



## **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, 4/14/16.***

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

***~ March 2016 ~***

### **9 participants Attended Support Group!**

Birkie stories shared – past and present; United Way supporting our families and opportunities to volunteer; One 5pm TV spot available for upcoming ALS walk; ALS trial hopes & frustrations – “The ALS Association sponsors many clinical trials. Other ALS trials are funded through other organizations. For a list of current clinical trails see <http://www.alsconsortium.org/search.php> and the NIH clinical trials at <http://clinicaltrials.gov/>”.

**12th Annual ALS Care & Research Symposium**, latest updates on research progress, potential drug treatments and other updates on the disease. **Saturday, April 30, 2016, 8:30 a.m.-2:00 p.m.** Sheraton Milwaukee Brookfield Hotel 375 South Moorland Road Brookfield, WI

visit <http://www.alsawi.org/#!als-symposium-2016/ld4ex> or call  
for more information 414.763.2220.

**Note:** In addition to our annual walk, Bracket Bar, 9150  
Beaver Creek Rd., Fall Creek, WI, will be holding their  
annual Charity Car Show, benefiting ALS of NWWI this year.  
The event will be held the second or third weekend in  
August. Exact date will be determined later this month – more info. to come!

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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.](#)

### **Skiers for Cures**

<http://www.birkie.com/live/skiers-for-cures/>

“We are very excited to join the fight against ALS through our ‘Skiers for Cures’  
program”, says Ben Popp, Executive Director of the American Birkebeiner® Ski

Foundation. “I hope our partnership will bring resources and visibility to their ongoing efforts to support those with ALS and find a cure for this terrible disease.”

‘*Skiers for Cures*’ is a charitable partnership which works to raise awareness and funding, to help find a cure for health issues affecting many in the skiing community. In the case of ALS, over 400 Wisconsin patients are battling the disease. With a new diagnosis made every 90 minutes, that is more than 5600 individuals every year afflicted by this terminal disease.

“While we’ve achieved a much greater understanding of the disease, the sad reality is that the cure still remains elusive. But every day and every research dollar raised brings us a step closer to unlocking a cure.” says Melanie Roach-Bekos, Executive Director of ALS Association – Wisconsin Chapter. “We’re still working on unlocking the ALS mystery. It’s heartening to know that more significant advances have been made in the past decade – especially with the ALS Ice Bucket Challenge – than the nearly century and a half since Charcot identified the disease. This gives us hope and encourages us to step up our efforts to find a cure. The time is now.”

“I’m stoked about the Birkie adding ALSA of WI as their new charitable partner!” says John Jaeckel, Hayward resident and 17-time Birkie skier, diagnosed with ALS in 2009. “I know too well the weight of being diagnosed with a disease that is untreatable and incurable. I believe that ALS is NOT incurable but just underfunded! This new partnership will help fund research that will discover new treatments and eventually a cure!” John & his wife, Deanna, worked tirelessly with ABSF Executive Director Ben Popp in order to bring ALS to the forefront of the Skiers for Cures partnerships. “It makes me very proud to have been part of this process.” says Jaeckel.

Through the ‘Skiers for Cures’ program ABSF & ALSA of WI hope to raise further awareness and much needed funding. Since its inception, the ‘Skiers for Cures’ program has helped raise over one million dollars towards research and helped raise awareness for the following non-profit programs: Susan G. Koman Foundation (Breast Cancer Research), the Multiple-Sclerosis Society and most recently JDRF (Junior Diabetes Research Foundation).

Learn more about ALS Association – Wisconsin Chapter at [www.alsawi.org](http://www.alsawi.org). Look for future communications in our monthly Carpe Skiem ezine, and on [Facebook](#) about the Birkie® Skiers for Cures partnership with ALS and how you can get involved.



## **Nutrition Ideas for Stress Reduction**

Today’s Caregiver.com by *Cheryl Ellis, Staff Writer*

## March 3, 2016 • Issue #896

Stress depletes the body of energy in a variety of ways. Loss of sleep, feelings of agitation or depression, and development of poor eating habits are “side effects” of stress that need intervention. Some stress can help us rise to the occasion and get things done, but too much stress drains the body. One way to break the stress cycle is by changing the diet to one that can actually help reduce stress.

