”[8] Whatever it is, it can be life threatening if not detected and treated.

An alternative

Choking signals the immediate problem of a blocked airway and the potential subsequent problem of an infection from aspirated food or liquid. Some individuals who have a lot of trouble swallowing decide not to rely on eating by mouth for their nutrition and choose instead to take nutrition via a feeding tube. A percutaneous endoscopic gastrostomy (PEG) tube is surgically placed through the abdomen and into the stomach, so nutrition and water can go through the tube directly into the stomach. This reduces the chance of choking and aspirating. Colin Portnuff is writing a Q&A user guide for the individual who is thinking about using a PEG tube.[9]

Friends and Relations

Individuals Take Charge

What can you do to lower your risk of choking or aspirating food and to increase your chances of receiving immediate and appropriate help should choking occur?

Here are examples of practical actions people on ACOLUG[10] reported taking to increase their personal mealtime safety.

Pay attention

It is easy to let your attention wander during meals, but someone has to be focused on what your body is doing while you eat, and that someone is you! It's a false economy to try to accomplish other tasks between bites and potentially dangerous to 'zone out'. Also, if you focus on eating, then the people around you are more likely to be attentive, too.

Be selective and creative in choosing food. Sharon King says, "I pick and choose foods that I can eat. A few foods, such as raw fruits and vegetables, I have processed. I love raw carrot and apple salad, finely chopped cole slaw."[11] Anne Whitehead, a personal care assistant (PCA), says she checks processed food for lumps, makes sure spoonfuls aren't too large and offers enough liquids "so everything goes down smoothly."[12]

Slow down. It is tempting to rush through meals, especially if someone else is feeding you. Taking the time to eat attentively now may give you more time in the future.

Know where you are. Everyone around you should be able to give emergency response dispatchers the phone number, address and cross street where you are at school, work and home.

Post info

Post emergency numbers near eating areas. Post emergency numbers near telephones. Ask cell phone users to store emergency numbers in their phones.

Put up posters, instructions or action cards explaining first aid for choking. Mick Joyce suggests "the best thing to do is to print up 'First Aid for Choking'[13] and post it where you eat."[14] Anne Whitehead adds, "We recently posted a (long) list of written instructions in the kitchen, next to the table. We also have an action card on how to do the Heimlich Maneuver and CPR, and a first aid book by the phone."[15]

Instruct

Do not assume service providers, cafeteria workers or PCAs know what to do. Make sure anyone who assists you in eating or eats with you is trained to deal with choking. Practice the procedures until you are sure they know what they are doing. As Mick Joyce states, "Go over it with your workers. I do not believe you can expect personal care agencies to teach it. We need to take charge."[16] Melinda Smith says she trains "anyone who works with me, including attendants, colleagues and also my friends what they should do."[17] Anne Whitehead says, "In a choking emergency, someone (everyone) has to be trained to respond immediately. 911 can't get there fast enough to save someone."[18] Joel Smith adds, "Everyone should know how to deal with choking—It is not difficult, and is easily learned."[19]

Be prepared

Develop a personal mealtime safety plan:[20] 1) Know what to eat, what not to eat and what to eat extra attentively. 2) Know safe ways others can assist with your eating and how to avoid unsafe ways. 3) Know what positioning, postures and tools make eating easier, safer or harder. 4) Adapt your strategies to compensate for fatigue, illness, excitement and challenging environments such as extreme heat, cold, or noise. 5) Know what to do if choking occurs. 6) Know what others should do if choking occurs. 7) Plan how to instruct others about your personal mealtime safety and instruct them.

Additionally, do some long-term planning to be able to recognize the changes of aging. A trusted speech-language pathologist can help an individual review his or her mealtimes on a regular basis. This process, if done consistently over time, may identify subtle changes in your ability to handle certain foods and liquids and changes in swallowing that could lead to choking.[21]

Working Together for Change

Calling for systems change in AAC makes me very uncomfortable because, unfortunately, in this field social policy decisions are usually made by medical and education professionals without the input of individuals with complex communication needs (CCN). Even if people who rely on AAC take part in the discussion, they don't speak with one voice since people who rely on AAC are individuals with a diversity of needs and priorities. Some individuals want to be kept safe; others weigh the value of freedom versus safety, privacy versus assistance, success versus risk and independence versus care. Tough choices are the daily bread for people like me.

