



WESTERN NEUROPATHY ASSOCIATION

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CELEBRATING OUR 26TH YEAR!

Neuropathy Hope

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

A newsletter for members of Western Neuropathy Association (WNA)

4 WAYS TO MANAGE THE EMOTIONAL STRESS OF NERVE PAIN

Trisha Gorny, PT, DPT, NCS, Neurological Physical Therapist; Loma Linda University Health Blog; March 21, 2022

Living with nerve pain is not easy. If it has lasted a long time, you may have feelings of hopelessness, sadness, anger or even depression due to the constant pain. You may withdraw from people close to you or stop doing the fun things you used to do. If you have trouble coping with the emotions caused by your nerve pain, here are four suggestions for taking charge of those emotions and finding new perspectives. Your mind is a powerful thing — and you can use it to make a change in your life.

1. Practice self-care. Surround yourself with friends, family and people who give you support. Be open to activities you love and that bring you happiness. Explore activities that will stimulate you mentally, such as reading or puzzles. Try to keep a balance in your life and focus on yourself as a whole person – not just a painful foot, arm or leg.

2. Manage your stress. Pain is worse when you are stressed. To calm yourself, try a breathing exercise in which you breathe in through your nose for four counts, hold your breath for seven counts and exhale to the count of eight. Repeat that cycle four or five times. (Read the October 2021 Neuropathy Hope issue for Three-Part Diaphragmatic Breathing)

Another technique that works well when you are at home or trying to go to sleep is progressive muscle relaxation. To do this, lie down in a dimly lit room and breathe in as you tighten a group of muscles and then breathe out as you release the tension. You can start at your feet and work up to your head or focus on big muscle groups first and then smaller ones. The result is that it relieves anxiety.

Yoga is another way to relieve stress and anxiety, as you focus on holding different poses. The stretching in yoga also helps to open up nerves and arteries to relieve pain. In addition, spiritual practices such as prayer and meditation can help to calm and ground you, providing relief from stress.

3. Talk about how you are feeling. Be open with the people you live with and others close to you. It's helpful for them to know how you are feeling, both physically and emotionally. Your family members can help you by listening and letting you vent when you are upset. They can provide hope and encourage you to keep up with your hobbies and interests. They may also be able to relate and provide ideas for coping. It can also be helpful to talk with a counselor who can provide you with objective, professional guidance on ways to cope with your physical pain.

4. Control what you can. Reducing the amounts of inflammatory foods you eat can help you feel better physically. Try decreasing sugar, dairy and gluten products to see if this improves how you feel both mentally and physically.

If your nerve pain affects your sleep, pay attention to small changes you can make. For example, if you have neuropathy in your feet, you may experience sensitivity to sheets rubbing against them or feel discomfort if there is a draft going across your feet. Try wearing thick socks to neutralize these effects. If your mind is racing, try the progressive muscle relaxation technique described above.

Setting a routine for yourself can also help you cope with the emotional effects of nerve pain. Create a list of tasks and goals for the day or the week. This will help motivate you to focus on daily activities rather than your nerve pain.

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PERIPHERAL NEUROPATHY SUPPORT GROUPS

VIRTUAL AND IN-PERSON FOR JUNE 2024

*Encourage, inform, share, support, and hope.
Join a meeting to help others, learn something new, and/or share experiences.
In-person or virtual – connect to others with peripheral neuropathy.*

