



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, 10/08/15.

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

Special Guest: Diane Fergot, CSW, Care Services Coordinator for the Wisconsin Chapter. Diane shares her professional knowledge of ALS as well as her personal walk in supporting a dear friend through the ALS journey.

~ September 2015 ~

11 people present. Various topics were discussed from Tobii communication devices, Feeding tubes, and Primary lateral sclerosis (PLS) which only affects upper motor neurons without the degeneration of spinal motor neurons as seen in amyotrophic lateral sclerosis (ALS). So good to see everyone who gathered!

*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, June 12, 2016!**

Informative miscellaneous articles

Today's Caregiver

Guide to Medicare By Dr. Rhonda Randall

More than [90 million](#) Americans provide care or support for loved ones with chronic illnesses, disabilities and frailty, according to the Caregiver Action Network. It can be a tough job – particularly when it comes to navigating health care.

As we observe [National Medicare Education Week](#), Sept. 15-21, I offer a bit of a refresher on Medicare that I hope helps caregivers who may be managing a loved one's health care, since Medicare's Open Enrollment Period (Oct. 15-Dec. 7) is just around the corner.

First things first – what do all of those Medicare letters mean?

- Part A: Part of Original Medicare, which covers hospital insurance.
- Part B: The other piece of Original Medicare, which covers medical insurance (doctor's visits, preventive care, etc.).

And what is Original Medicare? It is the health insurance program offered by the federal government, and generally covers 80 percent of medical expenses, with the individual responsible for the other 20 percent.

- Part C: Also known as Medicare Advantage, these plans include all the coverage of Original Medicare plus additional benefits such as access to a nurse helpline, hearing, dental and/or vision coverage, or a gym membership. All Medicare Advantage plans also have a maximum out-of-pocket limit, so you can better predict how much your loved one may have to pay for health care services each year.
- Part D: Prescription drug coverage, which is often included in Medicare Advantage plans but can also be purchased separately for those with Original Medicare.

Medicare Advantage plans and Part D prescription drug plans are provided through private insurance companies that are approved by the government. There is also Medicare supplement insurance – sometimes called Medigap. Medigap plans are also provided by private insurance companies and cover some of the costs that are not covered by Medicare Parts A and B for people with Original Medicare.

Once you understand the different types of Medicare coverage available, you need to look at the costs and coverage benefits to determine which plan is right for your loved one. When comparing the different options, take into account the following:

- The costs: Copayments/coinsurance/premium/deductible
- The health care providers: Review the plan's network of hospitals and physicians, if there is one, to make sure the health care providers your loved one uses are included
- The formulary: Make sure the prescription drugs your loved one takes are covered by the plan on the list of approved drugs, known as the formulary

I'll leave you here with one of the most important pieces of advice I can provide – don't be afraid to ask for help. Understanding Medicare is only one part of the challenge you face as a caregiver and there are resources available to help you, such as MedicareMadeClear.com. Caregivers can also visit a local SHIP (State Health Insurance Assistance Program) office with their loved one where they can speak with a counselor who can answer their questions and help them understand their health care choices.

Remember, the Medicare Open Enrollment Period is nearly upon us – Oct. 15 to Dec. 7 – so now's the time to start looking into Medicare options and determine which is best for your loved one.

ALS From Both Sides

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

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

Constipation in ALS

Although we joke about constipation, it is a miserable experience and should never be taken lightly in the ALS patient. Loss of appetite from frequent constipation leads to weight loss, weakness and dehydration. Constipation can progress to blockage in the intestines and nausea, vomiting, and abdominal distension. (Vomiting is very dangerous for a person who cannot turn over when lying on his back because it causes choking.) One early sign of blockage is often overlooked. Repeated small very loose or liquid stools may be ignored or thought to be sufficient when they are actually the result of a large amount of hard stool blocking the bowel with only liquid stool being able to pass

around it. The blockage can become so severe as to require hospitalization and possibly even surgery to correct.

What is constipation?

That may sound like a foolish question, but many people think of constipation as having infrequent, dry, hard bowel movements. It is actually defined simply as having stools that are hard to pass. Many people have only a couple of bowel movements a week, but if they do so without straining, they are not constipated.

Normally food is liquified in the stomach by digestive juices and moves through the small intestine in liquid form. Nutrients are absorbed in the small intestine. Waves of muscle contraction called peristalsis moves the remainder along into the large intestine. In the large intestine, water is reabsorbed from the left over waste product, leaving just fecal material (stool) which is moved along and passed out of the body in a bowel movement.