That said, I challenge the international AAC community to work together to begin to address the problem of choking and aspiration pneumonia in individuals with CCN. Everyone needs to know more about the problems related to choking and aspiration for individuals with CCN over the age span, what they can do to prevent choking and aspiration pneumonia, what they can do to be ready to act when choking occurs, and how to recognize changes that increase the risk of an individual choking and aspirating. To quote Colin Portnuff, "Knowledge is power, and you need all you can get."[21] We all must work together to gain more knowledge in this critical area. Researchers, clinicians, educators, policy makers, family members and individuals with CCN: It's time to step up and take action.

Educate and train

- Educate individuals with complex communication needs (CCN) and their families about the steps they can take to safely manage their own mealtime safety.
- Inform the medical community of these challenges and the variety of solutions.
- Develop convenient, low-cost first aid training.
- Find organizations that are willing to put out the word on a regular basis about risks, prevention, management, first aid.

Research

- Collate evidence that documents anecdotal reports of death from choking or aspiration pneumonia in individuals with CCN.
- Identify signs of changes in swallowing function that occur with age.
- Determine, prioritize and conduct research to increase understanding and decrease incidents of choking and aspirating in individuals with CCN.
- Describe the components of a mealtime safety plan that individuals with CCN can implement for personal mealtime safety.

Create public policy

- Set standards for the training of employees who assist in feeding individuals outside the home.
- Develop community supports for home use of feeding tubes by active people.
- Insure agencies report all deaths from choking and aspiration.
- Develop funding streams for PCAs to get paid while training their replacements.
- Redefine use of a feeding tube as 'eating' rather than as a 'medical procedure.'
- Develop procedures and funding for regular individual mealtime reviews.

RAVES & REVIEWS

An Unfortunate Event

by Michael B. Williams

It's like this: I'm at my sister-in-law's birthday party, and everybody is enjoying the traditional celebratory meal of tacos. Now I don't usually eat tacos. It's not because I'm prejudiced against Mexican food. On the contrary, I think burritos are heavenly and enchiladas verde devine.

However, I find tacos a bit of a challenge. Well-made tacos have that crunchy shell that demands a certain delicacy of bite from the person eating them. Taco shells take one look at my powerful CP jaws and know they'll shatter upon contact with my teeth, dispersing a misty spray of semi-solid taco bits several feet in all directions.

Then there are the ingredients that go in a taco shell—meat and bean glop, grated cheese, shredded lettuce, tomato bits, along with various exotic spices from Mexico. Taken individually, these ingredients pose little problem to my mealtime tranquility. Combined together, however, they represent a potential disaster on a plate.

So here I am at this birthday party where tacos are the order of the day. Not wanting to cause a big fuss, I decide to treat this problematic meal as a salad. I throw some taco ingredients into a bowl and crush a taco shell on top. I grab a spoon and go to work on the mess. This should work, I say to myself.

And it does—for a while.

All of a sudden, I can feel a good-sized taco bit sliding down my throat the wrong way. The wheels in my brain start to turn and produce the thought, please let it go down all the way, I don't want to cause a big fuss and ruin the party.

But of course it doesn't go down all the way. The damn morsel takes up residence in the narrowest regions of my throat and refuses to budge, no matter how many eviction orders I give.

The people at the table are murmuring amongst themselves and looking at me quizzically. Now and then I sporadically hear words and phrases being uttered.

"Choking?"

"Need help?"

"Choking!"

"Slap his back!"

I feel several hard whacks on my back, but the devil morsel isn't moving. I feel my brother-in-law standing behind me. I see his arms go around me; watch his fingers lock in position over my stomach. I feel his arms pull up on my ribs. Is he trying to squeeze the last molecule of air out of me? His arms tighten and pull up again and again I think I'm running out of air. But something else is happening, too. That evil morsel of food in my throat is coming up and out of my mouth along with a big glob of mucous that goes splat as it hits the side of my bowl.

"I sure know how to ruin a party," I say to the group.

