



ALSNWWI Support Group

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.

Questions, concerns, or input please contact:

Julie Chamberlain, LPN, 715.271.7257 or alsnwwi@gmail.com

JOIN US ON THURSDAY, 05/14/15, FOR THE NEXT MEETING!

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

~ April 2015 ~

12 people were present. Shelley-Rai Pehler, UWEC, department of nursing was present to survey our experiences with longing. Ms. Pehler and her team need help identifying if a diagnosis of Longing should be added to the NANDA-1 list of nursing diagnoses. Thank you to all who participated. Local caregiver shared her personal story of Trach surgery and the challenges associated with finding supportive homecare. (see pg. 3 for details on “The Vent Decision” & “Caregiver for Vented Pals”)

Upcoming Local Event:

Caring for the Caregiver

Friday, May 1, 2015 11:30am - 3:30pm

Location: HSHS Sacred Heart Hospital Community Auditorium 900 W. Clairemont Avenue Eau Claire, WI 54701

Join us for an inspirational workshop featuring Rachel Funk-Johnson, founder of Happee School (professional speaker and coach) and Amy Sergerstrom, Coordinator of The Healing Place: Center for Life's Journeys.

Light lunch, resource materials, & exceptional door prizes!

Cost to attend: \$5, plus a non-perishable food item for the St. Francis Food Pantry. To register call, 715.717.1600.

Note: Home Instead Senior Care will provide a professional caregiver on-site or in your home at no cost, call 715.552.8040.

Research Webinars and Videos

Upcoming Webinars
Provided by ALS Insights

The Neurocolaborative: Therapy Development for ALS

Speaker: Steven Finkbeiner, M.D., Ph.D. Professor, Departments of Neurology and Physiology, University of California, San Francisco

Date: May 5, 2015

Time: 4:00 - 5:00 ET

We welcome you and your families to celebrate birthdays and special happenings in your life at group. Please feel free to bring photos/treats, etc... to share as you desire. We also want to support challenging days and other events that may require extra care so please feel free to

reach out to us so we may rally together through additional emails, visits, etc! We are on this journey together!

Take good care of each-other!

*Deb Erickson, LPN
ALS Outreach Assistant
www.alsnwwi.org*

ALSNWWI Support Group is a non-profit organization that has been operating in the Chippewa Valley since 1992. 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. This year's walk will be held on June 14, 2015 at the Northern Wisconsin State Fairgrounds in Chippewa Falls – Save the Date!**

ALS From Both Sides

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

The Vent Decision

If you are evaluating the pro's and con's of going on a ventilator when the time comes, there are big questions you need answers to. What will it cost for the equipment? What help will I need at home? How will affect my quality of life and that of my family? It is hard to answer these questions because insurance coverage varies, the availability and willingness of family and friends to help varies, and each individual's adaptability to advancing ALS is different.

Breathing is not a problem if you opt for a vent and trach. Swallowing is not a nutritional problem with a feeding tube. That pretty much takes care of the actual life threatening problems of ALS!

A vent is not for everyone. Those with rapid progression and loss of nearly all movement will face being locked in (mind is working but with no way to communicate

even yes/ no) fairly soon. A patient can request to be taken off the vent and allowed to die at any time, and the process will be done under heavy sedation and other meds for a peaceful death.

The hard part is deciding "when". If the patient waits too long, he or she can be locked in with no way to say turn off the vent. Patients can live for years in this state. Most people consider that an extremely undesirable way to live. Family is stressed terribly. No one should go on a vent without deciding when they want the vent turned off and telling their family and doctors that decision. Giving medical power of attorney to someone they believe will carry out that decision is critical. Often the best person for that job is not an emotionally torn family member.

Going to a vent is not an easy decision. If you have read "Safe Harbor" you know that I have found vent life to be positive and I tend to be pro-vent. It is horrifying to me that only 5% of ALS patients in the United States opt for a vent while 50% of ALS patients in Japan do. But that is a topic about our pathetically bad health care system...

I definitely recognize that I have had all the breaks in the situation; a husband who was able to take early retirement to care for me, supportive family even though only one family member lives here and the rest are 800+ miles away. A couple of friends have pitched in to help so we don't have the expense of paid care. I am a couch potato by nature and can keep occupied and happy. Most of all, my ALS has been very slowly (but consistently) progressive making the decision to vent worthwhile. In spite of all that, I have tried to present the information here in an unbiased way as I can. I hope you find the information useful as you try to decide what to do.

