



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 not be until THURSDAY, 07/09/15.

***The Healing Place will be our special guest
sharing information about grief.***

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

~ June 2015 ~

**ALS Annual Walk & Wheel-A-Thon held
June 14, 2015 at Chippewa Falls Fair Grounds:**

Website: www.alsnwwi.org

Over 350 people were present to honor and remember loved ones touched by this horrific disease. Old and new friends gathered to share stories, bring awareness, and raise the necessary funds to support local families, as well as supporting research in finding a cure!

Thank you Brenda and the ALS walk committee for your dedication in planning this wonderful event and a special thank you to Ellen and the kitchen crew for working hard to provide us with our free picnic lunch! Last but not least... We are so grateful to each of you who attended as we realize it is not always an easy task for various reasons. Your presence alone makes all the difference!



Please go to www.alsnwwi.org to view photos of the day!

Caring for our Caregivers

**Sans Souci Massage
927 Loring St. Suite 4
Altoona, WI 54720**

Has generously offered a massage a month to our caregivers.

All appointments are made through Julie at the ALS Support Group Office 715.271.7257. If you are interested in this wonderful treat or you know of someone, please call.

Thank you Sans Souci for this generous gift!

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!](#)

Caregiver Stress

Provided by Today's Caregiver Newsletter

Caregiver Newsletter, June 11, 2015 • Issue #820 By Benjamin Lamm

5 Things Caregivers Need to Know About Medicaid-Sponsored Home Care

The home care industry is booming, in part because of the sheer size of the current generation of retirees. Also, because many baby boomers, famous for “doing things their own way,” are choosing to move away from traditional nursing home care and considering other senior living options, like aging in place, memory care or community living.

The Bureau of Labor Statistics foresees a 70 percent increase in the amount of people who will need in-home care over the next 10 years. Unfortunately, many people are not prepared to pay for their own in-home care, which means they may find themselves dependent upon assistance programs.

Does Medicaid Pay for In-Home Care?

The type and amount of coverage varies by state, and the eligibility guidelines are subject to frequent change. It is often advisable to reach out to a Medicaid planning expert or educate oneself thoroughly so one can gain access to the Medicaid-sponsored care one requires.

The short answer, though, is that every state provides some form of care options for the elderly or handicapped. Generally, Medicaid doesn't technically fund in-home care unless there is an express medical condition. Instead, waivers of Medicaid rules are applied, which in turn provide the funding for these home and community based services.

What In-Home Services Does Medicaid Offer?

Once again, specific services vary by state, but Medicaid in-home services are generally very limited. They fall under the heading of “Home Health Services,” and they are only allowed for direct medical care – typically for a short-term illness or recovery period. There is a limit on the amount of hours of care allowed over a set period of time, or limitations may be upon the amount of care visits allowed per week. For example, you may be allowed two physical therapy visits weekly, or only 120 hours of nursing visits over a six-month period.

What Exactly Are Home and Community-Based Services programs?

This brings you back to the home and community-based programs mentioned previously. The waivers issued for these services can give you access to in-home health and nursing care, physical therapy, and medical assistive devices and transportation. They can also help with ongoing care needs, such as adult daily living services, meal preparation or delivery, and adult day care services.

Who is eligible for Medicaid-sponsored in-home care?

Eligibility for Medicaid-sponsored care requires two parts, whether it's for Home Health Services or a waiver program;

First, you must show need for the services. This is done by both an evaluation by your doctor and from the program servicing center. Generally, need must be high enough that without in-home care, the applicant would require nursing home care.

The second part of the application process requires showing financial need for assistance. These programs are limited to low-income individuals with few assets. Exact income and asset ceilings depend on the state, but generally the waiver programs allow for higher income and assets than regular Medicaid allows.

Can a family caregiver get paid by Medicaid?

Sometimes it's preferable to have a family member provide care, such as a spouse, parent or adult child. The main problem with this is the family member likely will not have time to earn an income outside of the home. In some states, there are waiver programs available that pay family members for the in-home care they provide. You will have to check with your state's Home and Community-Based Service plans to see if they are available and if you qualify.

ALS From Both Sides

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

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

Effective Coughing

I remember all too well the hours spent try to clear my airway with a cough too weak to do the job. Frightening for everyone and so exhausting! Get a Cough Assist machine as soon as possible. A Cough Assist machine mimics a strong, natural cough. A full breath is pushed in through a mouth piece then the pressure is abruptly reversed to a suction level causing the equivalent of a good cough. Quick and easy. The machine can be set to automatic or to manual where the patient times his cough with the machine's inhale and reverse cycle. I don't recommend the manual setting because if you feel really short of breath it is hard to relax and time your cough. Not to mention that someone as uncoordinated as I am may never get the hang of it!



The Cough Assist can be used with a mouthpiece or a mask. It can also be put on a trach. It is portable at 10x11x17 inches and 26 pounds.