The body under stress will experience a reduction in vital nutrients, such as B vitamins, which are nervous system helpers. Depending on magnesium to help with muscles and calcium for bones, the overstressed system may benefit from vitamin and mineral supplements. Before starting a vitamin regimen, consult with your primary doctor about any special needs you may have. The doctor may be able to refer you to a nutritionist who can target specific requirements and make useful dietary changes.

When stressed, all individuals may go for “comfort food,” which can include coffee, even if it’s decaffeinated. Coffee, cola and chocolate are three major suspects when it comes to providing comfort while introducing caffeine, which will sap one’s ability to relax. Caffeine also dilates the kidneys, increasing the need to empty the bladder. While there’s nothing wrong with active, healthy kidneys, it becomes inconvenient in the middle of the night. Frequent urination also requires that we put the water back into our system, and a continuous cycle of tasty beverages with caffeine’s stimulating element can dehydrate our systems.

Dehydration is a common nutritional problem. We don’t wash our clothes in soda or tea, but we frequently “wash our insides” with these substances. Many people complain that “water is boring,” and they have a point. Some folks recommend adding a splash of cranberry juice, lemon or lime to adjust the flavor. There are vitamin supplements that can be added to water to provide a break, also. The added hydration can be a tremendous stress reducer, especially when incorporating exercise into a stress management program.

Small changes that focus on key areas such as fat, fiber and sugars lead to big improvements in overall health. Many of us opt for drive-thru or delivery to solve the stress of cooking a meal. Some fast food companies are offering healthier choices, but the old, less healthy favorites may be hard to get away from. If you find that you are having a problem acclimating yourself or your loved one to the “healthy” options, add on components such as salad or vegetables to round out the meal and incorporate fiber.

Fiber helps the body move food through the digestive system, enhances the “full” feeling and improves digestion by helping eliminate waste from the system. Constipation can increase stress in the body both physically and emotionally. A balanced system eliminates waste at the proper intervals, allowing the individual to feel comfortable physically, leading to emotional comfort as well as physical.

When it comes to vitamins, the first priority is to “eat” your vitamins through “whole” foods that retain their nutrients. Whole foods do not have to be served raw, but there

should be no processing that adds preservatives. Creating “whole food meals” can be done gradually by adding salads, or by blanching or steaming cut vegetables. Since time and energy are usually a factor, consider paying extra for pre-cut vegetables. When cooking “whole” foods for you and your loved one, you may need to add time on to the quick cooking for softer vegetables.

Even frozen foods, properly cooked and with a minimum of additives, can provide better nutritional alternatives than one might imagine. Opt for minimal processing. This includes the amount of sodium in canned, frozen or even in deli-prepared foods.

Salad bars or food bars in grocery chains may appear healthy, but combine questionable ingredients. For example, the “healthy” tuna salad may contain far more mayonnaise than some people might use. The same is true for salad dressings prepared at salad bars and added on to the greens. Most retailers and restaurants will disclose nutrition values, but you can get an idea by just looking at some offerings. One way around the confusion in salad bars is to mix “plain,” unadorned vegetables, nuts and pastas with a smaller portion of your favorite sauce laden dish.

Overeating can be a reaction to stress, but it is also something that creates stress on many levels. Experimenting with smaller portions and more frequent meals can reduce the demand on the body to process a big meal at once. This technique also cuts down on berating oneself for eating too much.

Any physical distress can result in generalized stress for the individual, which includes even a mild raising of blood pressure. Salt is a nutrient everyone needs; but when overused, can create bloating, mild dehydration and problems with blood pressure. Salt alternatives range from lemon pepper to products like dulse, a sea vegetable that adds salt flavor but may be healthier because it is not table salt. With any changes, look for items that may create food allergies. For example, sea vegetables can create allergic reactions in people who have an iodine allergy.

Sugar in moderate quantities can be metabolized and exercised away. The definition of “moderate” varies from one source (and one individual) to another. Cutting out sugar may be impossible, considering many foods (even ones from the health food store) contain some variation of sugar.

