



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, 11/12 /15.

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

~ October 2015 ~

13 Attendees

Special Guest: Diane Fergot, CSW, Care Services Coordinator for the Wisconsin Chapter. Diane shared her professional knowledge of ALS as well as her personal walk in supporting a dear friend through the ALS journey. The following topics/information was discussed: The importance of having advanced directives in place to avoid emergency room decisions; Medicare coverage change regarding speech generating devices (see detailed article on pg. 3 below); how bulbar onset differs from Limb onset. Rilutek/Riluzole benefits. Eye gauze equipment is most successful when learned early in the game, there is a desire to learn, and energy is present to do so; The frustrations of wanting to prepare ahead by getting resources and equipment in place for the ALS journey when Medicare won't cover the cost until it's deemed "necessary"; Hopeline Magazine can be viewed online at <http://www.alsawi.org/#!/hopeline/cjnq> Grant program into can be accessed at <http://www.alsawi.org/#!/brian-trinastic-memorial-grant-program/c23gr>

Thank you Diane!

Misc. discussions: Movies mentioned & recommended: "A Walk in The Wood" and "The Inter". ALS information flyers provided to local clinics and hospitals were requested.

*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

The Latest on Medicare Coverage of SGDsRecent changes in speech-generating device policies leave SLPs wondering: What, exactly, is covered?

Lisa Satterfield, MS, CCC-A Bottom Line | July 2015

“Upheaval” describes coverage of speech-generating devices (SGDs) for Medicare patients in recent years. In 2014, strict enforcement of the Medicare policy requiring a device to be “dedicated” only to speech-generation forced manufacturers to remove Internet, email and other non-speech features.

Medicare’s rent-to-own policies keep patients waiting 13 months to assume ownership of their devices. Medicare’s denials of eye-tracking features limited manufacturers’ ability to provide these medically necessary accessories for patients with severe physical limitations.

After concerted advocacy efforts, policies are shifting back in favor of patients.

Here’s where we are today.

Does Medicare now cover all augmentative and alternative communication devices?

No, it does not. Medicare will cover only equipment and devices that meet the definition of “durable medical equipment.” The only communication devices that meet this definition are SGDs and voice amplifiers.

Does Medicare cover tablets?

No, Medicare does not cover tablets or computers. SGDs are defined as durable medical equipment used solely by the patient with a severe speech impairment. Personal computers are defined as “non-medical equipment.” Speech-generating

software that patients download onto personal computers or devices, however, is a covered benefit.

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Can a patient “unlock” the Internet features on a device?

Yes, Internet accessibility is expected to be covered under regulations scheduled to take effect this month. The final National Coverage Determination (NCD) that defines SGDs would allow manufacturers to “unlock” these features on current devices. SGDs distributed after the start date of the NCD may have Internet and email, and additional non-covered features (such as video-conferencing and environment control) will not need to be locked. Manufacturers may distribute devices with these additional features, but the Medicare beneficiary is financially responsible for anything outside the speech-generation, email or Internet capability benefit.

Internet accessibility is expected to be covered under regulations scheduled to take effect this month.

Does this mean Medicare will cover Internet services?

No, “allowed” is not the same as “covered.” The regulation explicitly states that Internet and phone services, or modifications to a patient’s home to use the SGD, are not a Medicare benefit.

Will Medicare cover eye-tracking accessories?

Yes, eye-tracking will be covered. Although the rule was not explicit, Medicare officials have assured ASHA that medically necessary accessories are a covered benefit. Regional Medicare policies state that accessories are covered when reasonable and necessary.

Can my currently hospitalized patient get an SGD?

The hospital/inpatient facility is responsible for ensuring that patients have the medical equipment they need. However, an SGD for home use cannot be ordered while the patient is under the inpatient (Part A) benefit. Medicare covers SGDs for home use as an outpatient (Part B) benefit.

When does my patient own the device?

For devices distributed from April 1, 2014, through Sept. 30, 2015, Medicare pays the device manufacturer for the SGD over a period of 13 months, after which the patient owns the device. Pending legislation that has passed the Senate and the committee of jurisdiction in the House would lift this capped rental policy for devices distributed on or after Oct. 1, 2015, and the beneficiary would have immediate ownership. House passage is expected before Congress adjourns for the August recess.

How do I help my patient obtain an SGD?

