



## ALS Support Group of NWWI

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, 2/11/16.**

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

*~ January 2016 ~*

*10 Attendees*

*Various personal concerns and experiences were shared: How do we maintain and encourage our friendships when communication becomes difficult and our visitors are no longer comfortable with these changes so they stop visiting; Understanding the different respiratory options (BiPAP, Vents & Trachs) and the challenges associated with each; The importance of changing scenery through travel gives a well needed and deserved new perspective on life. Thanks to each of you who attended this month and shared yourself with others!  
Your presence meant more than you'll ever know!*

*Tis the season for New Year's Resolutions! Most of us are pretty good at caring for others. We ensure our loved one's needs are met in various ways: comfortable surroundings; social stimuli; good nutrition; rest; contentment, etc. Wondering if this year, we might pay a little more attention to caring for ourselves!? Maybe we start by giving ourselves a*

*small piece of time every day to ponder what brings our heart joy? What makes us smile? What makes us laugh? What brings us contentment? Let's give ourselves permission right now to feed our hearts, our smiles, and our contentment! A Blessed New Year to each of you!*

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*Take good care of each-other!*

*Deb Erickson, LPN  
ALS Outreach Assistant  
[www.alsnwwi.org](http://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!****

*Questions, concerns, or input please contact:  
Julie Chamberlain, LPN, 715.271.7257 or [alsnwwi@gmail.com](mailto:alsnwwi@gmail.com)*

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## Informative Articles & Info.

### **Emotional Fatigue**

### **To deal with it, you need to recognize it**

Today's Caregiver.com By Eileen Beal, MA  
January 7, 2016 • Issue #880

Former First Lady Rosalynn Carter, founder of the Rosalynn Carter Institute for Caregiving, says there are four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.

There should be a fifth on the list: Those who don't realize they have begun the caregiver journey – and their ranks are growing daily.

“They are helping Mom balance her checkbook, phoning Dad every morning to make sure he takes his cholesterol-lowering, diabetes, and arthritis medications, picking up groceries for a disabled neighbor – all sorts of things. They don't self-identify as caregivers because they are ‘just’ being a good daughter or son or neighbor,” says, Amy Goyer, AARP's caregiving expert and author of the recently published *Juggling Work & Caregiving*.

### **Why is it important to “self-identify”?**

Because the earlier you realize you have begun the caregiver journey, the earlier you'll understand the emotional weariness you may be experiencing – and start looking for ways to manage it.

“It [the weariness] encompasses a surprising range of feelings,” says Goyer, who is caring for her 90-year-old father, “and if you don't recognize what's happening and why, you'll just end up feeling guilty about your feelings...And guilt is a really useless feeling.”

### **Recognizing the symptoms**

“Early on, symptoms of emotional fatigue tend to come and go; and they tend to overlap, too, so people need to identify them – right off the bat – so they can take care of their emotional health and other needs,” says Jo McCord, a senior caregiver consultant at San Francisco-based Family Caregiver Alliance ([caregiver.org](http://caregiver.org)).

### **Initially, symptoms are insidious, but usually include:**

- Waiting-for-the-other-shoe-to-drop nervousness or tension
- Situational bouts of sadness, “the blues” or tearing-up
- Forgetfulness, inability to concentrate and/or mental sluggishness
- Intermittent feelings of frustration, anger or guilt due to interruptions and not being able to get things done
- Sporadic, and often situational, feelings of resentment, impatience, and/or irritability at colleagues, family members or the person you are “just” helping
- Poor or interrupted sleep
- A looming feeling of isolation
- A growing realization of the sacrifices – time, money, opportunities, etc. – you are experiencing
- An increase in aches, pains and, not surprisingly, blood pressure  
(Note: Recent research indicates this is worse for women than men.)

### **Five steps to better emotional health**

If you have just begun the caregiver journey, and are experiencing the above symptoms,

the following strategies will help you identify the new role you have taken on and help you manage the emotional stressors that can come early in the caregiver journey.

