



## 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, 5/12/16.***

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

*~ April 2016 ~*

11 attendees! Open group discussion today – lots of experiences shared! Don W. provided the group with Smokey Express & Community Gospel Choir DVD's. Janet Glodowski and crew have been ongoing generous supporters of the ALS Support Group and we thank them greatly! Lots of talk surrounding noninvasive vents vs invasive. Please see article below, "BiPAP to Vent" by Diane Huberty RN & ALS Patient. Counties recently served: Polk; Eau Claire; Chippewa Falls; Pierce; Rusk; Washburn; Barron; Dunn.

It is said that April showers bring May flowers. I've heard it said that this is also true with ALS. After the storm of an ALS diagnosis, the precious more colorful aspects of our lives become more apparent and vibrant. May your

spring be blooming with all things beautiful! And when the rain comes, know we are here together to hold each other's umbrellas!

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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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**12th Annual ALS Care & Research Symposium**, latest updates on research progress, potential drug treatments and other updates on the disease. **Saturday, April 30, 2016, 8:30 a.m.-2:00 p.m.** Sheraton Milwaukee Brookfield Hotel 375 South Moorland Road Brookfield, WI visit <http://www.alsawi.org/#!als-symposium-2016/ld4ex> or call for more information **414.763.2220**.

**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!**

Charity Car Show, benefiting ALS of NWWI, Bracket Bar, 9150 Beaver Creek Rd., Fall Creek, WI, in August 2016.  
More info. to come in May!



## Informative Articles & Info.

### **Medicare Webinar for People with ALS provided by The ALS Association**

The ALS Association is working with the Center for Medicare Advocacy (CMA) to better help people living with ALS navigate the complexities of Medicare home health benefits. As part of this collaboration, the CMA will be presenting a webinar that will discuss topics including: an overview of the Medicare program with particular focus on the home health benefit, Medicare eligibility and enrollment, and Medicare payment rules and assistance.

This webinar will be presented on three separate dates with a 30 minute live Q&A following each session. For more information and to register for a session, click the links below.

**Session 1: Thursday, April 28, 2016 (1:00-3:00 pm EDT)**

Register at: <http://bit.ly/240SapS>

**Session 2: Tuesday, May 3, 2016 (3:00-5:00 pm EDT)**

Register at: <http://bit.ly/22O32Fd>

**Session 3: Monday, May 16, 2016 (6:00-8:00 pm EDT)**

Register at: <http://bit.ly/1SZzK1a>



## **Nutrition Ideas for Stress Reduction**

Today's Caregiver.com *by Rita Miller-Huey*

March 3, 2016 • Issue #896

# Hydration in Elders: More Than Just a Glass of Water

As we enter the warmer part of the year, it is more important than ever to drink enough fluids. This is particularly true for children and for persons 65 and older - which could be both the caregivers and their loved ones. Not drinking enough fluids can cause unwanted symptoms, complications from existing disease conditions and may account for many hospitalizations of our elders. Water and juices are the best; coffee, tea and colas with caffeine as well as alcoholic drinks cause the body to lose fluids and are recommended only in small amounts.

Elders are at risk for dehydration for many reasons:

**Age related.** There is less water in the older body, greater difficulty for the older kidney to maintain fluid balance and less thirst sensations in older folks in general.

**Disease-related reasons** for dehydration range from the complex to the simple.

Infections such as pneumonia, chronic obstructive pulmonary disease (COPD) and urinary tract infections increase the need for fluids due to fevers and the overproduction of mucus. Some diseases, such as congestive heart failure, renal disease, stroke or other neurological disorders and diabetes, cause changes in the function of various hormones that regulate the fluid balance in the body. Also, there are acute reasons for dehydration such as prolonged vomiting or diarrhea, over-aggressive diuretic therapy and poor compliance to medication regimens.

**Environmental reasons.** A decrease in mobility for those with arthritis, diminished vision or confined to bed rest who cannot as easily meet their own needs. Those with diminished appetite or reluctance to bother others for something as simple as assistance in getting a sip of water are definitely at risk.

**Medication reasons.** May cause increased fluid losses through the kidneys. Diuretics, sedatives and laxatives are common, necessary drugs that require close attention to fluid intake. Other drugs and alcohol can cause the kidneys to work harder, and may damage them, making it harder to maintain fluid balance.

**Psychosocial reasons.** This is the elder who is cognitively impaired, and possibly unable to drink without full assistance, or those who may intentionally restrict fluid intake in the hopes of decreasing the risk of incontinence.

**Economic reasons.** This may include the lack of financial resources to maintain nutritional and fluid intake, extreme or prolonged weather fluctuations and the possibility of elder abuse.

