

# POLIO NETWORK NEWS

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## Sixth International Post-Polio and Independent Living Conference

### NEW SWALLOWING PROBLEMS IN AGING POLIO SURVIVORS

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In the normal swallowing process, three phases are typically described. The oral phase involves food being placed in the mouth, chewed if necessary, and positioned or formed into a ball (bolus) which is then moved backwards to the anterior faucial arch, an area near where the tonsils are, or used to be, and where the swallow response is triggered. During the pharyngeal phase, three things happen simultaneously. The tongue pumps the bolus back into the pharynx, the epiglottis, (a chunk of cartilage near the base of the tongue), slams down on top of the airway, the larynx (voice box) elevates slightly, and the vocal chords close. These activities prevent aspiration (food or liquid from entering the airways). If the synchrony of any of these is disturbed in any way, significant problems can occur. At the same time, the third and final phase of swallowing is occurring, a coordinated muscular activity which transports the bolus through the throat where a small sphincter (muscle) at the top of the esophagus called the cricopharyngeus relaxes (dilates) so that the bolus can enter the esophagus and eventually the stomach.

In 1988, three individuals triggered my interest in swallowing problems of post-polio individuals. They had a mean age of about 53 and were between 30 and 60 years post-onset. All complained of coughing and the sensation of food sticking in their throats. Examination found that some had reduced strength in oral musculature, some had problems with pharyngeal transit, and others had a delayed swallow response. Although there was no aspiration, all three were judged to be at risk. In 1991, a project I was involved with sent out a questionnaire to post-polio individuals. Twenty-nine of the 109 respondents reported periodic or consistent problems with their swallowing. Of 21 studied, 20 had some type of swallowing dysfunction, some with multiple problems. Nine had problems with bolus control or weakness of the musculature, four had a delayed swallow response, and 17 had problems with pharyngeal transit. While none aspirated, two were judged to be at significant risk.

#### PROBLEMS WITH SWALLOWING REPORTED IN THE LITERATURE ...

In 1991, a study published in *The New England Journal of Medicine* was conducted by Barbara C. Sonies, PhD, and Marinos C. Dalakas, MD. They followed 32 individuals. Only 14 of the 32 reported swallowing problems, but when examined 31 had objective signs of difficulty with swallowing. Problems were found during the pharyngeal phase, with pooling in the valleculae, the V-shaped space formed by the base of the tongue and the epiglottis. Two individuals with pooling aspirated.

Another paper published in 1991 by Alice Silbergleit, MA, et al, studied 20 post-polio individuals with a mean age of 49, 17 to 66 years post-onset of acute polio. Of these, 75% percent were noted to have reduced pharyngeal transit and pooling. Some also reported problems with esophageal motility and weakness of the oral musculature. Two individuals aspirated.

#### INTERACTION BETWEEN BREATHING AND SWALLOWING ...

Breathing and swallowing are reciprocal functions. When swallowing occurs, breathing halts. Seventeen of the 20 individuals in our study who had swallowing problems also had significant problems with decreased breathing capacity. There were some individuals with minimal swallowing problems, while others with very significant problems. Both groups also had moderate or severely reduced breathing capacities. It can be concluded that, although breathing problems can complicate or hinder swallowing, one cannot be predicted from the other. Significant breathing problems will not necessarily predict swallowing problems.

Currently, we are studying seven of the 15 of the original group of 21. We did a breathing assessment, a swallowing evaluation, and a vocal assessment because we are now looking at problems with voice. We measured strength and function of the oral musculature, ran a modified barium swallow, conducted pulmonary function testing, and voice testing.

continued on page 2

Of six individuals who demonstrated swallowing problems during the initial assessment, three demonstrated an increase in the severity of their swallowing problems, and three remained essentially unchanged. Generally speaking, those individuals who were most severely involved from the initial assessment were the individuals who demonstrated the most significant progression. Again, there was no aspiration, but the two who had been at risk previously, were judged to have increased risk. All five of the individuals who had significant breathing problems earlier had their breathing capacity diminished over the four year period.

### **DIAGNOSIS ...**

The modified barium swallow procedure is absolutely critical, not only for diagnosis, but also for focusing on the management of swallowing problems. It defines the physiology of the swallow. In addition to the standard modified barium swallow (MBS) procedure, we added what we call stress testing. Just because an individual goes through the standard MBS procedure and does not have difficulty does not mean that over the course of a normal meal they will not experience difficulties. In the stress testing, we increase the quantity of liquids, purées or solids for swallowing, and attempt to tax the swallowing system. We have also tested people after a full meal when there might be some fatigue, or we bring them in after a normal workday when there might be a fatigue factor as well.

