



WESTERN NEUROPATHY ASSOCIATION

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Neuropathy Hope

Hope through caring, support, research, education, and empowerment

A newsletter for members of Western Neuropathy Association (WNA)

DIETARY AGMATINE SULFATE – CLINICAL TRIAL RESULT (NCT01524666)

Rosenberg, M. et al. Feb. 2020. Evidence For Dietary Agmatine Sulfate Effectiveness In Neuropathies Associated With Painful Small Fiber Neuropathy. A Pilot Open-Label Consecutive Case Series Study. *Nutrients*, 2(2):576. doi: 10.3390

Peripheral neuropathies associated with painful small fiber neuropathy (SFN) are complex conditions, resistant to treatment with conventional medications. Previous clinical studies strongly support the use of dietary agmatine as a safe and effective treatment for neuropathic pain (see article below). Based on this evidence, we conducted an open-label consecutive case series study to evaluate the effectiveness of agmatine in neuropathies associated with painful SFN.

Participants diagnosed with painful SFN and autonomic dysfunctions were treated with 2.67 g/day agmatine sulfate (AgmaSet® capsules containing G-Agmatine® brand of agmatine sulfate) for a period of 2 months. Before the beginning (baseline) and at the end of the treatment period, participants answered the established 12-item neuropathic pain questionnaire specifically developed to distinguish symptoms associated with neuropathy and to quantify their severity. Secondary outcomes included other treatment options and a safety assessment.

Twelve patients were recruited, and 11 patients - 8 diagnosed with diabetic neuropathy, two with idiopathic neuropathy and one with inflammatory neuropathy - completed the study. All patients showed improvement in neuropathic pain to a varied extent. The symptoms most clinically associated with neuropathic pain numbness, tingling, and burning showed the greatest response to treatment with agmatine, suggesting that these neuropathic pain descriptors are associated with SFN involving autonomic nerves. Reductions in the categories least considered characteristic of neuropathic pain—electric, squeezing, and increased pain due to touch—did not reach statistical significance after agmatine treatment. The average decrease in pain intensity was 26.0 rating points, corresponding to a 46.4% reduction in overall pain (p < 0.00001).

The results suggest that dietary agmatine sulfate has a significant effect in reducing neuropathic pain intensity associated with painful SFN resistant to treatment with conventional neuropathic pain medications. Larger randomized placebo-controlled studies are expected to establish agmatine sulfate as a preferred treatment.

EFFECT OF AGMATINE SULFATE ON NEUROPATHIC PAIN

Tohidi, V. et al. 2014, April. Effect Of Agmatine Sulfate On Neuropathic Pain. *Neurology*, 82 (10 Supplement).

Based on previous studies suggesting oral agmatine was a safe and effective treatment for sciatica we began a prospective study of the effect of Agmatine Sulfate, a decarboxylated arginine, on neuropathic pain.

Patients diagnosed with neuropathic pain were recruited into this study after a diagnosis of a small fiber neuropathy was confirmed by skin biopsy and/or quantitative sensorimotor axonal reflex testing (QSART). The Neuropathic Pain Questionnaire was started initially, then monthly during a two-month treatment period with agmatine sulfate (3.670 g/day), the nutraceutical salt of agmatine. QSART was also repeated at the end of the study.

Five patients completed the study to date. Pain questionnaire evaluation was done comparing the initial pain questionnaire with the final answers. The Total Discriminant Function scores showed a significant decrease (p=0.03). The detailed categorization of neuropathic pain characteristics shows significant decrease in burning (p=0.02), tingling (p=0.04) and unpleasant (p=0.02) aspects of the pain.

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PERIPHERAL NEUROPATHY SUPPORT GROUPS DECEMBER SCHEDULE

*Encourage, inform, share, support, and hope.
Join a meeting to help others, learn something new, and/or share experiences.*

In-Person Support Group Meetings

December 3 (Saturday)

Houston TX Quarterly Meeting

1:00 pm Central, Memorial Drive United Methodist Church, 12955 Memorial Drive
Room DS100, enter at back (south) of building
Contact Katherine Stenzel at klstenzel@hotmail.com

December 5 (Monday)

Auburn CA Support Group

11:00 am Pacific, Woodside Village Mobile Home Park, 12155 Luther Road
Contact: Sharlene McCord (530) 878-8392, Kathy Clemens (916) 580-9449, kaclemens@earthlink.net

Grants Pass OR Support Group

Disbanded due to passing of David Tally. WNA sends prayers to his family and neuropathy friends.

