



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.

Our Next Meeting will be THURSDAY, 09/10/15.

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

~ August 2015 ~

18 people present. Thanks a bunch to all who made the trip to group today! It's never the same without you! 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 as we are on this journey together!

*Check out this guy's facebook page...
<https://www.facebook.com/teamjaeckel>*

August Special Guest: Gina Severson

Health Care Services Coordinator
Muscular Dystrophy Association/ALS
7401 Metro Blvd #325 Edina, MN 55439
952.697.3251

MDA ALS Caregiver's Guide

Download a printable PDF of the entire guidebook 

<http://www.mda.org/publications/mda-als-caregivers-guide>

The Journey

If you're reading this guide, it's probably because someone you care about deeply has ALS.

This guide will help you to help your loved one through the progression of the disease. It also will help you with your own journey as an ALS caregiver.

Being a caregiver for a person with ALS is emotionally and physically strenuous, but also deeply rewarding in highly personal ways. It's different from caring for a person with any other disease, and may be far more emotionally and physically demanding than other caregiving journeys. ALS caregivers have called the experience life-changing and found that it strengthens character, deepens compassion and brings relationships to new levels of love and trust.

And it's really hard work. It involves learning about new tasks and equipment, while going through the emotions that arise when a loved one has a progressive, debilitating illness. These pages contain practical and emotional strategies for being an effective caregiver. The **MDA ALS Caregiver's Guide** is meant to give guidance, assistance and advice in many aspects of caring for a person you love who has ALS.

It's full of references to other websites, publications, articles or organizations where you can go to find out more about a specific topic or product. And it's laced with quotations from other caregivers and people with ALS, meant to show you that others have dealt with everything you're facing, and they've felt the same fears, despair, exhaustion and hope that you'll be experiencing in this part of your life. You'll read many comments from people about the happiness and satisfaction they've found while living with ALS.

Resourceful caregivers have come up with ingenious solutions to their challenges. Not every suggestion works for every caregiver; sometimes you'll find a better idea than those mentioned here. Because caregiving is an ongoing, organic, creative process that's a little bit different for everyone engaged in it, this book can't include every possible idea. But we hope it provides a platform from which you can think creatively as well as information to get you started and many places in which to look for more solutions.

The primary family caregiver is the care coordinator for the loved one with ALS, the manager of the loved one's medical, social, financial and cultural life. The issue you'll face as primary caregiver will challenge you and your family in ways you've probably never before encountered. You'll make many personal decisions that will affect all of those close to you and your loved one.

Along the way, you'll interact with health care professionals, agencies, insurance companies and many other entities.

A good way to start your journey might be to hold a family meeting (including the person with ALS) and discuss who can cover which caregiving tasks, and how care for your loved one with ALS will be coordinated. One person — usually the spouse, but sometimes a parent or an adult child, sibling or other loved one — becomes the primary caregiver. Other caregivers should treat this person as the leader, the one who coordinates and keeps track of the loved one's many needs.

Those needs will change, sometimes rapidly, so more tasks will need to be assigned and your list of caregivers and helpers will grow. From the beginning, think of caregiving as a group endeavor, not something to be done by a single person — otherwise, burnout and collapse are more likely.

No doubt you've heard it said you must "care for the caregiver." This isn't an empty phrase. You must find a balance that allows you to give quality care to your loved one and still maintain your emotional and physical strength. This means that in the course of your journey, you'll need to find other people to help.

This guide offers strategies for maintaining your strength and finding help.

It frequently refers to MDA's [*Everyday Life with ALS: A Practical Guide*](#). Everyone with ALS who's registered with MDA is entitled to a free copy of *Everyday Life* from their local MDA office. These two books are meant to be used together. *Everyday Life* focuses on practical strategies and equipment, and is written for the person with ALS, though of course its information is invaluable for caregivers as well. *Everyday Life* covers: equipment for daily living, saving energy, home modification, equipment for mobility, speech and respiratory issues, transfers and exercise.

In the *MDA ALS Caregiver's Guide*, the approach is a little different. This book is geared to what caregivers need to know, including how to know when some aspect of your loved one's condition has reached a crisis stage, and provides answers to what caregivers can do at various points for their loved ones with ALS.

"I will forever treasure the time I was able to spend with my mom during her illness. I learned so much about strength, courage and grace from her. There were tough times (mostly due to my impatience!) but the good times were extraordinary!"

"I was worried about everything that people worry about in this situation. How would I take care of my husband? How would I keep my job? How does this disease unfold? How will I know what to do? How will this affect our son? Will my insurance be enough? Will we become destitute? Will I be strong enough to support him through this? Will I be physically strong enough to even move him? Will we be able to plan for the future? All the questions that people lose sleep over were the questions that plagued me day and night."

It's been nine years since Glenn was first diagnosed. I have changed. I discovered that I have faith in myself. I can trust my instincts, and I believe in my basic selfworth. I understand better who I am and what I'm doing with my life, and that is what really matters." — Caregiver's Reprieve, by Avrene Brandt, Impact Publishers, 1998

“As caregivers, we have the potential to burn out both emotionally and physically. My biggest piece of advice is: Don’t! I wore myself out, and that caused my husband more anguish.”