In-Person 1 Saturday	Houston TX Quarterly Support Group Saturday, 1pm – 2:30pm Central Memorial Drive United Methodist Church, 12955 Memorial Drive Room DS100, enter at back (south) of building, follow signs Hosts – Katherine Stenzel and John Phillips	
In-Person 3 Monday	Auburn CA Peripheral Neuropathy Support Group Monday, 12pm-1:30pm Pacific Beecher Room at the Auburn Library, 350 Nevada St., Auburn, CA Host - Kathy Clemens (916) 580-9449, kaclemens@earthlink.net	This group will not meet in July, August and September.
Virtual 8 Saturday	2nd Saturday – Peripheral Neuropathy Support Group Saturday, 11am - 1pm Pacific / 1pm - 3pm Central / 2pm - 4pm Eastern Meeting ID: 856 7106 1474, Passcode: 114963 Host - Katherine Stenzel, contact Katherine for Zoom link	
Virtual 12 Wednesday	2nd Wednesday – Chemo-Induced Peripheral Neuropathy (CIPN) Support Group Wednesday, 2pm - 3pm Pacific / 4pm - 5pm Central / 5pm - 6pm Eastern Meeting ID: 830 5538 3243 / Passcode: 396320 Host - Glenn Ribotsky, contact Katherine for Zoom link	
Virtual 19 Wednesday	3rd Wednesday – Peripheral Neuropathy Support Group Wednesday, 10am - Noon Pacific / Noon - 2pm Central / 1pm - 3pm Eastern Meeting ID: 833 4473 0364 / Passcode: 341654 Host - Glenn Ribotsky, contact Katherine for direct Zoom link	
Virtual 19 Wednesday	3rd Wednesday – CIDP and Autoimmune Support Group Wednesday, 3pm - 4pm Pacific / 5pm - 6pm Central / 6pm - 7pm Eastern Host - John Phillips, contact John for Zoom link	
Virtual 22 Saturday	4th Saturday – Peripheral Neuropathy Open Discussion Saturday, 11am -1pm Pacific / 1pm - 3pm Central / 2pm - 4pm Eastern Meeting ID: 851 7949 9276 / Passcode: 159827 Host - John Phillips, contact Katherine for Zoom link	
	Santa Cruz CA Peripheral Neuropathy Support Group – Meets in odd months	

VIRTUAL SUPPORT GROUP CONTACTS

Katherine Stenzel	kstenzel@hotmail.com
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John Phillips	johnphillips.wna@gmail.com
Erika McDannell	ejmcdannell@gmail.com

Support Group information can also be found on www.pnhelp.org under the Support Group tab.

FROM THE PRESIDENT Pam Hart, WNA President

Neuropathy vs Radiculopathy

When we are in pain, we understand that something is wrong. It is the body's way to put us on alert. Finding out what is causing the pain can sometimes be a challenge. Take neuropathy, for example. You may think you have neuropathy, when in fact you have radiculopathy.

Radiculopathy occurs when the patient has a pinched nerve or inflammation of a nerve in their spine. The most common location this is seen is in the lower back which is called lumbar radiculopathy. Cervical radiculopathy occurs in the neck, and thoracic radiculopathy occurs in the upper back. Thoracic radiculopathy is the least common. The symptoms of radiculopathy are generally pain, tingling sensations, numbness and weakness.

WOW this sounds just like neuropathy and the symptoms are overlapping. The difference is that the damage of radiculopathy occurs at the root (in the spine, like a herniated disc) and neuropathy (peripheral neuropathy) can occur at any part of the nerve. Some types of neuropathies you may not think of are cranial neuropathy that can affect sight and hearing, and autonomic neuropathy that can affect nerves in the involuntary nervous system – affecting bladder, bowels, digestion and perspiration as examples.

Finding the cause of your neuropathy is often frustrating, and as you can see from above, it is not always straightforward. Our support groups are there to help discuss these and other issues. Listening to stories of trial and error for diagnosis is heartbreaking, but informative. If you have such a story, we would love to hear it. You never know how your experience may help someone.

Blessings,
Pam
pamula1@hotmail.com

WHAT IS DYSESTHESIA? Katherine Stenzel, Editor

Dysesthesia means “abnormal sensation.” It’s usually a painful burning, prickling, or aching feeling. It can also feel like your hands or feet are wet and/or there is something crawling on them. You typically get it in your legs or feet but you also can have it in your arms and hands. Sometimes the pain feels like you’re being squeezed around your chest or abdomen. Some people call that the “MS hug.”

The pain may be acute, meaning it comes on quickly then goes away. Or it may be chronic, lingering for a long time. Sometimes the pain comes out of nowhere, and other times a normal sensation changes. For instance, your clothes suddenly feel like they’re burning your skin. Changes in temperature may make the pain worse, and you may feel it more after you exercise or when you’re trying to sleep.