Santa Cruz area CA Support Group - Starting meetings.

Contact Mary Ann Leer at (831) 477-1239 for meeting information.

Virtual Support Group – No December Meetings

AN OLD ANTI-PSYCHOTIC OFFERS A NEW WAY TO TREAT CHRONIC PAIN

B. David Zarley, Freethink.com, September 20, 2022.

To find and develop new and repurposed drugs to treat chronic pain, teams around the world are investigating gene therapies, psychedelics, and electrical implants, as well as reexamining decades-old dogma on pain treatment and turning to the vast array of natural toxins for new therapies.

Fluphenazine, once used to treat schizophrenia, was one of 1,000 FDA-approved drugs that researchers evaluated, hoping to find one that can reduce a chemical released by neurons (called BH4) that's linked to chronic pain. "We found that fluphenazine blocks the BH4 pathway in injured nerves," project lead Shane Cronin, a staff scientist at Austrian Academy of Science's Institute of Molecular Biotechnology (IMBA), said.

Clifford Woolf, a professor of neurology and neurobiology at Harvard Medical School, and his team's previous research had identified blocking BH4 as a possible chronic pain treatment. "The concentrations of BH4 correlated very well with the pain intensity," Cronin, a former postdoc of Woolf's, said. "So, we naturally thought that this was a great pathway to target."

They tested fluphenazine's ability to lower BH4 in mice, where it was determined that a painkilling dose was comparable to the low end of the dosing range used to treat schizophrenia. Interestingly, the team also found a direct connection between cancer and chronic pain. EGFR/KRAS signaling, a pathway involved in aggressive lung cancer, seems to share a pathway with BH4. When an enzyme in the BH4 pathway was eliminated, mice who were engineered to model the notoriously deadly KRAS-derived lung cancer developed fewer tumors and lived longer.

The same triggers that drive tumor growth appear to be also involved in setting the path to chronic pain, often experienced by cancer patients. Figuring out this interplay could lead not only to cancer therapies, but better management of the chronic pain of cancer patients.

FROM THE PRESIDENT Pam Hart, WNA President

With the giving season upon us, I can proudly report that WNA has just donated \$10,000 to Dr. Hammock and his team at UC Davis who are working on a new pain relief medication. We have featured Dr. Hammock's work for a few years now at our annual conference. It is a slow process to go through clinical trials in order to get FDA approval. Our donation is an un-restricted donation which allows them to use the money where they feel it is most helpful. Supporting this project is encouraging to us. As a Board member, I feel a real personal connection as UC Davis is my Alma Mater. They rank No. 4 among public universities nationwide (Forbes Magazine) and No. 1 for agriculture and veterinary medicine as well as diversity and inclusiveness (QS University Rankings). And they've just joined the nation's top 20 public universities in external research funding, confirming their status as a research powerhouse.

One of the other items we discussed at our last Board meeting is to have Regionally-based discussion groups to highlight helpful doctors in specific areas. If you have a great physician and would like to share with others, please contact Katherine Stenzel at klstenzel@hotmail.com. She will consolidate the information and organize regional online support group sessions. This seems to be a continually challenging issue, so when a good physician is found, we like to make that known! This reminds me to encourage you to provide your email address to the office if you are not getting the announcements of webinars and online support groups. Some upcoming webinar topics in 2023 will be Assisted Driving and Hereditary Neuropathy, so make sure we have your contact information.

I would like to thank Martin Price, one of our WNA Directors, for his webinar on supplements in November. This is also a reminder that these webinars are all recorded and available on our website about two weeks after the presentation. Please go to <https://pnhelp.org/resources/audio-and-video>. Our mission is to "encourage, inform, share support and help". If you have suggestions for webinar topics, please share them with us.

Giving Tuesday is coming up and so is the end of the year. Please remember that we accept donations via our website and that you can transfer your IRA distributed funds directly to our 501c3 organization. Using Amazon SMILE also helps (see below).

Blessings to all,
Pam Hart

Western Neuropathy Association Contact Information

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(833) 980-4181

WNA Admin Assistance (membership, website, etc.)