The process for getting a device has not changed. The speech-language pathologist performs a comprehensive evaluation and sends the report to the patient's physician. The physician attaches this report to the order for the SGD. The manufacturer provides the device and submits the claim to Medicare for reimbursement. The SLP should work with the manufacturer to ensure that the evaluation meets the coverage guidelines.

ASHA's website offers more [information about evaluation requirements and Medicare coverage for SGDs](#).

Nip Depression in the Bud: Warning Signs to Look For

Today's Caregiver.com
By Mary Damiano
Oct 27, 2015 - Issue #859

While caregivers are defined as the people taking care of those needing help, they sometimes overlook the fact that caregiving responsibilities can take a toll on their own health.

In addition to physical ailments, caregivers are at risk for depression. Depression can strike anyone, at any age. Caregivers need to be especially aware of depression because of the great load they carry. Many caregivers work at a full-time job and take care of a family in addition to their caregiving responsibilities. They often sacrifice their own health, well-being and social life in order to do everything that needs to be done.

One common denominator among caregivers is the desire and the belief that they must do everything themselves. Often, caregivers do not ask for help, opting instead to inadvertently play the part of the martyr. This leads the caregiver to become overwhelmed and an overwhelmed person is fertile ground for depression to dig in and take root.

The great strain caregivers face on a daily basis can lead to depression. One way to stop depression before it strikes is to be aware of the warning signs. According to the Administration on Aging, here are some red flags that depression might be creeping in:

- Sad, discouraged mood
- Persistent pessimism about the present, future and the past
- Loss of interest in work, hobbies, social life and sex
- Difficulty in making decisions
- Lack of energy and feeling slowed down
- Restlessness and irritability

Loss of appetite and loss of weight
Disturbed sleep, especially early morning waking
Depressive, gloomy or desolate dreams
Suicidal thoughts

If you feel yourself exhibiting these behaviors, do not discount them. They should be taken as seriously as you might treat a fever that won't go away or a persistent cough.

Below are some expert tips on what caregivers in particular can do to stop depression before it gets out of control:

Talk regularly with family, friends, or mental health professionals— it is very important that you do not isolate yourself. Join a local support group, or find one online. Share your feelings so they don't build up and escalate into problems.

Set limits— this can be hard for caregivers, because they are used to taking on everything that needs to be done. It's okay to say no to taking on more than you can handle.

Eat nutritiously, exercise regularly and get enough sleep— this can be difficult because of the irregular schedules caregivers must keep. But think of it this way: your body and mind are machines, and they must be properly maintained in order to function at their best. Nutritious food, exercise and sleep are the things that fuel these machines. Just as you would not let your car run out of gas, don't let your body run out of its fuel.

Let go of unrealistic expectations— caregivers often have unrealistic expectations of themselves, and therefore push themselves to meet these goals. Accept the fact that you can't do everything. Ask for and accept help, from friends, family and local agencies. Whatever you do, don't be a martyr.

Keep a sense of humor— we all know that laughter is the best medicine, so go ahead and take a few spoonfuls daily. Relax with a funny movie or TV show. Put on a comedy tape to listen to while you do your chores. Find the humor in everyday things.

Minivan or full size Van?

ALS From Both Sides

by Diane Huberty, Neuro RN & ALS Patient

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

Minivans:

- More appealing to those who don't want to drive a "truck".
- Will fit in all garages and parking ramps.

- Are lower to the ground making it possible to use a ramp for the wheelchair rather than a mechanical lift.
- Less interior space and less headroom makes it more difficult to use with a power chair, especially for a tall person. A power chair with rear wheel drive will not have the turning radius needed to get it into this size van. Most newer power chairs pivot closer to their center however, and should work.
- New Chevy and Pontiac models have the most headroom.
- Must have floor lowered to accommodate wheelchair. Lowered floors can bottom out when driving on rough roads or into driveways.

Full sized vans:

- More space for wheelchair and other gear.
- May not fit in some garages or parking ramps. Raised roof version will not fit.
- Must have floor lowered and/or roof raised to accommodate wheelchair and lift.
- Consider size of engine cowling between front seats. Can make it very difficult to move back to the passenger area if wheelchair passenger needs help.

Other options:

- Dodge Sprinter: Available from manufacturer in two roof heights, 64 or 72 inches of headroom, no roof raising/floor lowering conversion expense, just add a lift. High door height for even the tallest wheelchair user. Three lengths available. Ideal for traveling. Excellent visibility for wheelchair passenger. Side or rear entry.
- Ford Transit Connect. A small size utility van that is becoming very popular for wheelchair use. Rear entry only. Fold down ramp rather than lift. Two lengths available. Shorter length has seating for driver and one or two passengers. Longer length allows more passenger seating but puts the wheelchair in the 3rd row, and space may not be long enough for a power chair.