### **MANAGEMENT ...**

Compensatory positioning or relatively minor adjustments in posture during swallowing can significantly affect the swallow. Basic changes, such as dropping the chin or turning the head can help, the rationale being that many times the weakness in the pharynx is unilateral (on one side) and that by turning the head, the weakened side of the pharynx is shut off, forcing the bolus to go down the more intact, stronger side. Other management suggestions include dietary modifications and avoiding meals when fatigued. Longitudinal monitoring of swallowing problems, including pulmonary function testing is recommended. □

## **ADDITIONAL INSIGHTS**

*LARYNGEAL FUNCTION IN POST-POLIO PATIENTS by Brian P. Driscoll, MD and Carol Gracco, PhD (Yale School of Medicine), Carl Coelho, PhD, et al, was presented at the Eastern Section meeting of the Triological Society, Ottawa, Ontario, Canada, January 1994.*

Their conclusions include ... "each of the nine subjects in this group demonstrated some form of voice deficit. In the case of reduced or weakened glottic closure, voice treatments alone, or in combination with surgical intervention such as thyroplasty to improve closure seems highly appropriate. In many cases, neither the diagnostic examination or rehabilitation had been suggested during the 20-year course post-polio even in the face of overt symptomology."

**DR. COELHO** referred to studies conducted by Barbara C. Sonies, PhD, Chief of Speech Language Pathology, and Marinos C. Dalakas, MD, Neurologist, at National Institute of Neurological Disorders and Stroke (NINDS) at the National Institutes of Health. Dr. Sonies contributed Chapter 8, *LONG-TERM EFFECTS OF POST-POLIO ON ORAL-MOTOR AND SWALLOWING FUNCTION in POST-POLIO SYNDROME*, edited by Lauro S. Halstead, MD, and Gunnar Grimby, PhD.

*The additional insights below are extracted from Dr. Sonies' chapter.*

It appears that some individuals have speaking or swallowing problems of which they are unaware and which slowly emerge in the same manner as has been seen with limb muscles. This progression of symptoms in limb muscles may cause new disabilities. However, swallowing problems, and associated complications such as aspiration pneumonia, can be life-threatening.

Many, but not all, individuals with swallowing problems report having had acute bulbar polio. It appears that the more severe the original condition the greater the likelihood of new problems. In their study of 32 individuals, 31 had some difficulty with swallowing, even though only 14 reported being aware of symptoms. It should be noted that the severity of the swallowing problems found in the individuals reporting problems were significantly greater than those who did not. Normal aging does not cause changes in speech and swallowing, so any new signs of problems most likely are due to neuromuscular changes.

Common complaints reported by post-polio individuals included: intermittent choking on food, pills sticking in the throat, difficulty swallowing pills, food sticking in the throat, coughing during meals, and difficulty swallowing.

Individuals with suspected swallowing problems should seek an evaluation from a speech pathologist with expertise in dysphagia (swallowing). This evaluation will include a thorough history of eating, a clinical examination of swallowing, and a videofluorographic examination of the oral and pharyngeal swallow. Persons with complaints of indigestion may need evaluation of the esophagus — which can be done during the modified barium swallow study.

None of the individuals in the follow-up study at NINDS aspirated. Credit for improvement is given to the cooperation between therapists who developed the treatment plans and polio survivors who carried out suggested strategies.



**MARYLOU BREWER, RN**, *Director, Training and Information Dissemination, NIDRR Research and Training Center, Rehabilitation in Neuromuscular Diseases, Department of Physical Medicine and Rehabilitation, University of California, Davis, California 95616-8655 describes their current swallowing research project directed by E.R. Johnson, MD.*

The goals are:

1. To evaluate swallowing disorders in neuromuscular disease;
2. To develop and validate quantitative measurements of pharyngeal transit time using new techniques;
3. To determine the effect of bolus consistency, temperature, and head position on swallowing and kinematic pharyngeal transit times;
4. To develop and validate specific remedial rehabilitation techniques for individuals with neuromuscular disease. Data are still being selected and analyzed. Results are not yet available.

Nancy Seyden, from the above Rehabilitation and Neuromuscular Diseases Research and Training Center, reports that she received more than 500 requests to receive her Quality of Life Survey described in *Polio Network News* (Vol. 11, No. 2). Readers who volunteered to complete the survey will be receiving the comprehensive survey soon. Nancy was very pleased with the number of responses and encourages all who requested the survey to complete and return it. She is very interested in compiling the responses from the post-polio community.