Sugar’s other names are high fructose corn syrup, cane sugar, turbinado, dextrose, maltose and others. Sugar “alcohols” like malitol can still affect blood sugar. Artificial sweeteners have their drawbacks, too. Allergies, digestive intolerance and more are part of “real” and “fake” sugar. Until you allow your body a break from sugar, you may not be able to tell which reactions are due to its consumption.

Reducing allergens and foods that keep the body in a “hyper” state (caffeine, salty foods and sugars) take away the need for the body to work to process the ingredients. Taking a break from some foods and additives is one way to reduce stress on the body. Rather than a stressful and radical makeover of your diet, remove one item at a time, and rotate it

back into your diet about four days later. This can help you identify minor and major food stressors on the body.

Allergens, portions and “bad foods” can add stress to your life. Adjusting the content and quantity of food leads to less stress and better nutrition.



# *ALS From Both Sides*

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

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

## *Cause & Prevention of Swelling of Feet & Legs*

**Note:** Although the information here is useful for anyone with swollen feet, it is intended for people with an ongoing problem with swelling of feet and legs due to being unable to walk. If this is not your situation, please consult your doctor to determine the cause and treatment of your swelling. If there is swelling or puffiness of your fingers or around your eyes, see your doctor promptly.

### *The Cause of the Swelling*

The heart pumps blood through the arteries under high pressure. As the arteries branch out into smaller arteries and then into tiny capillaries, pressure decreases. Oxygen is removed from the blood in the capillaries and then the "used" blood flows into veins for the trip back to the lungs for another load of oxygen. Unfortunately, the pressure generated by the

heartbeat has been lost by then and the blood relies on simple back pressure to move back up to the heart. This is aided by muscle activity. Ordinary muscle movement "squeezes" the veins and pushes the blood along. The veins have little one-way valves all along the way that keep blood from draining backward as it is pushed upwards.

When muscle movement is lost, it becomes much harder to get the blood back up from the legs. It pools in the veins and causes them to get distended. Water seeps from distended veins out into the surrounding tissue and your legs and feet swell (edema). With repeated episodes of swelling, the little veins become damaged and leaky so that water seeps into the tissues even more easily. At the same time, the valves are collapsing under the heavy weight of all that blood that is pooled on top of them. That damage to the valves is **permanent**. Without the valves, the blood pools in the feet even worse than before and remaining valves are under even more pressure and more likely to fail. The circulation to the skin will be affected in time. The skin of the ankles and lower legs will be discolored (bronzing) and the skin fragile. Open sores called stasis ulcers develop. Because the blood flow to skin is poor, these ulcers are very difficult to heal.

### *Treatments*

Doctors aren't very good about helping with swelling. They will offer prescriptions for TED hose (somewhat helpful) and "water pills" (which should be used as a last resort only). And the first thing they will say is to put your legs up to minimize the swelling but they don't tell you how to do that effectively!

Don't be fooled by an adjustable bed or hospital bed. The gizmo that lifts your legs may only lift your knees. Your feet may be left hanging down on the far side of your knees. That is actually worse for circulation to them than lying flat. Put pillows under the foot of the mattress to get the feet back up to the level of your heart.

Look at is the chairs you sit in. A recliner may seem like the ideal way to keep your feet up and swelling down but it is **NOT!** There are two big problems with most recliners. First, the foot rest section is made in such a way that all the weight of your legs rests on the calves. That is really bad for circulation. Second, putting your feet up - even way, way up - without "unfolding" at the hips is minimally helpful as that bend interferes with the already difficult job of moving blood upward to your heart. Lift chairs are wonderful and most of them are recliners, but if you spend most of your time in a recliner, I strongly recommend that you bring the foot rest up only when you lower the back rest. Rather than spending all your time sitting up with the foot rest up, you will probably have better results if you leave the footrest down but take several breaks during the day to recline as flat as possible with the footrests up as far as possible. This self discipline is so easy to advise but such a nuisance to stick with!