“I’m not “saving” anything; we use our good china and crystal for every special event such as losing a pound, getting the sink unstopped or the first amaryllis blossom.”

“To be able to care for someone or to be needed is a pretty good high. There were good times and a few bad times – usually 3 a.m. and no matter how I placed the pillows he wasn’t comfortable. The bad times were few and far between. We caregivers are the lucky ones: You will never be a burden, let us have the good feeling by taking care of you. Besides, maybe we will find the cure soon. Every day is one day closer to the cure.”

***Questions, concerns, or input please contact:
Julie Chamberlain, LPN, 715.271.7257 or alsnwwi@gmail.com***

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.

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!**

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!**

Informative miscellaneous articles

ALS From Both Sides

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

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

Choking: Variations on a Theme

It's not uncommon in ALS for something unexpectedly and abruptly to aggravate your airway and throw you into a choking fit. I know from personal experience that these choking, gagging, gasping spells are physically exhausting, frustrating and extremely unnerving for both the choker and the caregiver. The actions to take for choking depend on the type of choking spell you're having. For example:

- The Heimlich Choke

A large piece of food completely blocks the airway. You can't speak or cough. This is an emergency! It requires the Heimlich maneuver, either by a caregiver or self-administered, to force the blockage up and out. If not successful in two tries, call 911 and continue trying the Heimlich while waiting for help.

- The Damn-Near Heimlich Choke

A pill or bit of food sticks in your throat. After a moment you can breathe but with a scary “heeee” sound. Just as you start getting a little air in, you start coughing and/or gagging again. Over and over. You can feel the darn thing stuck in your throat teetering between sliding up and making you gag and sliding down and making you cough. This is scary, exhausting, but you can get a breath in between coughing spells. The Heimlich or assisted cough technique may help. Focus on getting the obstruction up and out, not down the throat, because of the danger that it will lodge more firmly or go into the lungs. Therefore, avoid back whacking!

- The Foodless Sneaky Choke

You’re just sitting there minding your own business or even snoozing when suddenly you’re coughing and choking. A simple swallow of saliva goes awry and sends your larynx (vocal cords) into a spasm that closes off your airway. This is called a laryngospasm and isn’t uncommon in ALS. You fight to inhale but nothing happens. You can’t take a breath, can’t call for help, and panic crashes over you. After an eternity, you finally suck in a thin, wheezing, tiny “eeee” breath. Slowly the spasm eases.

The only thing I’ve found that helps me through these is the hard-learned lesson that they’re intense but short-lived. You’re not really choking, you can get some air, and the spasm will ease in just a moment or two.

Caregivers can help by giving calm reassurance, gentle back rubbing (not whacking) and other support in riding out the spasm.

- The Phlegm From Hell Choke

You try to clear your throat. Hrrrmph. Hrrrrrrrmph. No good. Over and over you try to break up and cough out the thick clog in the back of your throat until you’re worn out and gasping. My treatment is to take a dose of papaya juice or expectorant (guaifenesin, available over the counter) to thin the secretions. Then I lie down (BiPAP on) and have my caregiver do an assisted cough or use a cough assist machine. By lying down, I don’t have to fight gravity to bring the mucus up. Staying well hydrated can help keep secretions thinner.

- The Non-Choke Sticker

A pill or bit of tortilla chip sticks on the way down and sits there feeling like a thorn in your throat. This little sucker can hurt for a day or more. After taking a small sip to make sure I can still swallow, I try taking the longest drink I can. Sometimes this repeated swallowing does the trick.

Advice to Caregivers: In any choking situation, fake being calm and quickly go through a list of possible actions. Ask, “Do you need a Heimlich? Assisted cough? A drink? Cough medicine? Suction?”

Besides the physical and emotional stress of a choking attack, the real danger of suffocation and the loss of calories due to fear of eating, choking can lead to aspiration, in which food or pills go into the lungs and cause life-threatening pneumonia.

Prevention is the key here.

- A consult with a Speech Therapist and a Swallow Study needs to be done when swallowing problems begin. 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.
- People with even minimal swallowing problems should never eat when home alone.
- Soft, moist foods are generally easiest to swallow. Dry, crusty, flaky, crumbly foods, or those with small pieces such as rice, raw veggies, or ground beef are tricky. Adding sauces or gravy helps prevent choking.
- Cut everything into small pieces and take smaller mouthfuls.
- Bread and melted cheese are especially likely to form large "plugs" and require extra care.
- Alcoholic drinks before meals increase the risk of choking.
- The sensory stimulation of hot or cold foods and liquids can increase the muscle response when swallowing.
- Reduce distractions at meal times. Talking while eating may be sociable, but minimize your part in it.

- If you choke almost every time you eat and meal times are a dreaded experience, a feeding tube is overdue. 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.

Research Update - provided by ALSA

Upcoming Webinars

Why do people get ALS? Epidemiological studies to find answers

Speakers: Björn Oskarsson, MD, Associate Professor of Clinical Neurology, Director of UC Davis Multidisciplinary ALS Clinic; D. Kevin Horton, DrPh, MSPH, CPH, ATSDR; Hiroshi Mitsumoto, MD, DSc, Eleanor and Lou Gehrig MDA/ALS Research Center.

Date: September 22, 2015

Time: 4:00 p.m. EDT

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