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

Our Next Meeting will be THURSDAY, 08/13/15.
(Second Thursday of each month, 1:00pm – 3:00pm at Chippewa Valley Bible Church, 531 E. South Ave. Chippewa Falls, WI 54729)

Special Guest: Gina Severson
Health Care Services Coordinator
Muscular Dystrophy Association/ALS

~ July 2015 ~

Our special guests, Amy & Jane, from the Healing Place were present to share thoughts on grief.

"Grief is the outward sign of bereavement and mourning. People with ALS often feel anticipatory grief. This occurs when those who are ill and their loved ones begin to experience loss and

change. Anticipatory grief has a defined beginning – when the person begins to cope with challenges, changes and losses of the disease – and a definite ending.

Suggestions for Dealing with Anticipatory Grief: Confront the feelings of grief by defining and naming them; Talk about your feelings with others. Some feelings – quilt, anger, anxiety – may be hard to share. Enlist the support of someone is objective, accepting, empathic and not afraid of strong feelings. You may prefer to speak to a professional counselor or join a support group; Resolve and forgive past wrongs; Make plans for the future. Deal with financial changes, tax issues, insurance, medical and personal choices, a will and funeral arrangements and distribution of assets and belongings. Although it is often difficult to confront these tasks, early preparation eases the decision-making process; Leave a legacy. Think about how you want to be remembered. Tell your life story. Document your special memories in a journal, or on audio or video tape. Leaving your mark-on-the –world may elicit feeling of satisfaction of a life well-lived. Make a lasing testament for survivors to remember how you loved your life and the meaningful time that you shared together; Live in the present. Try to relax whenever possible. Enjoy and celebrate life's joys and pleasures."

The Healing Place

A program of Sacred Heart Hospital
1010 Oakridge Dr. Eau Claire, WI 54701 (715) 717.6025

The Healing Place provides individual, couple and family counseling services to those who are dealing with life adjustment issues such as death, divorce, illness or disability.

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Caring for our Caregivers

Sans Souci Massage
927 Loring St. Suite 4
Altoona, WI 54720
Generously offers a massage a month to our caregivers.
All appointments are made through Julie at the ALS Support Group Office 715.271.7257. Please call if you are interested or you know of someone. Thank you Sans Souci for this generous gift!

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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, 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!***

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The Fearless Caregiver Manifesto

Provided by Today's Caregiver Newsletter
Caregiver Newsletter, July 2, 2015 • Issue #826 By Gary Barg

I will fearlessly assess my personal strengths and weaknesses, work diligently to bolster my weaknesses and to graciously recognize my strengths.

I will fearlessly make my voice be heard with regard to my loved ones care and be a strong ally to those professional caregivers committed to caring for my loved one and a fearless shield against those not committed to caring for my loved one.

I will fearlessly not sign or approve anything I do not understand, and will steadfastedly request the information I need until I am satisfied with the explanations.

I will fearlessly ensure that all of the necessary documents are in place in order for my wishes and my loved ones wishes to be met in case of a medical emergency. These will include Durable Medical Powers of Attorney, Wills, Trusts and Living Wills.

I will fearlessly learn all I can about my loved one's healthcare needs and become an integral member of his or her medical care team.

I will fearlessly seek out other caregivers or care organizations and join an appropriate support group; I realize that there is strength in numbers and will not isolate myself from those who are also caring for their loved ones.

I will fearlessly care for my physical and emotional health as well as I care for my loved one's, I will recognize the signs of my own exhaustion and depression, and I will allow myself to take respite breaks and to care for myself on a regular basis.

I will fearlessly develop a personal support system of friends and family and remember that others also love my loved one and are willing to help if I let them know what they can do to support my caregiving.

I will fearlessly honor my loved one's wishes, as I know them to be, unless these wishes endanger their health or mine.

I will fearlessly acknowledge when providing appropriate care for my loved one becomes impossible either because of his or her condition or my own and seek other solutions for my loved one's caregiving needs.

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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

Oxygen Use with ALS

At some point in ALS progression the question of using oxygen to ease breathing difficulty will come up. Getting enough oxygen is not a the problem in ALS. There is nothing wrong with the lungs, just the muscles needed to inhale. The problem is muscle weakness that prevents inhaling deeply enough to get enough air in. If a machine such as BiPAP or a ventilator is used to push enough air in, the lungs can absorb oxygen from room air without difficulty. Therefore the treatment for breathing problems in ALS is mechanical support, not oxygen. For people with ALS who also have lung problems that directly affect the ability of the lungs to absorb oxygen (such as pneumonia, COPD, emphysema or asthma) in addition to ALS, oxygen may be necessary.