Caregivers for Vented PALS

When someone is considering going on a ventilator one of the first concerns is the added work for the caregivers. The amount of time added varies with the frequency of suctioning and that generally decreases as patient and caregiver adjust to the vent, get organized, ***and learn that much of what they were told needed to be done is for hospital care, not home care!*** In addition to suctioning there will be daily washing of the trach area and, depending on the type of trach you have, cleaning the trach tube. Cleaning suction equipment is daily. Changing vent hoses and filters generally drops from weekly

to whenever unless infections are frequent. Ordering supplies should only need to be done once a month at most. Any significant increase in care needs is far more likely to be the result of advancement of ALS weakness rather than going on a vent. 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.

The reality is that the extra daily workload is manageable but the added months or years of care may not be.

Many people are told that they will have to hire round the clock nurses. Big lie! Or they are told that they will have to hire a vent qualified nurse anytime your caregiver leaves the house. Also not true. If all you need is someone to give your main caregiver time out of the house for shopping, errands, appointments, or just plain escape. Not a nurse, just a relative or friend or two willing to learn how to suction you--and that is nothing more than a minute of glorified vacuuming--and the basics of the vent. *You have to ask. No one is going to know that you need help unless you tell them!*

The company supplying your vent may offer a training class for anyone willing to help but that isn't a requirement. In fact, they may scare off volunteers with a lot of technical jargon! You can show someone the ropes in ten minutes of instruction and demonstration plus time for them to practice suctioning you. The learning curve is not steep! Vent basics include deciphering vent beeps. If the vent beeps you either need suctioning, a hose is off or loose, or the battery is low and the vent needs to be plugged into a wall outlet. If the problem isn't found they just need to use the ambu bag while waiting for the vent supply company to show up. Suctioning is simple vacuuming. The hardest part is getting a glove on and then remembering not to touch anything except the suction tube with that hand! Most reasonably coordinated people can be shown the procedure, practice it a couple of times, and be ready to go.

If you want a home health care agency to provide care, that can be slow to get started. Check with available agencies early in your planning. Most agencies don't have many, if any, nurses trained and legally allowed to care for vent patients. Even if they are, their

visits will probably be restricted to an hour or two once or twice a week. You can get aides to help with bathing and getting you out of bed etc. but someone else must be there to assume responsibility for the vent care. They won't be allowed to give tube feedings or medications either. LPN's and RN's can do those things even if they aren't allowed to be responsible for vent related things. Because of the legal liability limits of Home Health Agencies, the cost, the rather frequent problem of them not showing up, and the possibility of getting someone you just don't want caring for you, friends are most often a better solution for shorter periods of care. If their visits are scheduled on a regular basis it is much easier for your regular caregiver and your other helpers to plan ahead.

The handbook, "Share the Care" is a guide to finding and organizing a group of helpers to form a strong working support group for people and families overwhelmed by care needs. The "Share The Care" handbook is available for you to purchase from Amazon or at Barnes & Noble online and at bookstores for \$16.

[Lotsa Helping Hands](#) gives a place where volunteers and paid help can see your calendar, view requests for assistance such as time for shopping, cleaning, cooking, appointments, view gaps in care coverage, and sign up to help when needed. They can sign up for a single spot or schedule themselves for regular help.

Another option is to hire your own caregivers. As long as they are not RN's, LPN's, or CNA's, they won't be risking losing their license if you train them to do vent, meds, and feeding tube care. The problem here is the same as finding a sitter for little kids; safe, motivated, compatible personality, adaptable, honest, no criminal background, reliable. If you put out an ad for someone, don't include details beyond "home care help needed". Do background checks, ask for five or more references for work history and personal attributes -- and follow through on them. A good source of caregivers are local nursing or other health care schools (they don't have a license to risk until they graduate) or volunteers from your church.

A live-in caregiver can be great even if they are also working at another job. You can negotiate any pay expected so this saves money. A live-in is a much more personal arrangement so it definitely requires the right personality as well as passing the other checks. It also requires laying out of non-care rules such as smoking, pets, visitors, groceries, etc.

Some states will now pay a small hourly wage to family members who provide your care. They realize that whatever they pay is far more cost effective for the state than forcing you onto Medicaid and into a nursing home.

So, Home Health is not required as long as you have enough family, friends or privately arranged caregivers trained to manage basic vent problems and suctioning. Or, you can use Home Health at first and once you are settled in at home you can train your own people (they definitely don't have to be nurses!) and let Home Health go.