Then I compose a memo to myself. Taking its inspiration from Scarlett O'Hara's exit line in *Gone With the Wind*, it says: "I'll never eat tacos again."

ACOLUG: AAC Online

by Mick Joyce

Humans by nature are social creatures. We communicate and interact with each other constantly—exchanging information and entertaining each other, talking about the weather, politics and the hot chick down the block. People share experiences, ideas and opinions.

When I want to talk about living with a communication disability, I look for someone who has the firsthand knowledge of a consumer, or a knowledgeable AAC professional who can really cut away from the textbook lesson and move into the realm of reality. This kind of knowledge is hard to find in my city. Rather than heading out the front door in search of this community, I am more likely to fire up my Internet connection.

Virtual community

Technology can connect people in real-time ways. A listserv, or electronic mailing list, is a list of email addresses, managed by a computerized mailing program that forwards email messages to individuals in a group. Generally, a mailing list is used to discuss a certain set of topics, such as AAC. Members of the group write email messages to the list for all other members to see. The responses can be lively and informative, and questions are answered quickly.

For individuals who rely on a speech generating device (SGD), there is ACOLUG,[1] the Augmentative Communication Online Users Group, an outreach project of the Rehabilitation Engineering Research Center on Communication Enhancement (AAC-RERC). This project is led by AAC-RERC partner Diane Nelson Bryen at Temple University. More than six hundred ACOLUG members of all ages from a dozen countries discuss a wide variety of topics related to AAC.

ACOLUG provides a forum for consumer-to-consumer discussion as well as consumers-to-professionals and consumers-to-researchers. ACOLUG members can drive research, public policy and community action in a positive way. An active listserv, such as ACOLUG, helps promote a healthy community, which sends a beacon of light far beyond its own neighborhood.

The fact that the Internet is accessible worldwide gives variety to the feedback one receives on ACOLUG. Members can be counted on for advice and support. Younger members look toward older, more experienced members as role models and mentors. This community changes the way individuals look at themselves and builds self-esteem and self-respect. ACOLUG is especially handy for sharing an experience with people who have been there.

Discussion topics

Just about all AAC subjects are discussed at one time or another. Discussions on devices from SGD repair policy to mounting systems to icon-based displays are frequent. Other device-related themes include speedier electric wheelchairs, joysticks and computer adaptation.

Possibly most important are the health-related discussions. For example, aspiration and choking by people with complex communication needs were recently covered. Topics like this come up in a free-flowing style that is less intimidating than other ways of exchanging information. Discussions such as these serve health promotion purposes and may even save lives as there are not many sources for this type of information.

Summary

ACOLUG serves as a vital information link. It keeps consumers in touch, professionals involved, and researchers down to earth, close to consumer needs. This electronic mailing list is a way for consumers to drive research, policy and community action as well as to take charge of their quality of life. If you're not a member of ACOLUG and need a community and some good practical advice, consider joining the six hundred members including me. You might find it a pleasant experience. I know I do.

AAC-RERC
SPREAD THE WORD

To learn more about the AAC-RERC and to monitor the projects, visit http://www.aac-rerc.com

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Thanks to my brother-in-law for learning how to do the Heimlich maneuver.

Thanks to Gail Gordon for showing people who rely on AAC how to “be in their bodies.”

Thanks to Colin Portnuff for teaching me how to talk about feeding tubes.

Thanks to ACOLUGers for sharing what they do to eat more safely and how they prepare for when choking occurs.

Thanks to guest author Mick Joyce.

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tion needs is not surprised when eating temporarily becomes more difficult because of short-term changes such as fatigue, excitement or illness. It is expected that the nervous system will be quick to react and slow to adapt to change and resistant to regaining equilibrium; however, there is anecdotal evidence that a significant change in swallowing occurs with aging. Howard Shane at Children’s Hospital Boston summarizes, “Remember CP is considered a non-progressive disorder, yet there is no doubt in my mind that there is a change in swallow patterns over time and this leads to aspiration pneumonia (Our team has noted frequent occurrences.) or worse, a full-blown choking incident.”[6]

We must address this risk with education, training, research and social policy. It will take the best people putting forth their best efforts to unravel this complex issue, and the time to start is now.