



## ALS Support Group of NWWI

A Gathering of Individuals Touched by ALS  
Share Joy, Sorrow, Laughter, Tears, and Hope.

Receiving a diagnosis of ALS is challenging and can be very overwhelming. The ALS support group provides a safe place where patients, families, & friends Gather to share information, support, and resources with others who understand.

**Our Next Meeting will be THURSDAY, 3/10/16.**

(Second Thursday of each month, 1:00pm – 3:00pm at Chippewa Valley Bible Church,  
531 E. South Ave. Chippewa Falls, WI 54729)

*~ February 2016 ~*

*Valentine's Day - A time to honor our loved ones.*

*This can be such a bitter-sweet time as many of us may have been facing challenges that prevented us from fully participating in this "love" holiday celebration or maybe our loved one is no longer here to celebrate alongside us. Wherever you found yourself this past February 14<sup>th</sup>, I want to remind you that you are loved and cherished and those special times shared can still be honored! Anytime, no matter the month, we can reflect on the joy and good memories we've shared with that special person. Maybe we take out old photos, love letters, or share stories with a trusted friend, neighbor, or family member. Wherever you are in your journey, may you be surrounded in the love and warmth of those dear to you!*

**12 participants Attended Support Group**

*Special guest, Bonnie Christensen, joined us to discuss an array of topics related to Acupuncture: traditional Chinese medicine therapy; Korean hand therapy for pain relief; emotional freedom; constipation dietary supplements.*

**Thank you Bonnie for sharing your time and talents with us!**

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*Take good care of each-other!*

*Deb Erickson, LPN  
ALS Outreach Assistant  
[www.alsnwwi.org](http://www.alsnwwi.org)*

**ALSNWWI Support Group is a non-profit organization that has been operating in the Chippewa Valley since 1992, serving over 9 counties. Services include: Monthly support group meetings; Outreach support service for home visits; Local resources & referrals, Educational materials; Financial assistance for items not covered under Medicare or private insurance; Community advocacy. **Annual Walk & Wheel-A-Thon is held the second Sunday in June at the Northern Wisconsin State Fairgrounds in Chippewa Falls – Save the Date, June 12, 2016!****

*Questions, concerns, or input please contact:  
Julie Chamberlain, LPN, 715.271.7257 or [alsnwwi@gmail.com](mailto:alsnwwi@gmail.com)*

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**Informative Articles & Info.**

**Laughter is the Best Medicine**

Today's Caregiver.com By Helen Hunter, ACSW,LSW  
February 4, 2016 • Issue #888

**When was the last time you had a really good laugh?**

The scientific definition of laughing is a “successive, rhythmic, spasmodic expiration with open glottis and vibration of the vocal cords, often accompanied by baring of the

teeth and facial expression”. That doesn’t begin to tell the story of what laughing does for us, however. The bottom line is that laughing is medically beneficial.

Laughter establishes or restores a positive emotional climate and a sense of connection between two people. In fact, some researchers believe that the major function of laughter is to bring people together – the more social a person is and the more social support a person receives, the more likely that laughter will result from that social connection. Mutual laughter and play are an essential component of strong, healthy relationships. By making a conscious effort to incorporate more humor and play into your daily interactions, you can improve the quality of your relationships.

### **What are the Physical Effects of Laughing?**

Laughing makes people feel good for a reason. Studies have shown that laughter boosts the immune system and triggers the release of pleasure-inducing neurochemicals in the brain. The immune system, which contains special cells that are responsible for defending the body against infection, have been shown to increase during the act of laughing. In the central nervous system, the brain releases powerful endorphins as a result of laughing. Endorphins are natural, morphine-like compounds that raise the pain threshold, produce sedation and induce euphoria (commonly called a “natural high”). In other words, we feel better when we laugh because endorphins reduce physical and mental pain. While this may be a wonderful feeling, laughing has other benefits as well:

During a laugh, respiration, heart rate and blood pressure temporarily rise. This causes oxygen to surge through the bloodstream that then results in lower blood pressure.

Laughter improves the function of blood vessels and increases blood flow, which can help protect against a heart attack and other cardiovascular problems.

Laughter reduces pain and allows toleration of discomfort.

Laughter reduces blood sugar levels, increasing glucose tolerance in diabetics and non-diabetics alike.

Laughter relaxes the whole body, relieving tension and stress. It has been shown that following a good, hearty laugh, muscles in the body are relaxed for up to 45 minutes afterward. Laughing burns calories – laughter is sometimes referred to as “inner jogging”. A hearty laugh gives the muscles of the face, chest, shoulders, stomach and diaphragm a good workout.

Laughter also helps to create a positive mood. It allows the expression of happiness and the release of anxiety. Humor eases tension and is a great antidote to a stressful situation. Laughter is often seen as a temporary vacation from everyday problems, bringing us to a paradise in which worries do not exist. Humor and laughter are natural safety valves that shut off certain hormones that are released during stressful situations. In fact, your sense of humor is one of the most powerful tools you have to make certain that your daily

mood and emotional state support good health.