Caregiver Stress

Provided by Today's Caregiver Newsletter

Caregiver Newsletter, April 28, 2015 • Issue #807 by Kathy Bosworth



More than one quarter of the adult population (26.6%) has provided care for a chronically ill, disabled or aged family member or friend during the past year. Based on current data, that translates into more than 50 million people! Sixty-one percent of “intense” caregivers (those providing at least 21 hours of care a week) have suffered from depression. Heavy-duty caregivers, especially spousal caregivers, do not get consistent help from other family members. One study has shown that as many as three fourths of these caregivers are “going it alone.” Is it any surprise that caregiver stress or burnout is becoming a critical issue?

Dealing with stress is not a new concept. None of us have immunity from the challenges of getting through life with the least amount of stress. Some people drink, over eat, smoke, bite their nails, yell at the cat, or retreat inside themselves when the going gets too tough. I’m sure you have your own ways of protecting yourself from the ravages of stress. I have often thought my cat has the right idea when stress enters her life. After one loud meow and an angry swish of her tail, she retreats to another room to take a nice long two-hour snooze. Bamm! The stress is gone. Unfortunately, people do not have the same luxury.

Are you caught in the web of stress while being a caregiver? In the book, “Living with Stroke”, there is an interesting section on stroke stress analysis. People list nine sentences that sum up all the different ways that stress exhibits itself in families of stroke

survivors. Do any of these ring a bell with you?

Panic	“Ohmigod, I can’t handle this.”
Anxiety	“What if he needs me in the middle of the night and I can’t hear him?”
Denial that leads to over-optimism	“Oh, he’ll be fine. He just needs to come home.”
Irritability and Anger	“It’s all the rehabilitation team’s fault.”
Frustration	“I can’t stand one more thing going wrong!”
Fatigue	“I’m utterly, completely exhausted from the experience.”
Hopelessness and helplessness	“What’s the use? Nothing’s going to change.”
Guilt	“How can I be so angry at him? It’s not fair.”
Ambivalence	“I don’t know how I feel anymore. I can’t make a decision about anything.”

If you are a caregiver, I’m sure you find yourself nodding your head at more than a few of these stress indicators. I often say that caregiving is not something that people plan on or sign up for. It is a situation that sort of plops itself in your lap, totally unexpected. Caregivers are usually overwhelmed, untrained, and uneducated in the beginning. With time comes a sense of control that can help you through. Being out of control in any situation can knock a person off balance. Don’t be too hard on yourself as you muddle through this. You are a rookie now, but you are getting some heavy on-the-job training.

Here are some tips that I have found to be helpful in getting your life in balance again.

- When well-meaning people offer to help, accept their help. Be specific in things you could use help with. Now is not the time to show the world how strong you are. You will only burn out quicker without help.
- Watch out for signs of depression. Get professional help if you need to.
- Educate yourself about your loved one’s condition. Information is empowering!
- Trust your gut feelings. I’m a firm believer in our innate instincts. If something sounds out of whack to you, keep asking questions until you are satisfied that the best care is being administered.
- Find other caregivers to connect with. There are many caregiver websites and support groups that can be found. If there are none in your area, start your own. Believe me, you need somebody to talk to that understands what you are going through.
- Be kind to yourself. Even if you only take a ten-minute walk around the block to alleviate some stress, DO IT. A caregiver with a lower stress level makes a much

better caregiver. Getting enough sleep, exercise, and eating balanced meals reduces stress.

- If you are caring for a parent and have siblings, be vocal about what they can do to help. Some people are not comfortable with the day-to-day care but they might be willing to grocery shop for you, pick up meds, or do a doctor's run or two. Don't be a martyr. Your emotional health cannot take it. Face it and get on with it.
- Take charge of your life and continue to do things that you find relaxing or pleasurable. If a loved one's disability always takes center stage instead of your needs, you will become a resentful caregiver. Not good for anyone.
- Write down things to keep your head uncluttered. Having ongoing lists of medications your loved one is taking will not only alleviate the stress of trying to remember what and when, but it is also a valuable tool when visiting the doctor. It's all written out and accessible. Doctors are often rushed and cannot wait around while you try to remember which meds are causing what side effects, etc. Keep it simple and easy on yourself in ways that you can.
- Keep your sense of humor. It's the most important tool you have and it's free. Humor can be found in the most surprising places, even hospitals and nursing homes. Laughter is good for the soul.
- Know your limitations! Don't let guilt get in the way of making the best decision for your family member and yourself. Not everyone can be a caregiver no matter how good their intentions might be. If you cannot be a caregiver due to an emotional, physical, financial or locational burden, you do have choices. You cannot help another if you yourself need help. The medical needs might warrant the need for assisted living or long term care. If you must find alternative living arrangements, make sure they are ones you can live with and serve the best interest of your loved one! Stay involved and vigilant that the care remains good.