(888) 556-3356 or admin@WNAinfo.org

Donation Pick Up from Thrifty Bargain

WNADonations@gmail.com

Neuropathy Hope – Editor

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AmazonSmile is an easy and automatic way for you to support WNA every time you shop, at no cost to you. When you shop at smile.amazon.com, you'll find the exact same low prices, vast selection and convenient shopping experience

as Amazon.com, with the added bonus that AmazonSmile will donate a portion of the purchase price to the Western Neuropathy Association! Make sure you type in our organization.

You can also support WNA by shopping at one of the 1700+ stores at [iGive.com](https://www.igive.com) and selecting the Western Neuropathy Association as your charity of choice - they will donate a rebate of your purchase at no extra cost to you!



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If the number is not in your area, call the one listed and ask for the right number.

Medicare

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The Affordable Health Care Act

For current information go to www.HealthCare.gov

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Health Insurance Counseling

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www.cahealthadvocates.org/HICAP/

Call (800) 434-0222 to ask a question or to make an appointment.

...

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Serving Placer, El Dorado, Yolo, & Sacramento Counties, regardless where you receive your health coverage.

Toll free (888) 354-4474 or TDD (916) 551-2180.

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DRA's Health

Access Project Free publications about the health care, insurance rights and concerns of people with disabilities and serious health conditions. For more information, go to <https://dralegal.org/> and click on "Projects".

HOW TO UNINVITE NERVE PAIN FROM YOUR HOLIDAYS

Bussell, MD., Lola Linda University Health, December 11, 2019.

Traveling in confined spaces 101

Crammed seats and long flights while traveling with nerve pain can be difficult. Nerves become stretched during long, upright confinement, causing symptoms of dyskinesia, numbness, tingling and restlessness. You can avoid these symptoms by first drinking plenty of water. Also, watch the weight of your luggage — packing too heavily can worsen your pain. Lastly, stay moving where you can. Whether stretching and walking between flights, investing in an aisle seat to stretch out, or using the restroom in flight, all of these little movements can help lessen the pressure on the nerves.

Holiday travel can be quite stressful, and proper management of that stress is necessary to avoid nerve pain. No matter your traveling method, look at what you can do to minimize the stress involved. This can include planning to leave at a time that is most optimal for traffic, creating a fun playlist to listen to, purchasing an audiobook and packing your favorite snacks. All of these small things can help in making the trip more comfortable, less stressful and less painful to your nerves.

Prepare for holiday activities

The holiday season can usher in a slew of pain-related problems. Nerve pain can occur while standing on your feet for too long while shopping, hanging decorations, lifting heavy items or wrapping presents. While these can't be perfectly avoided, the trick is mitigating what you can, and that starts with knowing your limits.

If you can't lift more than a specific amount of weight all year, don't try just because it's the holidays. Ask for help. Also, if you know your carpal tunnel will act up after wrapping so many presents, make it a time for bonding. Invite friends or family to watch a movie and wrap with you. Going to a parade or outdoor choir event for that loved one? Make sure you prepare for the cold by bundling up and wearing loose-fitting shoes with good arch support.

Do not try to muscle through your pain — that will only worsen it for you. Make sure you plan for breaks as needed, don't push beyond what you do the rest of the year, and take your medications as directed by your physician.

Share your favorite dish

Cookies, cakes, and candy — the holidays are full of sugary temptations. While there is nothing wrong with a little treat once in a while, people with nerve pain and food sensitivities know all too well how these can cause discomfort. Before indulging in that treat at the office potluck, consider advocating for healthier options with your coworkers by bringing a healthier dish you make well. There are plenty of cuisine options, from dark chocolate treats, flavorful veggie dishes and healthy crockpot meals that can be the star of any holiday party.

Avoid the binge

Whether we ate too much, didn't want to miss a moment of our teams' game, or lethargically wanted to marathon a TV show for the day, we've all binged at some point. The winter vacations beg us to slow down and relax. While taking time to relax can be a good thing, it's important to stay accountable for our health. One recommendation is to have an accountability partner for the holidays so you can help each other stick to exercise routines.