Often the response to the use of oxygen is that it is dangerous for ALS patients. That is both true and false!

Respiratory drive runs on CO2 levels. Oxygen levels contributing very little to the process of stimulating breathing. CO2 is produced by working cells and sent through the blood to the lungs to be removed during the process of breathing. The CO2 is exchanged for oxygen and the CO2 is exhaled. When that exchange is impaired, CO2 levels rise and the respiratory regulatory center in the brainstem coordinates an increase in breathing rate and depth to blow it off. An ALS patient with weak respiratory muscles can't breathe deeper so the CO2 levels are harder to bring down.

Over time body chemistry allows the respiratory system compensate and to work with these levels as the "new normal". When the compensatory measures are maxed out by increased weakness of the respiratory muscles or lung congestion or pneumonia, that small amount of respiratory drive from oxygen becomes very helpful. But if oxygen is given and the O2 Saturation increases to about 90%, that part of the respiratory drive stops because the O2 level is near normal. Loss of that small part of respiratory drive is enough to tip the drive from "barely enough" to "not enough". The rate of failure begins

to increase and the patient may stop breathing entirely. The risk of adding O2 is therefore very real -- but only if the patient is retaining CO2 enough to rely on compensatory body chemistry.

So when does this risk begin with ALS? It is a basic rule in medicine that you don't automatically give more than 2 liters per minute of oxygen to anyone. This amount is considered low enough to be safe for anyone even if they are retaining carbon dioxide (CO2). O2 Saturation (monitored with a simple fingertip monitor) does not reflect CO2 levels and O2 levels remain normal until CO2 levels are high so that is not an early indicator. The person's CO2 levels have to be checked to see if he is retaining CO2. This can be done using a PcCO2 device applied to the skin if that equipment is available. If not, arterial blood can be taken and tested. (ABG's). ABG's show not only the CO2 level, but also if the body is already using compensatory chemistry.

The issue of using oxygen frequently comes up when the insertion of a feeding tube is planned. Since that can be done before breathing is compromised enough to cause CO2 retention, oxygen can be used safely. When feeding tube insertion is done later, it can be a problem. My suggestion is that anyone who is planning a PEG insertion have their CO2 levels checked a few days before to determine the degree of risk from oxygen and a consult between the Pulmonologist and GI doctor inserting the tube concerning the need for BiPAP and use of oxygen versus changes to the BiPAP settings if sedation and pain meds slow respirations.

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Research Updates provided by ALS July Connections

New ALS Therapy Target Highlights Role of RNA Processing in the Disease

Researchers have identified a new therapy development target that strengthens the evidence that defects in cellular processing of RNA are important in the development of ALS. The identification of this new target may be relevant to over 90 percent of people with ALS.

The research showed that motor neurons can be protected from disease-related toxicity by human up-frameshift protein 1 (hUPF1). When either of two disease-related proteins, called FUS and TDP43, were expressed in cultures of motor neurons at levels sufficient to cause neuronal death, co-expression of hUPF1 saved up to half the neurons.

The researchers, including The ALS Association-supported scientist Steven Finkbeiner, M.D., Ph.D., of the Gladstone Institutes in San Francisco, showed that the protective effect was due to its promotion of a process called nonsense-mediated decay of messenger RNA (mRNA). mRNA is an essential cellular messenger between genes and the proteins they encode. Disturbance of mRNA processing has been implicated in several forms of ALS. hUPF1 did not protect against ALS due to mutations in the SOD1 gene, which is not believed to involve disruption of mRNA processing.

“These important results tell us in even stronger terms that ALS is not a single disease,” according to Lucie Bruijn, Ph.D., M.B.A., Chief Scientist for The ALS Association. “These findings emphasize the importance of RNA processing for most forms of ALS, and suggest that promoting hUPF1 might be therapeutic. They also tell us that therapies for SOD1-related ALS might require different strategies and that clinical trials may have the greatest chance of success if they target people with similar forms of ALS.” http://web.alsa.org/site/PageNavigator/connections_research1.html

Navigating Life with ALS

This tool provides an overview of the many things to consider when ALS has touched your life, personally or professionally. Please see the following website.

http://webmn.alsa.org/site/DocServer/NAVIGATION_TOOL_updated.pdf?docID=112081

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