**In *POLIO NETWORK NEWS***, (Vol. 6, No. 4), in the article, "A Review of Swallowing Difficulties in Post-Polio Individuals," Roberta Simon, RN, offered these common-sense suggestions:

Chew slowly. Cook all foods until they are soft. Do not talk while eating. It can increase the risk of aspiration.

Avoid large bites and big gulps of liquid. Liquids are, at sometimes, managed better if the chin is tucked down to delay the swallow.

To control choking on saliva, avoid foods that thicken secretions, such as milk and milk products. Discuss calcium supplements with your physician if you do limit milk products. To control choking, eat in an upright position at all times.

Do not eat when fatigued. Consider eating several small meals each day. Combining different textured food makes eating and swallowing easier for some. Place a sauce or gravy on a dry, difficult-to-swallow food such as meat.

If liquids are a problem, thicken them with commercial starches or preparations to facilitate swallowing. Liquid soups are not recommended for individuals with tongue weakness. Cream soups are better tolerated as are juices with a thicker consistency such as nectars and tomato juice.

If taking medication is a problem, applesauce or jelly may help, and so may drinking water through a straw to get the medication to the back of the throat. It is a dangerous practice to elevate your chin to get the medication to the back of your throat. Raising your chin causes the vallecular space to disappear and swallowed material may drop directly into the airway. Avoid this practice.

Esophageal problems can be managed by eating in an upright position. Drinking a glass of water after eating helps in clearing the contents of the esophagus into the stomach. If a stricture is found during an esophageal evaluation, dilation may be needed.

If weakness is present on only one side of the throat, turning the head to the opposite side while swallowing is, at times, helpful.

Weight loss may be a problem and a high protein or high calorie liquid substitute is advised. Seek your physician's assistance so your nutritional intake may be monitored.

Surgical intervention is the extreme end of treatment for these difficulties. Care must be taken in any corrective surgical procedure because of the weak, underlying muscles.

Vocal cord weakness can be a problem for some and speech therapy is helpful in providing compensatory techniques. A small microphone to amplify the voice can be prescribed. Fatigue seems to play a role in vocal cord weakness.



continued on page 4

**JUNE PRICE**, editor of *LIVING SMART*, a newsletter for individuals living with spinal muscular atrophy, and Nicole Roberts, suggest the following from their personal experiences on ways individuals with swallowing problems can better cope with eating out.

Be honest with hosts ahead of time about your problem/needs. Tell people what you can and cannot eat. Sometimes it may be better to be up front and say no to their desire to feed you.

A solution at restaurants is simply to eat ahead of time, or after. Drink a protein shake before going to a friend's house and then nibble.

At restaurants, instead of a large meal, order an appetizer to be served with the dinner course. Salad bars are usually filled with soft peas, beans, cottage cheese, tomatoes, soups, sauces, puddings, as well as the hard-to-eat lettuce and crunchy, raw vegetables. Potato bars offer cream sauces and finely minced meat and vegetables.

Do not be afraid to ask for substitutions, or a reduced volume of food (so you do not have to stare at a huge plate of uneaten food). Make up your own meal. If all you want is a baked potato and applesauce, ask for it.

For more information about Living SMART or a complimentary issue, contact June Price, 3576 South 43rd Street, #32, Milwaukee, WI 53220-1550 (414/541-2848 voice and FAX; LivngSMART@aol.com).

## SHARING EXPERIENCES

*I am honored to tell my mother's story and have used her own words from letters and other documents as much as possible.*

My mother, Bernice Alexander, New Jersey, had bulbar polio in 1948 at the age of 21. She was hospitalized for four months. Polio atrophied her vocal cords and her voice changed radically to a monotone. Atrophied neck muscles made swallowing and breathing difficult. At the most critical acute stage, due to the inability to swallow, she "drowned" from fluid in her lungs. She was brought back to life but had various problems with swallowing for the next 45 years. Reeducation was directed at swallowing, speech, and trying to turn and hold her head up. Physiotherapy focused on use of all her muscles: arms, legs, posture, etc. She learned to "balance" her head with the use of substitute muscles, primarily her hands.

The left side of her throat was worse than the right. She would chew her food VERY thoroughly, in small

bites, before attempting to swallow on the right side of her throat. Choking was not uncommon. These bouts of choking took quite a long time to subside due to the breathing difficulties. She would often use small pieces of bread or warm water to help dislodge whatever was stuck.

There were various stages of swallowing problems experienced due to post-polio syndrome. She started to avoid foods including tomatoes and other fruits and vegetables with seeds as well as most red meat. She preferred to eat custard, yogurt, chicken, and bananas.