What Causes It? Dysesthesia is neuropathic pain. Although you feel the pain in your feet or skin, that isn’t where the problem is. It comes from the breaking down of the myelin sheath – the covering that protects your nerves. That interrupts the messages between your brain and the rest of your body. Your brain can’t read the nerve signals correctly, so it tells you that you feel something you really don’t.

How Is It Treated? Doctors usually prescribe one of two kinds of drugs for neuropathic pain:

- Antidepressants like amitriptyline (Elavil) and duloxetine (Cymbalta) can change how your body responds to pain.
- Anticonvulsants like gabapentin (Neurontin), or pregabalin (Lyrica) work to calm overstimulated nerves.

Also a pain-relief cream that has lidocaine or capsaicin may soothe tingling and burning.

Some pain management strategies for dysesthesia don’t involve medicine. You may be able to change pain to a different feeling with warm or cold compresses or compression socks or gloves. Alternative therapies can also be part of an overall treatment plan for chronic pain. These include acupuncture, biofeedback, exercise, hypnosis, meditation, and stress management.

REFERENCES

“What Is Dysesthesia (Multiple Sclerosis Pain)?”; Christopher Melinosky, MD; Webmd.com; August 16, 2023
Neuropathy; East Texas Foot Associates; retrieved February 19, 2024

HEALTH CARE CHALLENGES WEBSITES (updated)

SHIPs

State Health Insurance Assistance Programs

www.shiphelp.org
(877) 839-2675

Help for navigating the complexities of Medicare. Search the website for your specific state program.

Medicare Rights Center

www.medicarerights.org
(800) 333-4114

Non-profit that works to ensure access to affordable health care for older adults and people with disabilities.

Medicare

www.medicare.org
(800) MEDICARE
(800) 633-4227

Get started with Medicare, options, news.

Benefits and Insurance for People with Disabilities

www.usa.gov/disability-benefits-insurance
(844) USAGOV1
(844) 872-4681

For those with a disability, learn how government programs and services can help in your daily life.

OFFICE APPROACH TO SMALL FIBER NEUROPATHY – PART 2: SEROLOGIC TESTING

Jinny O. Tavee, MD. (2018). Office Approach To Small Fiber Neuropathy. *Cleveland Clinic Journal of Medicine*, 85/(10), 801-812. DOI: <https://doi.org/10.3949/>

INITIAL TESTING FOR AN UNDERLYING CAUSE

Although up to half of cases of small fiber neuropathy are idiopathic, it is important to search for an identifiable underlying cause amenable to treatment. A cost-effective approach is to start with a battery of blood tests that cover the most common causes, and then proceed with second-tier testing as needed (Table 1).

FIRST-TIER TESTING

Glucose tolerance test for diabetes

Diabetes is the most common identifiable cause of small fiber neuropathy and accounts for about a third of all cases. Impaired glucose tolerance is also thought to be a risk factor and has been found in up to 50% of idiopathic cases, but the association is still being debated.

While testing for hemoglobin A1c is more convenient for the patient, especially because it does not require fasting, a 2-hour oral glucose tolerance test is more sensitive for detecting glucose dysmetabolism.

Lipid panel for metabolic syndrome

Small fiber neuropathy is associated with individual components of the metabolic syndrome, which include obesity, hyperglycemia, and dyslipidemia. Of these, dyslipidemia has emerged as the primary factor involved in the development of small fiber neuropathy, via an inflammatory pathway or oxidative stress mechanism.

Vitamin B12 deficiency testing

Vitamin B12 deficiency, a potentially correctable cause of small fiber neuropathy, may be underdiagnosed, especially as values obtained by blood testing may not reflect tissue uptake. Causes of vitamin B12 deficiency include reduced intake, pernicious anemia, and medications that can affect absorption of vitamin B12 (eg, proton pump inhibitors, histamine 2 receptor antagonists, metformin).