Put a name on what you are doing. Caregiving isn't just helping out, it's taking on responsibility for the well-being of another person. "The quicker a person self-identifies as a caregiver, the quicker they'll be able to recognize and deal with the emotional roller-coaster [symptoms] that can come as caregiver responsibilities increase," says McCord.

Listen to what your emotions are telling you. "Those feelings [see above] are normal responses to caregiving...Realizing that – that you are experiencing what everyone else is experiencing – will go a long way toward helping you take action for your own well-being and not react to them in a negative way," says Jody Gastfriend, LICSW, the VP of Senior Care Services at Care.com, an online resource connecting families and caregivers.

Embrace change. "Early on, people need to understand that the keys to being a successful caregiver are flexibility and adaptability on the journey," says Goyer.

Let go. "Most of what's causing [feelings of emotional fatigue] is out of the caregiver's control, so early on, caregivers need to recognize their limitations and give themselves permission to let go of or delegate some of the responsibilities they have taken on," says Gastfriend. "When they do that," she adds, "they can get the 'replenishment' they need to continue replenishing others."

Get help. A recent study published in the International Journal of Geriatric Psychiatry shows that, even at the earliest stages of caregiving, caregivers experience increased feelings of well-being when they seek help.

But, cautions McCord, every caregiver's situation is different so "the options that are going to help them have to be individualized."

To find those individualized options, tap into the wide array of home-based services and community programs and supports that are available, no matter where you live. Some are paid for on an hourly or daily basis; some are provided for a small or sliding fee; some are free.

Perhaps the fastest way to find the ones you want, will use and can afford is to check with the HR department where you work. "More and more companies have recognized that their employees are also caregivers and use consultants to help them deal with caregiver issues," says Gastfriend.

But you can find a consultant on your own, too, by contacting local care managers, social service agencies, and/or national agencies, such as the National Association of Geriatric Care Managers. The caregiving expertise and knowledge of community resources these professionals can provide will help you prioritize your needs and help you locate the services, agencies and organizations that can provide the help you need to manage the emotional stress that comes with caregiving.

“This can be an expensive option, but they’ll be doing a lot of the heavy lifting for you...and often you only need a couple of consulting sessions to get things moving in the right direction,” advises McCord.

To find information on your own, start with your local Area Agency on Aging’s Family Caregiver Support Program and then widen your search net to include county or municipal offices on aging/disability, disease specific organizations (many publish excellent caregiver resource lists and guides), religiously-affiliated service groups, reputable caregiver Web sites and/or help lines, including those provided by Elder Locator (1-800-677-1116) and Family Caregiver Alliance (1-800-445-8106).

Probably the most overlooked options for help, however, are support groups. “Connecting with others who ‘get’ what you are experiencing gives you a ‘safe’ place to talk about your feelings and hear about the options – the practical things, the strategies and tips – you can use to cope with your emotional stress. And they can help you deal with isolation, too,” says Goyer.

But, stresses McCord, “You won’t even think about it [joining a support group] unless you identify as a caregiver.”

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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>

## **What Is BiPAP?**

**BiPAP is a non-invasive ventilatory assist machine. Non-invasive ventilation (NIV) machines are those that can help breathing without requiring a tube inserted into the persons airway. By pushing air into the lungs through a mask worn over the nose, NIV assists breathing. This technology was developed in the 1980's to help people with sleep apnea, a condition where the airway collapses during sleep causing the person to stop breathing repeatedly. By pushing air in, the machine keeps the airway "inflated" so it won't collapse. This is CPAP, Continuous Positive Airway Pressure.**

**In the 1990's computer technology added a new dimension to NIV. Now the machine could push air in until a preset pressure was reached, then reduce the pressure to allow the person to exhale easily. Repeating this cycle made breathing more comfortable and suitable for people with neuromuscular diseases who could not exhale against the higher pressure. This type of machine was sold by Respironics**

**using the brand name BiPAP (Bi-level Positive Airway Pressure). Like the brand name "Kleenex", BiPAP has become the common name for all such products.**