After double pneumonia in 1989, she never seemed to regain full strength. She would be short of breath when walking and did not sleep well. After a New Jersey post-polio conference in 1990, she consulted a specialist in polio breathing problems who prescribed breathing support by using a Bi-PAP® machine while she slept. She used this for over six months and experienced better sleep and heightened mental alertness. However, the daily shortness of breath remained.

During the week of October 15, 1991, she had a minor head cold. Her voice was getting weaker but she did not realize it. On October 18th, her throat started to get sore, and by the next day, it was very sore. This was not the sort of sore throat associated with a respiratory infection. It was becoming more difficult for her to speak as the day progressed, due to the tightness in her throat and chest.

She was rushed to the hospital that evening. Her larynx and vocal chords were paralyzed. There was a lot of swelling so very little air could move through her trachea. Mom also had a low platelet count. Hematology support was required to raise the platelet level before a tracheostomy could be performed to allow her to breathe. After the tracheostomy, mom used a nebulizer at night instead of the Bi-PAP® machine.

Mom was very focused on obtaining more information on post-polio problems and participated in a study in January 1993, at Yale University by Dr. Carol Gracco and Dr. Carl Coelho. Food types of varying consistency were used and tested for her swallowing. The diagnosis read "pharyngeal transit was mildly decreased with minor pooling in the pyriform sinuses noted after each swallow. Subsequent dry swallows only partially cleared this status." The recommendation was to alternate liquid and solid swallows.

In a letter she sent to me, she said "I now have a different life living with a trach. The ambiguity of the situation is that my breathing, especially while sleeping is very much improved. The other side of the coin is the time and care involved in maintaining the trach. My low platelet count leaves me open to bleeding problems, and I have not been to work, a mall, or a movie since October. I wish I had understood my problems more clearly. When my breathing insufficiency was



diagnosed, I did not understand that the root cause was not any new involvement with my lungs or diaphragm, rather they were being affected on a secondary basis by the gradual weakening of my vocal chords and their inability to permit air to travel through them normally."

Mom passed away on July 23, 1993, of lung cancer. She was a courageous lady with a very full life — raised a family on her own, cared for a home, pursued a professional career, traveled, and was actively involved in her church.

If mom were alive today, she would recommend that whatever problems you may have with post-polio syndrome, be it swallowing, breathing, etc., do not get discouraged. Seek out additional physicians. Help them to find more answers and better equipment to solve, or at least ease, the problems. Reach out and help them to help you and others.

Kim Johnson, Arizona

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**Thank you for thinking of me. I hope my experience and suggestions are helpful.**

Let me encourage anyone with swallowing and aspiration problems, and fatigue to the point where it is impossible to meet nutritional needs through using the canned formulas, (including adequate water intake, medications, etc.), to get a gastrostomy tube, also called a "stomach peg." That is the route I chose in the summer of 1993, and I have never regretted it. The most important advantage is that I can control the fatigue of the swallowing muscles. Before the tube, the fatigue kept getting worse, and I was aspirating to the point of chronic bronchitis.

Another important advantage of my tube is that it solved my terrible anxiety about how I was going to eat and drink. My family, doctors, and even the nurses were amazed at all my anxiety. I was climbing the walls! It is amazing what you can get used to and even learn to love.

I can now take in some liquids and purees by mouth, but all my main nutrition goes in the tube. I eat no solid foods. Cool or cold water is difficult to control because it feels "slippery" in the mouth, so I take small sips of warm or hot water instead.

When my throat and mouth muscles are tired, all my liquids and formula go in the tube. I am not losing weight, am healthy, and lead a fairly normal life. Few people, except those I choose to tell, know. When I go to a restaurant, I order ice cream, which is easy for me to eat. I go to the pool for water exercising with no problem. My "balloon-type" tube needs to be replaced about every six months, which is an easy, pain-free procedure done in the physician's office.

Another issue that is very important to me is speech. My throat and mouth muscles become easily fatigued by too much speaking. I take a pad and pencil with me wherever I go and use it to help control the fatigue. This takes a lot of self-discipline ... I would rather talk!

I also recommend someone with speech problems to see a speech therapist affiliated with a hospital to learn new speech habits. A therapist has worked with me to change my voice pitch and breathing patterns while speaking. I am now learning sign language, which is a big undertaking, but lots of fun and very interesting. I know that using a small microphone can help but, I have not tried that ... yet.

Talking on the telephone seems to be the most fatiguing of all, so I have a TDD and use it when I am really fatigued. Other than that, I try to space my calls and keep them short.

Patricia Novak, Ohio