How could you tell if your loved one might be becoming dehydrated? Ask yourself if they have any of the above mentioned risk factors. If they complain of nausea, are

lethargic, have headaches, vomiting or dizziness, these could all be signs of dehydration. Call your doctor if your loved one had any or all of these symptoms.

**Keep track of how much your loved one actually drinks in a day.** A simple way to do this would be to put two quarts of water in the refrigerator first thing in the morning. Give all fluids for your loved one from his or her special pitcher. By the end of the day, they should have drunk most of the 2-quart pitcher. It could be plain water, water with lemon or other fruit juices made with water. Regular tea and coffee do not count because they promote fluid loss. Decaffeinated teas and coffees are OK (if your loved one will not drink plain water or juices) because they are less likely to promote urination. Foods that melt at room temperature, such as gelatin or ice cream also have a lot of water content. Serve foods with sauces, juices and gravies - every little bit helps.

There are some diseases for which it is not appropriate to offer so many fluids: congestive heart failure, cirrhosis of the liver and kidney disease. However, for most of us, young and older, the rule of thumb is to drink, drink, drink to keep the body hydrated, and stay away from the hospital and all the tubes and therapy needed if dehydration does occur.



## *ALS From Both Sides*

*Caring for an ALS Patient by Diane Huberty, Neuro RN & ALS Patient*  
<http://www.alsfrombothsides.org/index.html>

### **When a Vent and Trach is Better Than BiPAP**

When neuromuscular disease weakens the muscles used for breathing, many people benefit greatly from non-invasive ventilation (NIV), which can add years of breathing support. But when a ventilator and tracheostomy are suggested for better breathing, some people see NIV/BiPAP as “enough” and a vent and trach as “too much.” When a person’s overall quality of life is no longer acceptable, that’s certainly a valid choice. But a trach and vent shouldn’t be ruled out if quality of life problems are due in large part to respiratory problems.

Why Switch from NIV?

NIV assists breathing through face masks, nasal plugs or tubes to “sip” air, without the need for surgery. So why would anyone even consider going to a trach tube?

NIV can prove inadequate for a variety of reasons:

1. Facial features such as a crooked nose or a deviated septum can make finding a mask that doesn't leak or breathing entirely through the nose difficult and very frustrating. Although most masks are adjustable and therefore called "customized", truly custom made (molded) masks are now available. Most insurance limits the number of masks per year making finding the right one expensive, and insurance may not cover a custom made one. Adding to the problem is that the facial contours change significantly with weight loss or gain and development of facial weakness.
2. NIV may aggravate sinus problems and lead to chronic sinus infection.
3. For some people, NIV pushes air into the stomach and causes very uncomfortable abdominal distension.
4. Some find anything on the face claustrophobic.
5. Facial weakness reduces necessary jaw closure and ability to use a mouthpiece or mask.
6. It can take months to find the right settings and mask or device and get used to NIV, so if knowledgeable support or strong motivation is lacking, NIV probably won't work out.
7. When BiPAP use extends into daytime use, going out becomes more difficult because of equipment needs, although BiPAP units are being changed to be more portable. Wearing the mask in public is unacceptable to most users because of the headgear. Nasal plugs still require headgear -- they aren't the simple tube worn by oxygen users. NIV headgear definitely looks more "Star Wars" bizarre than "Top Gun" cool. Although a sip tube is much better in that respect, its use is limited because the patient must be able to form a seal around the tube and suck strongly enough to trigger the machine to deliver a breath.
8. Ventilators have an alarm system which a BiPAP machine may not have.
9. Portability. BiPAP machines are just now catching up with ventilators in terms of size and portable power supply.
10. Using a ventilator for BiPAP greatly eases the transition to full ventilation if that is being considered. Familiarity with the machine goes a long way even though the settings are different.
11. The most common reason for switching, however, is that after successfully using NIV for some time, a person's breathing muscles weaken further. Several symptoms show that this is occurring, such as:
  1. Frightening spells of suffocating or choking congestion caused by thick mucus and a poor cough. Breath stacking, manual cough assistance or a CoughAssist device work very well for some, but others find these methods minimally effective. The inability to clear congestion is exhausting, frustrating, and dangerous. A trach solves this problem
  2. The hours the person needs to use NIV increase from overnight to most of the day.
  3. Because NIV can only assist breathing, not entirely breathe for the user, as a person's breathing capacity deteriorates, he or she slides back into the fatigue, poor appetite and anxiety of pre-NIV days.
- 12.

4. Pneumonia or a simple chest cold results in a respiratory crisis. The additional settings available on a ventilator may be needed and the ability to remove secretions is critical. At this point a trach is generally more effective than CoughAssist.