Ideally you have a Pulmonologist and if you don't it is time to get one. A neurologist and family doctor are not the ones qualified and experienced with the breathing problems in ALS. The pulmonologist will likely be the one who sees you through to the end.

While waiting for the Cough Assist machine to arrive, here are some things you can do. Buy an expectorant cough medicine containing gauifenesin or only gauifenesin. It quickly loosens mucous. When you feel congested, take a generous dose of the cough medicine. Give it a few minutes to work, then lie down. This will feel like the absolute wrong thing to do! But lying down will allow the mucous to be propelled upward more easily with gravity less a factor. Lying down will also allow someone to help by applying a manual assisted cough. To do this place both hands on the abdomen just below the ribs. This can be done with the hands one on top of the other as is done in CPR, or with the thumbs together in the center and hands out toward the sides. Have the patient take three deep breaths if possible and on the third to cough. With the cough, apply a quick thrust, not just pressure. Direct the thrust upward under the ribs. This will give that "Oof" of having the wind knocked out of you. That will add force to the cough and move the mucous upward. Repeat a couple of times. Rest between assists and repeat until the airway is cleared.

You will also want a suction machine and what is called a "tonsil tip" plastic wand (brand name Yankauer) to help remove the mucous from the mouth if necessary. You may not have to use the tonsil tip suction wand at all, but just having it ready is a much needed reassurance for everyone.



Increase water intake to keep the mucous from being thick and sticky. If swallowing water is difficult, make sure it is hot or cold. In between, the water won't trigger a good swallow. You can also try adding a thickener such as "Thick-It" to any liquids to make them just a tiny bit easier to swallow. Water is actually the hardest thing to swallow. Flavored or fizzy drinks may go down better as will milk (not advisable as it can increase congestion) or orange juice. If swallowing liquids is difficult, it is time for a feeding tube. You may not need it yet for nutrition, but good hydration is critical for the lungs. A cup of water down the tube about four times a day helps all body systems including the ever problematic bowels!

Research Updates provided by ALS June Connections

New Mouse Model of the Most Common Genetic Cause of ALS

May 21, 2015

Researchers funded by The ALS Association have for the first time created a mouse model of the disease using the mutant C9orf72 gene that displays key elements of disease pathology. The model will likely prove highly valuable in studying the disease process and testing therapies against this form of the disease. The study was published in the journal [Science](#) on May 14, 2015.

An expansion mutation in the C9orf72 gene is the most common genetic cause of ALS, responsible for up to 40 percent of inherited cases and about 6 percent of sporadic cases. The same mutation is also a cause of frontotemporal dementia (FTD). The mutation increases the number of “CCCCGG” repeat units in the gene from the normal number of less than 10 to hundreds or thousands. This extra DNA leads to production of “sticky” RNA, which may cause disease by sequestering multiple proteins, and to the production of unusual proteins, called RAN proteins, which may themselves be toxic.

The new study was led by Leonard Petrucelli, Ph.D., and conducted by Jeannie Chew, both of the Mayo Clinic in Jacksonville, Fla. The researchers created mice carrying the C9orf72 gene with either two (normal) or 66 (mutant) repeat units. In the mutant mice, cells throughout the central nervous system showed the accumulations of RNA and presence of RAN proteins seen in people with this form of ALS. Affected cells also developed aggregates of the protein TDP-43. Such aggregates are the pathological hallmark of most forms of ALS. Neurons in the nervous system died, and the mice displayed both behavioral and movement symptoms analogous to those seen in ALS and FTD. Other mouse models in development (currently unpublished but presented at scientific meetings) and supported by The ALS Association using the C9orf72 mutation show some interesting aspects of the human disease but have not been able to reproduce this same level of widespread pathology. These models are generated mostly by introducing the repeats onto a bacterial artificial chromosome. In contrast Dr. Petrucelli created their model using adeno-associated virus (AAV) to deliver the mutant gene throughout the mouse nervous system. This illustrates the importance of supporting multiple approaches to generate models for ALS. AAV is being widely studied as a tool for delivering therapeutic genes to the brain and spinal cord, including in ALS.

“This is a significant advance in our quest to understand ALS due to the C9orf72 gene mutation,” said Lucie Bruijn, Ph.D., M.B.A., Chief Scientist for The ALS Association. “This new model will allow us to understand better how the mutation causes disease within a mature nervous system, and what protective mechanisms we can take advantage of to slow the disease process, both for ALS due to this mutation and to other forms of the disease. Just as importantly, we can test treatment strategies that shut down the

expression of the mutant gene, which may be the most direct avenue for therapy in this form of the disease.”

Further details of the study and the potential reasons why this approach is more successful in generating a model that looks more like the human disease are discussed in an article on the [Alzforum website](http://www.alzforum.org/news/research-news/first-c9orf72-mice-mimic-key-pathology-behavior). <http://www.alzforum.org/news/research-news/first-c9orf72-mice-mimic-key-pathology-behavior>

End.