If you do want binge watch a show or game, plan some fun movement in there. Take advantage of commercial breaks to stretch and have your family do it with you. While sitting, flex your toes and stretch your feet to keep the pressure alleviated. For movie marathons, plan an intermission where you walk around the block or go out to grab healthy snacks from the store. When possible, find a moment to include some movement for the body.

EXERCISES TO IMPROVE BALANCE FOR THOSE WITH PERIPHERAL NEUROPATHY

EBFAFITNESS, Barefoot Strong Blog, February 4, 2022.

This article will go into a few of the most effective exercises and techniques for improving foot awareness and balance in those with peripheral neuropathy. All of these recommendations can be performed on a daily basis.

Exercise #1 –Sensory Stimulation

Bringing in sensory stimulation and strengthening the nerves in the bottom of the feet is important to overall movement function. Foot sensory stimulation can be in the form of textured insoles or socks, such as those by Naboso, vibration platforms and rollers, and barefoot stimulation. These products can be used throughout the day or integrated in 30 minute doses. When going barefoot or using sensory-based products always perform a foot check before and after to ensure that the foot skin is clean and in-tact.

Exercise #2 – Forward Lean

This simple exercise is one that connects our postural muscles to our feet. Start by standing barefoot on a clean surface, placing feet shoulder width apart. Keeping the body tall and straight, start to gently shift or lean the bodyweight forward until you feel the feet engaged and the toes push down into the floor. After you feel the toes engage, resume your starting position and relax the feet. Repeat the forward lean 10 times. If balance is a concern, you can stand next to a wall and gently place one hand on the wall.

Exercise #3 – Sit, Stand & Turn

This exercise trains all sensory input systems which are needed for balance including the visual, vestibular, proprioceptive and tactile. Start by sitting in a chair with your feet flat on the ground. Stand up from the chair and turn in a full circle in one direction then sit back down. Repeat by standing up and turning in a full circle in the other direction and sitting back down. Repeat 5 times in each direction. When turning go as slowly as you feel comfortable and ideally perform this exercise barefoot to increase foot stimulation.

Exercise #4 – Eye Movement Exercises

This series of eye movement exercises can be done sitting in a chair or standing for an increase challenge.

For the first eye movement exercise you are going to hold a pen in one hand directly in front of you and with the arm straight out. Slowly move the pen side to side or in figure 8 and track it with your eyes only. Try to keep the head still so only the eyes are moving. Perform for 10 seconds with the pen in one hand and then repeat holding the pen in the other hand.

The second eye movement exercise is called a saccade. To do this exercise you want to keep the head still, shift only the eyes and look all the way to the right and then all the way to the left. Repeat back and forth, right to left for 10 seconds. Rest for 10 seconds and repeat for another 10 seconds.

The final eye movement exercise is targeted at strengthening the peripheral vision. In a seated or standing position, focus your gaze all the way across the room and stare at one object in the far distance. While keeping the eyes locked on this object, start to notice other objects in the room that can be found in your peripheral vision. Do not turn your head or shift your gaze when noticing the objects in the peripheral vision. Perform for 30 seconds.

Conclusion

When performed consistently, all of these exercises have been shown to improve body awareness and postural perception when standing and walking. Together our feet, posture, vestibular and visual system all play an important role in maintaining balance. For those with peripheral neuropathy and decreased sensation in the feet, training all these input systems is important to ensuring movement longevity.

DISCOUNTS FOR WNA MEMBERS

The following companies or individuals have agreed to give WNA a discount to WNA members. Give them a call or visit. If you choose to purchase the service or wares of any on this list, pull out your WNA Membership Card and claim the discount.

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Infrared Light Therapy equipment - **12% off all home units.**
Contact: 800-521-6664 or www.anodynetherapy.com

Auburn

The Footpath

825 Lincoln Way
(530) 885-2091
www.footpathshoes.com
WNA Discount: 10% off the regular price shoes.

Elk Grove

Shoes That Fit

8649 Elk Grove Blvd.
(916) 686-1050
WNA Discount: 20% off the regular price shoes.

Fortuna

Strehl's Family Shoes & Repair

Corner of 12th & Main
1155 Main Street
(707) 725-2610
Marilyn Strehl, C.PED
is a Certified Pedorthic
WNA Discount: 10% off the regular price shoes.