Anything that changes the speed with which foods move through the large intestine interferes with the re-absorption of water and causes problems. Rapid passage causes diarrhea, slowed passage allows too much water to be reabsorbed, leaving hard, dry stool that doesn't move easily through the bowel. Common causes in ALS patients include:

- Many medications affect bowel function. Prescription pain medications are especially constipating.
- Certain foods, a poor diet or changes in diet.
- Constipation is very common in anyone with poor mobility because lack of activity and exercise slow bowel motility.
- Long delays in getting to the bathroom further complicate the problem by keeping the stool in the large intestine longer where it becomes drier and harder.
- There is some evidence that ALS can affect the autonomic nervous system as well as skeletal muscle and slow the entire digestive process.
- In ALS swallowing problems make getting a good diet and sufficient fluids and fiber difficult and the problem gets worse.

- Breathing problems make it difficult to take a deep breath and bear down, something we don't even realize is important in having a bowel movement until we cannot do it.

Because so many things contribute to constipation in the ALS patient, the solution may change over time.

How to Prevent or Treat Constipation

- **Diet**

The first - and best - way to approach constipation is by improving your diet.

1. Drink lots of fluids.
2. Eat lots of high fiber foods. (Check with your doctor if you have other digestive or bowel problems or are on a special diet.) There are many high fiber cereals available and granola bars are convenient and easy to handle when feeding yourself begins to be difficult. Raw fruits and vegetables are also easy to eat sources of fiber if swallowing is not a problem.
3. If you are using tube feeding, fiber is added to most tube feedings formulas. Check the label to see if your brand has added fiber.
4. When diet alone isn't quite enough, try the old remedy of prunes or prune juice for occasional constipation. It really does work!

- **Laxatives**

There are many types of laxatives available without a prescription. For frequent or chronic constipation common to ALS patients it is very important to begin with the mildest types. Everyone's bowel pattern is different. Very few people need to have a daily bowel movement. Every other day or every third day is probably most common. Insisting on a daily bowel movement and using laxatives to try to attain it is asking for trouble!

There are 5 basic types of laxatives:

1. **Fiber (Bulk)**
 - a. Fiber laxatives supply the fiber necessary to add bulk which holds water and makes it easier to move the stool through the bowels.
 - b. Today's over-processed foods are low in fiber to begin with and when swallowing problems begin there is usually even less fiber in the diet.

- c. Fiber laxatives are very slow acting and are taken daily to prevent constipation rather than for relief of existing constipation.
- d. Generally the first laxative recommended for frequent constipation, fiber laxatives are also ideal for long term use because the fiber is not absorbed.
- e. Two well known brands are Metamucil and Citrucel. Available without a prescription, some use natural fiber (agar, psyllium, kelp and plant gum.) Others are synthetic cellulose (methylcellulose). Natural and synthetic bulk-forming laxatives act similarly.
- f. Fiber laxatives are available as a powder (which is mixed with water or juice and generally needs to be swallowed fairly quickly before it thickens to a goo, though newer brands without that problem are available.), a tablet, or a wafer.
- g. It is possible to be allergic or sensitive to flavorings or other additives. Some brands may also contain enough sugar as to cause problems for diabetics.
- h. For the ALS patient there are two concerns with this type of laxative;

1. *It is essential that fluid intake be very good.* 8 ounces of fluid must be taken immediately with each dose and more throughout the day is needed for safe, effective use. Taking fiber laxatives without enough fluid can cause intestinal blockage.

2. *They are not to be used when swallowing problems begin.* Failure to drink enough water to wash down the fiber might allow it to begin to swell in the esophagus and this requires immediate medical attention. Fiber laxatives can safely be given through a feeding tube, but the fiber needs to be promptly followed by flushing the tube with water to prevent clogging.

2. **Stool Softeners**

Stool softeners, also called emollient laxatives, also keep the water content of the stool higher which keeps it softer and allow it to move more easily through the

bowels. Stool softeners are often ideal for ALS patients. Not only do they help keep the stool soft when fiber and fluid intake is difficult, but they also are very helpful when breathing problems make it difficult to bear down and push. They do not cause frequent bowel movements, cramping or urgency but greatly reduce the amount of straining needed to have a bowel movement. Stool softeners are taken daily as a preventive measure rather than to force a bowel movement on a certain day.

Stool softeners are available in pill or liquid form. Colace is the most commonly prescribed stool softener, but there are many non-prescription brands of the active ingredient, docusate, available, such as Surfak. Liquid docusate is also available without prescription but the pharmacist will probably have to special order it for you as it is seldom stocked by drug stores. (Note: liquid ducosate needs to be diluted in juice for drinking or it burns all the way down!!!!)

3. *Hyperosmotics*

Hyperosmotic laxatives draw water into the bowel from surrounding body tissues, softening the stool. There are three types of hyperosmolar laxatives.

- a. The saline type is the most well known -- and disliked! Saline laxatives are harsh, fast acting, and total in effect. They are primarily used to completely clear the bowelin preparation for surgery or bowel exams.
- b. The polymer type is a a large molecule that causes water to be retained in the stool to soften it and increase the number of bowel movements. It is not used long term.
- c. Of the three types of hyperosmotic laxatives only one, lactulose, is useful for preventing constipation. It's action is so much less rapid and harsh than the saline that it is often used for long-term treatment of chronic constipation. Because it has sugar-like properties it may not be suitable for diabetics. Lactulose is available only by prescription.