Caregiving is a huge responsibility. Keeping the caregiver healthy— physically, mentally, and emotionally — is vital. Try to find the right balance in your life that allows you to care for your loved one while caring for yourself.

Other helpful websites for caregivers:

Family Caregiver Alliance: www.caregiver.org

National Family Caregivers Association: www.nfcacares.org

National Alliance for Caregiving: www.caregiving.org

Today's Caregiver: www.caregiver.com

ALS Advocacy & Public Policy Conference Washington DC May 10-12

- Tune in for the live streaming of the research sessions on Monday, May 11.
 - 9:15 am – The State of ALS Research: The ALS Association’s Chief Scientist, Dr. Lucie Bruijn, will share the latest news about The Association’s TREAT ALS program and other promising developments in clinical trials and ALS research, including how the Ice Bucket Challenge is advancing ALS research.
 - 11:00 am - Government ALS Research: Join us for this plenary session to learn how government programs, such as the National ALS Registry and the ALS Research Program at the Department of Defense, are advancing the search for the cause, treatment and cure for ALS.
- Participate in our **Virtual Advocacy Day** on Tuesday, May 12. Check back on Tuesday, May 12 to learn how you can help make a difference.
- Follow us on [Twitter](#) and on [Facebook](#) for live updates throughout the conference.

For more information see <http://www.alsa.org/advocacy/advocacy-day/>

Research Updates

Two ALS Researchers Win Sheila Essey Award

March 12, 2015

The American Academy of Neurology and The ALS Association are awarding the 2015 Sheila Essey Award to Robert P. Bowser, Ph.D., from Barrow Neurological Institute in Phoenix, Arizona, and Adriano Chio, M.D., F.A.A.N., from the University of Turin, Italy. The \$50,000 prize is given to continue ALS research.

The award recognizes significant research contributions in the search for the cause, prevention of and cure for amyotrophic lateral sclerosis (ALS). Drs. Bowser and Chio will receive the award at the American Academy of Neurology's 67th Annual Meeting in Washington, D.C., April 18 to 25, 2015. The Annual Meeting is the world's largest gathering of neurologists with more than 12,000 attendees and more than 2,500 scientific presentations on the latest research advances in brain disease

“The ALS Association is proud of the work performed by both Drs. Bowser and Chio to advance the search to identify biomarkers and mechanisms of ALS,” said ALS Association Chief Scientist Lucie Bruijn, Ph.D., M.B.A. “Their accomplishments should help us in the effort to find truly effective treatments and ultimately a cure.”

Dr. Bowser is receiving the award for his research on identifying ALS biomarkers in the blood and cerebrospinal fluid of ALS patients. Biomarkers are anything that can be measured and used to determine a change in a person as a result of a disease. They can also help measure a disease's progression. "We have discovered a protein biomarker

signature that distinguishes ALS patients from non-ALS patients," said Dr. Bowser. "The findings are helping us discover new ways by which ALS may initiate, and new targets to develop drugs to treat ALS patients."

"I am truly honored to be a recipient of this year's Shelia Essey Award for ALS Research," Dr. Bowser added. "It is a privilege to be included with my many esteemed colleagues that have won this prestigious award in the past, and I remain committed to my research efforts to help define the pathophysiology of ALS and find improved drug treatments for ALS."

For his award-winning work, Dr. Chio established the Piedmont registry to document and track many aspects of ALS, including genetic and environmental risks, progression, and survival rates. In particular, he was among the first to describe the increased risk of ALS among Italian soccer players and the potential risk that physical activity and traumas may play in a person's risk of the disease. "The Piedmont registry has shown us that ALS is not simply one disease, but rather it is a collection of diseases that look the same, which is a major step forward in our efforts to develop personalized treatment and effective medications to slow down the disease," Dr. Chio said. "I am greatly honored and thankful to receive the Sheila Essey Award. The award is a strong motivation to proceed with even more dedication toward the goal of a world without ALS," he added.

Funding of the award is made possible because of the generosity of The Essey Family Fund, through The ALS Association Golden West Chapter, in memory of Sheila Essey, who battled ALS for 10 years and died from the disease in 2004. Richard Essey, Sheila's husband, served as a National Trustee of The ALS Association and is one of the founders of the Greater Bay Area Chapter, now the Golden West Chapter.

End.