Here are some ways to bring more humor and laughter into your life:

**Smile:** Smiling is the beginning of laughter. Like laughter, it's contagious. When you look at someone or see something even mildly pleasing, practice smiling!

**Count your blessings:** Literally make a list. The simple act of considering the good things in your life will distance you from negative thoughts that are a barrier to humor and laughter!

**When you hear laughter, move toward it:** People are very happy to share something funny because it gives them an opportunity to laugh again and feel the humor in it. When individuals hear laughter, they seek it out and ask "What's funny?"

**Spend time with fun, playful people:** These are people who laugh easily, both at themselves and at life's absurdities and who routinely find humor in everyday events. Their playful point of view and laughter are contagious!!

**Bring humor into conversations:** Ask people: What's the funniest thing that happened to you today? This week? In your life?

**Laugh at yourself:** Share your embarrassing moments.

**Attempt to laugh at situations rather than bemoan them:** Look for the humor in a bad situation, the irony and absurdity of life. This will help improve your mood and the mood of those around you.

**Surround yourself with reminders to lighten up:** Keep a toy on your desk or in your car. Put up a funny poster in your office. Choose a computer screensaver that makes you laugh. Frame photos of you and your family having fun.

**Keep things in perspective:** Many things are beyond our control, so make the best of a situation and find the positive in the situation.

**Deal with stress:** Stress is major impediment to humor and laughter.

**Pay attention to children and emulate them:** They are the experts on playing, taking life lightly and laughing!!

Here is a simple prescription for a healthy life:

Thirty minutes of exercise at least 3 times a week, and 15 minutes of laughter on a daily basis!!

The bottom line – laughter may just be the best medicine on the market today!

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# ALS From Both Sides

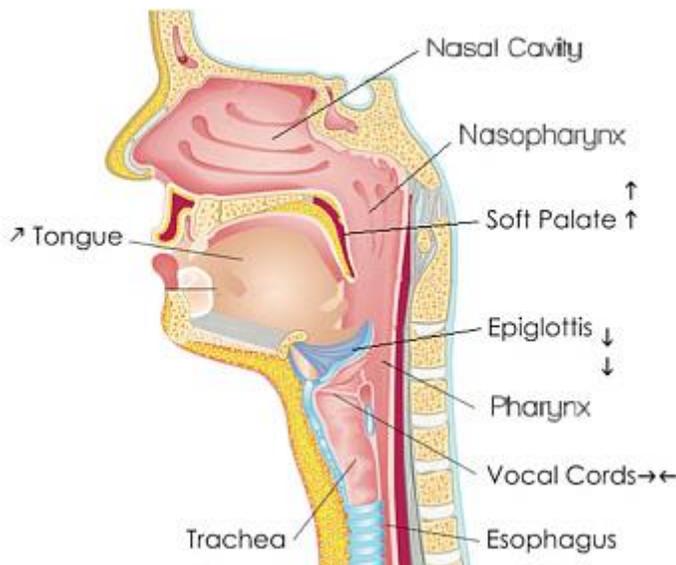
*Caring for an ALS Patient by Diane Huberty, Neuro-RN & ALS Patient*

<http://www.alsfrombothsides.org/index.html>

## Swallowing: A Risky Business

Remember the old drinking toast "Over the lips and past the gums, look out stomach, here it comes!" A fun drinking salute but misguided. It isn't the stomach that needs to be on the lookout, it is the lungs that are at risk if anything goes wrong! Swallowing is a coordination of effort by a number of sensory and motor nerves in a series of reflexes, and a missed step has that food or drink headed for the lungs.

The swallowing process has three stages. The oral phase includes chewing the food using the tongue to move the food around and saliva moistening the food. Then the tongue lifts up in front and pushes the food to the back of the mouth. All this is voluntary movement and voluntary movement is what is affected by ALS. Tongue movement, chewing, and the ability to close the lips are all affected.



Usually however, the second phase of swallowing is hit first. The second phase of swallowing is a series of reflex movements we have no control over. One the series is triggered by the food entering the top of the throat, the food moves down whether or not all the reflexes are in working order. The soft palate moves up to block food from going

up into nasal passages. (Everyone who has burst out laughing mid-swallow of a liquid knows that this reflex doesn't provide a strong seal!) The epiglottis begins the most important part of the swallow; keeping the food or drink from entering the trachea and lungs. The epiglottis is like a trap door that is reflexively triggered to drop down over the tracheal opening. Just below it, the vocal cords squeeze together to form an even stronger barrier. With nowhere else to go, the food or drink is pushed down into the esophagus by the muscles of the pharynx, not pulled by gravity. The esophageal phase of swallowing moves the food or drink on down into the stomach.