4. *Lubricant Laxatives*

Lubricants use mineral oil to coat the stool for easier passage. Mineral oil should

not be taken by patients with even the slightest swallowing problem. Aspiration of oil into the lungs causes chemical pneumonia.

5. *Stimulant Laxatives*

a. Stimulant Laxatives increase the muscle contractions (peristalsis) of the bowel which moves the stool along. Most are intended to be fairly gentle and result in a bowel movement within 6- 12 hours, but even these can cause cramping. If constipation is already making you uncomfortable, stimulant suppositories will provide relief within a hour but are likely to cause cramping.

b. Stimulant laxatives are not for continuous or long term use! Even in ALS, they should be reserved for occasional use until other methods fail. Frequent use of stimulant laxatives can actually aggravate constipation because the bowels become dependent on them for the stimulation for even normal peristalsis. These laxatives work by irritating intestinal nerve endings, which in turn stimulates muscle contractions that move the irritant through the gut and out of the body. After a while the nerve endings no longer respond to this amount of stimulation and larger doses are needed. For long term ALS patients, after years of frequent use, the nerves of the colon slowly disappear, the colon muscles wither, and the colon becomes dilated and unresponsive to laxatives.

c. The majority of non-prescription laxatives are stimulants and contain senna, castor oil, cascara, aloe, bisacodyl, or combinations. These laxatives are often marketed as being safe, "natural" remedies because the active ingredients come from plants. That makes them " natural" but does not make them safe, because like many other plants, they are basically poisonous. That is why the body finds them irritating and reacts so quickly to get rid of them.

Reglan

Another medication sometimes ordered is Reglan. Reglan works primarily in the stomach to empty it faster in order to reduce nausea, vomiting, or esophageal reflux. It's value in treating constipation is minimal.

Enemas

Enemas are necessary for relief occasionally, but are the last resort as a routine method of bowel management. The repeated distension of the bowel will eventually cause loss of

bowel tone which aggravates the problem. This "eventual" problem is not a concern for the ALS patient who does not plan on going on a vent, but should be considered when planning a bowel program for long term use.

Establishing a Bowel Routine

Very few people need to have a daily bowel movement. Every other day or third day is typical. Having a routine time when you can spend a longer period of time on the toilet is helpful. Although choosing a time is probably going to be more a matter of convenience for your caregiver, if you already have a certain time of day you are more likely to have a bowel movement, try to arrange for that time.

If having a bowel movement at a consistent time of day is important because you don't always have the necessary help to get to the toilet the rest of the day, you can encourage that schedule. Begin by using a stimulant laxative suppository to promote bowel movements on the scheduled day at the chosen time. After 2 weeks, use the suppository only if you can't have a bowel movement on your own. Within a month, you should be able to reduce reduce the stimulant laxative use to infrequent.

An unrushed and private bathroom trip is ideal, but safety and security need to be assured. Having some type of buzzer or doorbell type button (available from Radio Shack) to call for help works well. Arm rests and a seat belt might be necessary for safety. (The correct and safe angle for a seat belt is diagonal as they are in cars: The belt is around the hips and anchored lower. A belt anchored behind you at stomach level will allow you to slide down through it and end up tight around your chest.)

Sitting upright and as comfortably as possible is also important. A padded toilet seat can be a life saver!

Using a footstool will help put you in the most natural position for a bowel movement, a squatting position. It really does make a difference! Leaning forward over a pillow can help provide the necessary intra-abdominal pressure for pushing.

Drinking a cup of coffee or other hot beverage before or while in the bathroom will often help. Warm water through a feeding tube works as well.

Updates - provided by ALSA

Influenza (“flu”) is a contagious disease that occurs every year, usually between October and May. People with ALS are already at increased risk for respiratory problems associated with viral and bacterial infection, and the flu can lead to pneumonia and serious blood infections. The flu can also cause decreased appetite and a severe cough, both of which are significant problems for people with ALS. Each year thousands of people in the United States die from influenza, and many more are hospitalized. The flu vaccine can keep you from getting the flu, make the flu less severe if you get it, and keep you from spreading it to other people. A dose of flu vaccine is recommended every flu season for people with ALS, their family, and caregivers. Only one dose of the vaccine is needed each flu season. There is no live flu virus in flu shots. They cannot cause the flu. It is also recommended that people with ALS receive the pneumonia (Pneumococcal) vaccine to help prevent pneumococcal pneumonia, caused by the pneumococcus bacteria. Immunity to the pneumococcus lasts several years but you need a new flu shot each year. Talk to your healthcare provider or ALS Clinic about whether or not you should receive these valuable vaccines

End.