**BiPAP is a ventilatory assist machine, but it is not a full featured traditional ventilator. There are several critical distinctions between BiPAP and a traditional ventilator:**

- BiPAP is "non-invasive", requiring only a mask that can put on or taken off as needed. The acronym "NIV" (Non-Invasive Ventilation) is used to differentiate traditional, trached ventilation from CPAP and BiPAP. A traditional ventilator is "invasive" meaning it requires that a tube be put down your throat or through your neck (tracheotomy) into the lungs. The tube remains in place as long as the patient needs to use the ventilator even if they reach a point where they can be off the ventilator for hours at a time. A growing trend is to use a hybrid ventilator such as the Trilogy which can be set for bilevel ventilation with a mask or mouth held tube, giving the non-invasive benefits of BiPAP, or for use with a trach and vent. This option makes the transition to trach ventilation easier if it becomes necessary. Getting insurance coverage for an expensive vent to be used for BiPAP is likely to be difficult however.
- BiPAP is not generally considered "Life Support Equipment." A ventilator can be set to completely take over breathing, BiPAP can only assist the breathing.
- A ventilator is generally set to deliver air according to volume. It pumps air in until a certain volume has been reached, then releases it. BiPAP delivers air according to pressure, stopping when it senses resistance that tells it that the pre-set amount of pressure has been met. That is a technical difference that probably means very little in how it feels to be on a ventilator versus BiPAP. It may however affect how well lung function is maintained. A volume based air delivery will continue to inflate lungs fully and help prevent atelectasis (loss of the ability of the little air sacs at the furthest reaches of the lungs to expand) and pneumonia. A pressure based delivery system will sense resistance and not try to push air into stiff or clogged air sacs and therefore won't be as helpful in keeping them working.
- BiPAP cannot support breathing adequately as ALS progresses. When breathing becomes very shallow, BiPAP doesn't have the sensors to recognize this nor the built in ability to compensate by increasing pressure. A ventilator will sense this and alarm. A ventilator can deliver higher pressures than BiPAP is designed to give.
- Because BiPAP only pushes air in until the set pressure is reached, it won't deliver enough air when the lungs are filling up with congestion. It will reach the set pressure faster and switch to exhale, leaving you dangerously under-oxygenated, struggling for more air, and exhausting your breathing muscles. A trip to the ER and facing the question of whether to go on a full vent and trach is next.
- Ventilator patients can be fitted with trach tubes that allow them to eat and even to speak, but occasionally this is not possible for ALS patients. Because it does not require a trach, BiPAP does not interfere with any speech or swallowing they can still do.

- ALS patients often reach the point of not being able to cough effectively. With a ventilator and trach, secretions can be removed by passing a suction tube through the trach to remove secretions. If suctioning is needed by patients using BiPAP, the tube has to be passed through the nose or mouth.
- The presence of the trach increases the risk of lung infections because it bypasses some of the normal protective barriers. Use of BiPAP also creates some increased risk for lung infections and sinus infections.

**One final comparison between Bilevel respiratory support is the warning that a ventilated person requires 24/7 care. That is true and yet misleading.**

- How many people who are on bilevel ventilation during the day, whether parttime or full time, are safe at home alone anyway? Arm weakness is usually a big part of the picture by this point so putting on or adjusting the head gear requires assistance as does using a cough assist. Power outages, equipment malfunction, toileting, choking, mosquito attacks, fire, etc. all require assistance 24/7 regardless of the type of respiratory equipment needed.
- The care required can be provided by anyone given ten minutes of instruction on how to suction and the opportunity to practice doing so. A little info on how to troubleshoot a beeping vent and using an ambu bag and they are all set. No licensed nursing care needed.
- The caregiver doesn't need to be in the room or even in the house. As long as they are close enough to get back in a minute or two and a reliable method for the PALS to summon them has been set up they can have the freedom to spend the afternoon outside or at a neighbors watching football.

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**END!**