What you need is a chair that can recline fully to what is called Trendelenberg position, feet slightly higher upper body. I found some at [SpinLife](#), a website that specializes in equipment for wheelchair users, but has a large selection of recliners. This page has a comparison chart that shows which chairs have Trendelenberg. These chairs are all recliner/lift chairs and all the pictures show them in a lift position. None show the chair reclined so I can't tell if any have the type of footrest that supports

the entire leg, not just propping up the calf. There is a reference to "full chase pad" on some models and that may differentiate the better type of leg rest. If I were buying, I would check that out first. I would also find out about returns if the chair doesn't fit you!

All too often I see PALS and other people in wheelchairs whose foot drop has been allowed to progress to the point where their feet cannot rest flat on the footrest. This guarantees that the feet and lower legs will swell badly and the valves will collapse like dominos! Don't let this happen! As soon as foot drop droops its ugly head, start using a footrest or positioning boots in bed whenever you are on your back. A footrest can be as simple as a plywood or plexiglass piece between the mattress and foot board and pillows in front of it to keep the ankles at a normal angle. While up during the day, wear your AFOs (Ankle Foot Orthotics. These below the knee braces the keep the foot at a right angle to the ankle to prevent tripping.).

Once you quit walking you don't need the AFOs but you do need to keep your feet flat on your footrests. People complain that the footrests are hard and cold. Slippers solve that but aren't as good as wearing shoes for correct positioning of your feet. All too often PALS quit wearing shoes because their toes curl under when they try to get them on. Unless your spasticity is bad, here is how to keep wearing shoes.

- Buy lace up shoes a full size larger than your normal and extra wide (W) or WW wide.
- Remove the lining of the shoes if it is spongy or soft. The inside has to allow your foot to slide in easily.
- Find socks that are thin and smooth for easy sliding. Compression hose work very well. (Don't buy the kind with open toes. They are for

hospital use to check for circulation after leg surgery or a cast is first put on.)

- When putting the shoes on, pull the tongue forward to loosen the laces as wide as possible. The toes will still want to curl under but unless your spasticity is bad, they should relax after a minute and slide into place. Twisting the toe of the shoe side to side will help get the toes comfortably positioned.

Whether you sit in a regular chair, recliner, or a wheel chair, it must be properly fitted to you. You need to make sure that your leg to floor/foot rest distance is short enough that there is minimal pressure at the back of the lower thigh and knee. Having your feet "dangle" is a sure-fire way to cause swelling! Put a box/platform under your feet (an old hard side suitcase worked great for me - lightweight and had a handle) or raise your wheelchair foot rest an inch or so. The objective is to make certain there is minimal pressure on the back of your knees/thighs. If you add a ROHO or other cushion you need to adjust your platform/foot rest upward to make up for the height of the cushion. A note of caution: If your feet are too high, your weight will be shifted back on your tail bone and cause a pressure problem there. It is a balancing act to find the happy medium for footrest height!

Standard power wheelchair leg lifts are fine for adjusting your legs while sitting up, but when you lie back in your chair and raise the footrests, the footrests are suddenly too short! Your knees have to bend or you need a big pillow to get your heels above the footrests. Very inconvenient and hard to get comfortable! The solution is to order "articulating" leg rests. These lengthen as they lift so that your legs aren't

scrunched even with the legs all the way up. Comfortable for elevating your feet to reduce swelling or just catching a nap!

The best treatment for leg swelling that I have found is something that I discovered entirely by accident: **More time in bed.** When my husband was working, I spent about seven hours in bed at night and then would lie back in my recliner for another two or three hours in the afternoon. Even with that, my legs were swollen by noon, miserably uncomfortable by evening and absolutely painful by bedtime. When my husband retired, I was able to go to bed at the usual time, listen to books on tape for an hour or two, and then sleep late in the morning. Instead of spending 10 hours lying with my feet up in two separate sessions, I began spending 10 hours or more in bed all at one stretch. Within a matter of days after starting this routine, I noticed that the swelling was minimal. Now I don't even have to lie down in the afternoon in order to be comfortable in the evening! I don't know if this is due to spending more time lying down at one stretch, spending all my lying down time in a bed rather than a recliner, getting more sleep, or some combination of the three. All I know is that in this has made an incredible difference for me. Not only has it made my problems with swelling minimal, I feel better in general.