#### Why the Resistance to a Breathing Upgrade?

One problem is, as so often the case, cost. Because a ventilator is capable of more than just delivering BiPAP, it is more expensive. For this reason most people are limited to a BiPAP machine until the switch to full ventilation is required. Cost is certainly a factor but it is hard to discuss cost because insurance coverage varies drastically. Some people have complete coverage, others have sizable copay. The best I can do is give you my cost. (Remember, this is my cost and every equipment supplier and insurance is different!) Go to [Cost of Vent Equipment](#)

It is possible to purchase your own vent but you will not receive any of the services provided along with vent rental. When you rent, a Respiratory Therapist visits frequently at first, then less often. The therapist does no patient care. The therapists are there to check the equipment, not me. If I have any problems I call the doctor and the therapist can intervene to work with the doctor to change settings or recommend other equipment. During visits the therapist will run checks on the vents, suction machines, batteries, chargers or other equipment. They arrange for very prompt replacement if needed. They keep records of all the machines so they are regularly exchanged and sent in for a full "tune up". They are on call 24/7 for equipment emergencies. Equipment is replaced at no charge if there is a problem with it. We order our supplies by phone through Apria as well and they are very prompt with most items.

Perhaps another source of resistance is all the emotional baggage the word ventilator carries, primarily the words "Life Support." Sadly those words always conjure up images of death bed scenes where life support is withdrawn. Yet the reality is that ventilator use is far more positive in the vast majority of cases. Premature babies, people having major surgery, accident victims, people with severe pneumonia all survive because of ventilators. And so can ALS patients. Granted the differences for ALS patients are major; permanent ventilation versus temporary, advancing disability versus recovery. But when the major obstacles to quality of life are the fatigue, loss of appetite, anxiety, depression, repeated bouts of life threatening congestion all caused by respiratory problems, a ventilator can restore quality of life at least for a while.

One of biggest reasons for resistance to venting is, sadly, negative comments and advice from doctors and nurses. The information you get from doctors and nurses is so out of touch with reality! Some of my favorites are:

1. *"You won't have any quality of life being tied to a ventilator."*

*Well, the patient is the only one who can judge his quality of life and if it isn't satisfactory, he can have the vent removed. My quality of life improved drastically with the trach and vent. ([Summary of quality of life studies.](#))*

2. *"You can never be left alone if you are on a vent."*

*True. But is it really possible or safe for you to be alone if you are at the point of needing a vent? No! A good call system is essential either way.*

3. *"You will need expensive round the clock nursing care."*

*Nonsense. Family and friends can do it. Managing vent maintenance requires an hour or so of training but anyone, including kids and probably chimpanzees, can suction, handle vent alarms, and use the ambu bag if necessary with just a few minutes of explanation and hands-on time.*

4. *"The burden on your caregiver(s) will be heavy."*

*An significant increase in care needs is far more likely to be the result of advancement of ALS weakness rather than going on a vent. The additional work for your caregiver(s) because of the trach and vent will be suctioning you (less often as time goes by) and daily cleaning of your trach area and, depending on the type of trach you have, cleaning the trach tube. After a period of adjustment I think you will find your caregiver is actually less stressed, at least by the breathing aspect of your ALS. Congestion that now leaves you both wondering if you can cough it out or if you are going to die this time will be nipped in the bud with suctioning. Any choking spell can still be exhausting but the trach and vent will assure that your airway can't be blocked and you will continue to breath throughout the choking spell.*

5. *"Your house will look like an Intensive care unit."*

*Only if you want it to. Suction machines and other equipment are right at hand even in a cabinet or drawer. Trach supplies don't need to be sitting out anymore than your toothbrush and deodorant do. Being in a wheelchair required infinitely more expensive and highly visible changes to my home than going on a vent!*

6. *"You can't taste or smell when you have a trach because the air isn't passing through the nose."*

*This falsehood is all the more irritating because it is a quote from Dr. John Bach, the guru of non-invasive ventilation. (Quoted in "MISSION POSSIBLE?: Converting to Non-invasive Ventilation By Jean Dobbs for New Mobility Magazine, May 1996.) This may be true for some trached people, but definitely not for all! My sense of taste is, unfortunately for my waistline, unimpaired. My sense of smell is limited only in that I cannot sniff well enough to smell something*

*being waved under my nose. A scent that permeates the air such as food cooking, a vase of flowers, or something going bad in the fridge is very obvious to me!*

7. *"Trachs are complicated, time-consuming, problem-prone, ugly, uncomfortable, expensive, prevent talking and eating."*

These comments deserve a separate page for disproving! [Trach Care: The Rest of the Story.](#)



**END!**