All these reflexes require motor responses from cranial nerves, including V, VII, IX, X and XII. The cranial nerve centers are all in the brain stem, the connection of the brain to the spinal cord. Some anatomical wit thought the brain stem looked like the bulb of a plant, so we have the term "bulbar" to refer to anything going on in the brain stem, especially involving the cranial nerves. With ALS we may have bulbar onset. In addition to early signs of swallowing problems beginning with a simple cough when swallowing, a change in the tone and quality of the voice is often noted. Even without bulbar onset, ALS progresses to include bulbar problems. Choking on food or liquids begins intermittently and progresses to inevitable.

The immediately life threatening problem is choking badly enough to block the airway. A slower but inevitable and potentially fatal problem happens as the muscles needed to swallow safely weaken, and food and liquids are aspirated into the lungs causing pneumonia. When the swallowing muscles are no longer working it is possible to swallow without coughing because the cough and gag reflexes are gone. This is called Silent Aspiration. The food or liquids go into the lungs with no cough to signal a problem.

As swallowing worsens, health and quality of life deteriorates. Dehydration causes low blood pressure, dry mouth, and adds to problems with lung congestion and constipation. Meals are long and drawn out from difficulty chewing, exhaustion, and frightening choking episodes. Both patient and caregiver dread meal times and fear that each choking episode may be the last. Food choices become limited, and eventually even blenderized food is dangerous. Weight loss is significant. If you persist in trying to get all your food and fluids by mouth, you will develop pneumonia from the food getting into your lungs.

This is not a "Maybe." This is inevitable. A feeding tube will allow you to get optimal nutrition and fluids, and allow you to continue enjoying those things you can safely swallow as long as possible.

When choking first begins it is time to have a swallow study done. It is unlikely that an early swallow study will indicate that you must quit eating and drinking. Instead it will show which swallowing muscles are causing the problem and the therapist will give instructions on how to swallow more safely, such as double swallowing, head position, etc. You will be given various textures of food to chew and swallow. The food is mixed with tasteless white goop so that as you swallow, all the stages of swallowing can be seen on X-ray. A therapist can then see how bad your swallow is and recommend ways to make eating safer.

People with even minimal swallowing problems should never eat when home alone. Alcoholic drinks increase the risk of choking and should be enjoyed after a meal, not before. Reduce distractions at meal times. Talking while eating may be sociable, but minimize your part in it.

There aren't any specific rules about what foods to eat, just suggestions. It really is a matter of trial and error to see what foods go down easily. Most people find anything that is crumbly or has dry crumbs, such as chips, cake, cookies, dry toast, corn bread, or hard or crusty bread, etc. cause coughing. But dunking these in liquids, or buttering them, or mixing with ice cream may get them to a safe level for swallowing. Don't try taking a drink after putting these foods in your mouth to soften them. The drink can get to the back of the mouth quickly and trigger a swallow before the food is chewed enough to go down. Drown the food first! Any type of sauce or gravy will help.

Foods that need chewing are a problem not only when the muscles for chewing are weak, but also because the chewing tends to trigger a swallow before the food is well chewed. Meats are especially bad for this reason. Small bites are helpful but I personally find tiny mouthfuls to be unsatisfying! Grinding the meats with a baby food grinder or a blender can help especially with gravy added. For myself, I find hamburger to be a problem. I just can't chew it down enough to get rid of the little pieces that stick in my throat like crumbs!

Raw vegetables are usually the first thing to be taken off the menu, and even steamed or boiled vegetables have to be overcooked to the point where a chef would be mortified to serve them. Casseroles go down well if moist and are a good place to add vegetables and meats. Pasta or rice is easier if it is overcooked too and served with a sauce. Melted cheese and soft breads have to be taken in smaller bites. Even a person without swallowing problems can choke if a mouthful of those get stuck on the way down.

Apples, like vegetables, have to be cooked, but applesauce is to keep on hand. Maybe it is just me, but I find grapes and watermelon to be tricky. One bite and the juice is triggering a swallow before I am ready!

Of course anything that is blenderized or even liquefied is easier to swallow. Smoothies are great but may be difficult to suck through a straw and are better if thicker and using a spoon. No raw eggs added! While balanced nutrition is important, ALS requires a lot of calories, especially when breathing becomes even a minor problems. ALS patients seem to do better if they can maintain their weight, so calories are good. Protein is important and protein powders can be added to smoothies. Egg custard goes down without chewing and is a good source of protein. A lot of calories can be added with milk and ice cream, but that can cause thick phlegm that is hard to cough up.

Although our swallowing problems are strictly a muscle problem, triggering the sensory system can improve swallowing by stimulating a stronger reflex by whatever muscles are still working although weak. That is especially true for liquids. Liquids are the hardest to swallow safely! They go down so quickly that the weakened swallowing process isn't ready for it. Hot or cold foods and drinks are better than room temperature. A hot or cold drink, especially one with a strong flavor goes down best. Thicker liquids such as orange juice or using a tasteless thickener such as Thick-It will help. The body needs plain water too. It is absorbed without having to go through the entire digestive process to filter out flavorings and doesn't add to the work of the liver and kidneys. A feeding tube makes getting enough water easier.

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**END!**