Another thing that helps is **muscle activity.** Granny's old rocking chair served a real purpose beside putting babies to sleep! I find that the swelling is minimized on days when I am most active. (Interpret that as days when I am frequently hauled in and out of my chair and forced to stagger a few steps, whining all the way!) I guess I have some muscles left in my legs, even though I sure can't feel 'em! Even passive range of motion exercises help.

Keep cool. A few minutes of being too warm, toasting my feet by the fire, or just sitting in the summer sun is all it takes to turn my feet into balloons. (Blood vessels dilate when we are warm.) Simply keeping my legs in the shade makes a difference, but I have also been known to pour cold water over my feet on hot days when I need to be outside. Wet socks and tennis shoes are still more comfortable than that miserable burning sensation of swollen feet!

Sometimes I also have problems with a burning sensation in my feet in bed at night. It doesn't start until my feet began to warm up. It can get really bad in the middle of the night if I have the electric blanket on and my feet get really warm. That is a real nuisance because the rest of my body gets really chilled and I can't move at all if I pile on extra blankets. So, in cold weather I end up sleeping with the electric blanket on, but my feet sticking out!

For some people, this burning pain becomes severe and doesn't seem to be relieved by getting the swelling down. This might be the end result of long term or severe swelling. Some people find that aspirin (not Tylenol) helps. Do not take aspirin if you are on anticoagulants (medications to thin the blood). If burning pain is felt when swelling has not been a problem, discuss it with your neurologist.

**Limiting salt intake** used to be high on the list of things to do to minimize swelling, and your doctor may suggest it, but the need for that is questioned these days. I guess it is enough to say don't over-indulge with salty foods.

Hospitals often use **devices to improve blood flow** to the feet of patients who are going to be stuck in bed for a while in order to reduce

the risk of blood clots. TED (elastic or compression) stockings are by far the most common. By simply squeezing the legs and feet a little, they help keep the veins from getting distended. You can ask your doctor for a prescription for these stockings, but unless you have strong hands and arms, you will need help getting them on.



Hospitals also use Sequential Compression Devices that inflate and deflate to help pump the blood along. Originally used for hospitalized people at risk of blood clots, they are now available for home use to improve blood flow. This is very effective in reducing swelling as well as the risk of blood clots in people who are not able to walk. They have some type of leg sleeves or boots or wraps that are connected to a pump that causes compression in a sequential upward direction to improve blood flow. With help from your doctor you may be able to get your insurance to cover the cost of this equipment. It is not complicated to use, but you must be very careful to make sure that it is not rubbing anywhere and causing breakdown of the skin. SCDs can be used while up in a chair which makes using them convenient.



Another option is a leg massage device. They are not medical devices and are probably less effective for swelling than compression devices but may be very helpful. They don't squeeze the

blood upward, just massage the feet and legs. One big advantage is that they don't require any type of boot or wrap, just placing your legs in the massager which is easier. Massagers are generally used while up in a chair.

If you complain about swollen ankles and feet to your doctor, odds are he will whip out the old prescription pad and put you on **diuretics**. I have real reservations about this because many of us are borderline dehydrated half the time anyway. (Another contributing factor for the development of blood clots.) It gets hard to reach a drink, or hard to swallow, or it is simply too hard to get to the bathroom so we don't drink as much as we should. Diuretics cause your kidneys to remove more water from your blood stream. The "thicker" blood is then able to "sponge up" more water on its travels through the body so it does reduce the edema. It does nothing about the cause of the edema -- poor blood flow -- however. Using diuretics for swollen legs is kind of like taking a diuretic to lose weight - sure it "works", but it doesn't really solve the problem.

I certainly won't say diuretics should never be used -- if nothing else works well enough to keep the swelling under control, they need to be used because the swelling further damages the veins and valves and the situation just gets worse. But all the things described above should be implemented first before diuretics are even considered.



END!