Lower the floor or raise the roof?

- Sitting in a wheelchair puts the person sitting too high to see anything out the window beyond the edge of the road. Raising the roof doesn't add height to the windows. Lowering the floor is somewhat better but the wheelchair passengers view is still quite limited.
- In order for a caregiver to stand up in the van, a real help but not essential, both floor lowering and roof raising must be done.
- A lowered floor or raised roof are generally not available as factory options and must be done by a van conversion shop.

Side or rear wheelchair entry?

Rear entry

1. Allows the wheelchair user to get in without maneuvering to turn the chair.
2. Rear entry limits the seating available for other passengers.
3. Rear entry eliminates the problem of being blocked from using the lift by other parked cars, but requires loading and unloading in traffic lane of a parking lot.

Side entry

1. Requires turning the chair to face the front. Riding sideways is unsafe as well as nauseating.
2. Requires about 8 feet of space, and another car parking too close can require moving the van to get back in. That is a mere nuisance if you are a wheelchair passenger, but if you are still driving yourself it leaves you stranded.

Folding or slide out lift?

Folding

1. Takes up some space in passenger area and partially covers the window.
2. May prevent front passenger seat from being able to move back (reducing leg room) or reclining.
3. Can be operated manually if controller fails.

Slide Out

1. Doesn't take up passenger space or block the window but does take 1.5 inches away from the headroom, a small but critical amount.
2. Harder to deploy manually if something happens to the controller.
3. May require modifying exhaust system, gas tank.
4. Enclosed but somewhat more exposed to water, snow, salt.

Automatic Lift?

- Manual is least expensive, requires a caregiver to operate.
- Semiautomatic raises/lowers the lift with a switch located on the lift, requires a caregiver to open the door.
- Fully Automatic opens door, raises/lowers the lift, and closes the door with switches located on the lift. Can be used independently if hand/arm strength allows.
- Remote control can be used instead of switches. Requires full attention and caution to be used safely.

ALS Association and Target ALS to expand Tissue Core for ALS Research

ALSA (Connections eNewsletter)

The ALS Association and Target ALS are pleased to announce the launch of a new collaborative effort to expand the collection of biofluids from people with ALS, to be used for research to better understand the disease and ultimately develop new treatments.

The ALS Association will be investing \$1,392,668 over the next 38 months. Funding from The ALS Association will allow pre-mortem biofluids (serum, plasma, and cerebrospinal fluid) to be collected and stored at the sites that comprise the Target ALS Postmortem Tissue Core at Barrow Neurological Institute/Saint Joseph's Hospital in Phoenix, Columbia University in New York, Georgetown University in Washington D.C., Johns Hopkins University in Baltimore, and University of California at San Diego. Detailed genetic analysis will be performed on all these cases at The New York Genome Center, all the data will be linked, and all of the samples and data will be made available for researchers around the world.

ALS is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord. Eventually, people with ALS lose the ability to initiate and control muscle movement, which often leads to total paralysis and death within two to five years of diagnosis. For unknown reasons, veterans are twice as likely to develop ALS as the general population. There is no cure, and only one drug approved by the U.S. Food and Drug Administration (FDA) modestly extends survival.

The Target ALS Postmortem Tissue Core is a unique resource in the field of ALS research, providing high-quality post-mortem tissue for academic and industry researchers throughout the world. Target ALS has invested \$1.04M to date into the core. The addition of pre-mortem biofluids from the same individuals will greatly expand the potential utility of the samples, by allowing researchers to explore biomarkers in biofluids that correspond to changes in tissues.

“The studies that will be made possible by the addition of biofluids to the Tissue Core have the potential to deepen the understanding of the ALS disease process and, through discovery of new biomarkers linked to specific aspects of the disease, accelerate the search for new treatments,” said ALS Association Chief Scientist Lucie Bruijn, Ph.D., M.B.A. “We are very pleased to be partnering with Target ALS on this important initiative.”

“This partnership has created a first-of-its-kind resource to lower the barriers for, and accelerate the pace of translational research in ALS. Target ALS is delighted to partner with The ALS Association on this much-needed initiative”, said Target ALS Executive Director Manish Raisinghani, M.D., Ph.D.

End.