West Sacramento

Beverly's Never Just Haircuts and Lilly's Nails

2007 W. Capitol Ave
Hair - (916) 372-5606
Nails - (916) 346-8342
WNA discount: 10% off the regular price.

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HOW TO GET CHRONIC ILLNESS NEEDS MET AT WORK

Modernneuropathy.com, December 12, 2020.

Working with a chronic illness is very challenging, especially when you are concerned that no one understands your unique needs. By communicating to your employer those needs, work can go much smoother, and you at least won't have that unnecessary stress looming over you.

Everyone facing chronic illness has different needs in the workplace. When dealing with peripheral neuropathy, for example, one person may experience burning pain in their legs after standing a length of time. While another may experience weakness in their hands and are at risk for dropping things. Some may prefer that no one at their office know their health status, or at least its full extent. But others are better off explaining to those around them how a condition may impact their work.

When slight adjustments in your job expectations could benefit both you and your employer, your best bet is probably talking honestly and openly about your needs. If you decide you'd like to begin a conversation with your employer about your chronic illness, here are some strategies to help.

Start With the Goal In Mind

What is it that you want to communicate? It's easiest to communicate important information effectively by reviewing it thoroughly beforehand while keeping a clear end goal in mind. If you're just interested in making your employer aware of your situation, think through how much or how little they need to know. This can help you avoid saying too much or too little, or confusing the matter with unnecessary details. Come up with some clear options and tangible actions your employer can take to help you succeed in the workplace. Keep in mind that talking to your boss should not be about complaining, it's about informing in order to reach a particular goal.

Read the Employee Handbook

Explore your employee handbook so you know what kinds of expectations are already in place and how your needs might fit into them. If you need to rethink your schedule, is flex scheduling allowed? If you're hoping for breaks during the day, are there rules in place already you don't know about? Your workplace might already have protections or procedures in place for health-related complications. If nothing else, do your best to see how your requests might fit into the employee guidelines or the culture of the company.

Know the Americans with Disabilities Act (ADA) Guidelines

If your condition qualifies as a disability, your employer is required by the Americans with Disabilities Act (ADA) to make certain accommodations. While they must be within reasonable limits, sometimes modifications as simple as adjusting your schedule, providing an adjustable chair, or more frequent breaks can be helpful.

Here's how ADA describes reasonable accommodations: "Reasonable accommodation is any modification or adjustment to a job or the work environment that will enable a qualified applicant or employee with a disability to participate in the application process or to perform essential job functions. It also includes adjustments to assure that a qualified individual with a disability has rights and privileges in employment equal to those of employees without disabilities."

Set Up a Meeting

Feel prepared? It's time to talk to your boss or human resources. Hopefully, you have a general sense of who can help you with this kind of request. If not, the HR office is an excellent place to start. Set up a formalized meeting to help avoid misunderstanding and to ensure the person has time to talk.

Highlight Employer Benefits

In addition to explaining your situation and requests, focusing on how these changes might benefit your employer will help your case. Keep in mind the basic psychological principle that people want to understand personal context (in other words, what's in it for them) before they can accept change.

Let's say you have trouble with stairs and would do best to have your office on the first floor. Maybe you can explain how catching your breath after the stair climb means you lose 15-20 minutes of work.

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VITAMIN SUPPLEMENTS - WHAT ARE THEY AND CAN THEY HELP? A SERIES STARTING WITH ALPHA-LIPOIC ACID

Martin Price, WNA Director

I have used vitamin supplements for fifteen years for my Diabetic Peripheral Neuropathy (DPN) and would like to share my experience to help others better understand their usage and importance. I have found that many in the medical world do not always tell us about vitamin supplements and their benefits. There are many vitamin supplements to take but I will discuss in this series of articles the ones that have benefited me.

It is important to understand that as we age the body slows in its production of many vitamins. Thus, vitamin supplements are used to help restore vitamin production in the body. Note that vitamin supplements take time to work just in the same way the body slows in its natural production of vitamins. Vitamin supplements can be taken with or without prescribed medications.

Alpha-Lipoic Acid

Its common name is ALA, and it is believed to have ten to fourteen important benefits. ALA can be found naturally in potatoes, heart, liver, spinach, and broccoli. The recommended daily dosage for DPN is 600-1800 mg. I take 600-1200mg daily with good results.

ALA has a second stronger form called R-lipoic Acid, which is believed to be many times stronger. It is produced in a lab which can provide a consistent quality control. The cost of R-lipoic acid is substantially more expensive. I felt at the time the ALA form versus the R form cost was not needed or of greater value after trying both over several months use. However, today it may have been worth the additional cost. I learned I should have continued the R form for increased pain relief as peripheral neuropathy never stops its progression. It may slow but can return and for me it returned more aggressively.

Alpha-lipoic acid has the potential to reduce diabetes by lowering the sugar level in the blood as high blood sugar is the root cause of diabetes. As a diabetic I found this to be true because after 6 months of diet control of my sugar intake my A1c number slightly declined. I then added ALA which I'm sure helped further reduce my A1c to a lower level. But this reduction was not enough to stop taking prescribed diabetic medical control.

My nerve pain is caused by the breaking down of the myelin sheath which protects the nerve. This breaking down is caused by a lack of nourishment of the nerve cells. Too much sugar in the blood will cause the blood to thicken and can't pass thru the tiny capillaries to nourish the nerve. Thus, the nerve begins to wither and die. Over time, the nerve pain will continue to grow worse if action is not taken.

ALA seems to delay diabetic peripheral neuropathy progression through its many antioxidant properties. This is the key reason I take it daily. It also can reduce diabetic nerve pain and improve nerve function. I have found that to lessen my nerve pain was only possible by taking a prescription for it. But I continue to take ALA in the hope it will reduce the progression and its other benefits.

References

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Kelly, G. October 13, 2021, Alive.com. 10 Benefits Of Alpha-Lipoic Acid. <https://www.alive.com/health/10-benefits-of-alpha-lipoic-acid/>

WebMD.com. Alpha-Lipoic Acid – Uses, Side Effects, And More. <https://www.webmd.com/vitamins/ai/ingredientmono-767/alpha-lipoic-acid>

DISCOUNTS FOR WNA MEMBERS

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Neuropathy Support Formula/Nerve Renew

(1-888-840-7142) is a supplement that a number of people are taking and reporting it has helped them. The company gives members of WNA a discount and free shipping. The 30-day supply is \$40 (normally \$49.97). It can be auto-shipped monthly for the same. A 3-month supply via auto-ship is \$95.00. They also have a Nerve Repair Optimizer that is available for \$20 with free shipping. Marsha, the manager, said that if anyone wants more information about the product, they can call and ask for her. If she is not readily available, leave your number and she will call you back. They now have Nerve Renew Fast Acting Cream at \$20 for WNA members. It reportedly takes the edge off numbness.

Building Better Balance DVD, Developing Spine Health

– The DVDs are \$30 each. The price of a full set (4 DVDs) is \$100 (that's a 20% discount). You can order the DVDs by going to the website www.building-better-balance.com. Shipping is free. You can also order the DVDs over the phone using a credit card. Call (707) 318-4476 and leave a message. Vanessa Kettler, Balance and Fall Prevention building-better-balance.com (707) 318-4476

Additional Discounts

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We'll mail an agreement form to the business, and once we have it, we'll add them to this list.



WESTERN NEUROPATHY ASSOCIATION

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HAPPY HOLIDAYS

From All Of Us At WNA

How To Get Chronic Illness Needs Met At Work

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You'd love to use those extra moments of energy to improve the company. (See how that works?)

Tips for Success

Take time to review some tips on communicating your chronic peripheral neuropathy illness successfully.

- Keep it short and sweet.
- Speak confidently and clearly.
- Remember that kindness will usually be met with kindness.
- If things don't go well, remain calm and don't give up. Seek outside help.

Final Words

Sharing with someone your medical illness, especially an employer, can be scary. But accurately and effectively explaining your needs and accommodation ideas will help you both. By applying these communication strategies, you will be better prepared for that conversation with your boss. Feeling prepared leads to greater self-confidence. This results in a more effective conversation leading to a more successful outcome for everyone involved.



Western Neuropathy Association (WNA)

A California public benefit, nonprofit,
tax-exempt corporation.

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Our mission is to provide support, information and referral to people with neuropathy and to those who care about them, to inform and connect with the health care community, and to support research.

Dues - \$30 a year

All contributions and dues are tax-deductible.

We are supported by dues-paying members, contributions by members and friends, and occasionally, small grants and fundraisers.

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