Testing should include:

- Complete blood cell count to evaluate for vitamin B12-related macrocytic anemia and other hematologic abnormalities
- Serum vitamin B12 level
- Methylmalonic acid or homocysteine level in patients with subclinical or mild vitamin B12 deficiency, manifested as low to normal vitamin B12 levels (< 400 pg/mL); methylmalonic acid and homocysteine require vitamin B12 as a cofactor for enzymatic conversion, and either or both may be elevated in early vitamin B12 deficiency.

Celiac antibody panel

Celiac disease, a T-cell mediated enteropathy characterized by gluten intolerance and a herpetiform-like rash, can be associated with small fiber neuropathy. In some cases, neuropathy symptoms are preceded by the onset of gastrointestinal symptoms, or they may occur in isolation.

Inflammatory disease testing

Sjögren syndrome accounts for nearly 10% of cases of small fiber neuropathy. Associated neuropathic symptoms are often non-length-dependent, can precede sicca symptoms for up to 6 years, and in some cases are the sole manifestation of the disease. Small fiber neuropathy may also be associated with vasculitis, systemic lupus erythematosus, and other connective tissue disorders.

Testing should include:

- Erythrocyte sedimentation rate, C-reactive protein, and antinuclear antibodies: though these are nonspecific markers of inflammation, they may support an immune-mediated etiology if positive
- Extractable nuclear antigen panel: Sjögren syndrome A and B autoantibodies are the most important components in this setting
- The Schirmer test or salivary gland biopsy should be considered for seronegative patients with sicca or a suspected immune-mediated etiology, as the sensitivity of antibody testing ranges from only 10% to 55%.

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TABLE 1 - Serologic testing to find the cause of small fiber neuropathy

First-tier studies	Associated conditions
2-hour oral glucose tolerance test, hemoglobin A _{1c}	Diabetes, impaired glucose tolerance
Extractable nuclear antigen testing for Sjögren syndrome A and B antibodies	Sjögren syndrome
Thyroid-stimulating hormone, free T ₄ , T ₃ levels	Hypothyroidism
Vitamin B ₁₂ , methylmalonic acid, homocysteine levels	Vitamin B ₁₂ deficiency
Serum and urine monoclonal protein analysis	Paraproteinemia
Tissue transglutaminase, antigliadin antibodies	Celiac disease
Complete metabolic panel	Renal, hepatic impairment
Complete blood cell count	Hematologic abnormalities
Human immunodeficiency virus (HIV) and hepatitis C virus antibodies (may be second-tier tests if no risk factors)	HIV, hepatitis C
Fasting lipid panel	Hyperlipidemia
Erythrocyte sedimentation rate, C-reactive protein, antinuclear antibody	Inflammatory disease
Liver function tests, gamma-glutamyltransferase	Alcohol abuse
Second-tier studies	
Angiotensin-converting enzyme	Sarcoidosis
Thiamine (vitamin B ₁)	Vitamin B ₁ deficiency
Pyridoxine (vitamin B ₆)	Vitamin B ₆ deficiency
Copper	Copper deficiency
Serum and urine monoclonal protein analysis, fat pad analysis, nerve biopsy	Systemic amyloidosis
Paraneoplastic autoantibody panel	Paraneoplastic disease
Ganglionic acetylcholine receptor antibody	Autoimmune autonomic ganglionopathy
Genetic studies	
<i>SCN9A</i> and <i>SCN10A</i> genes	Hereditary small fiber neuropathy
<i>GLA</i> gene	Fabry disease
Transthyretin gene	Familial amyloidosis
<i>ABCA1</i> gene	Tangier disease

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Thyroid function testing

Hypothyroidism, and less commonly hyperthyroidism, are associated with small fiber neuropathy.

Metabolic tests for liver and kidney disease

Renal insufficiency and liver impairment are well-known causes of small nerve fiber dysfunction.

Testing should include:

- Comprehensive metabolic panel
- Gamma-glutamyltransferase, if alcohol abuse is suspected, since heavy alcohol use is one of the most common causes of both large and small fiber neuropathy

HIV and hepatitis C testing

For patients with relevant risk factors, HIV and hepatitis C testing should be part of the initial workup (and as second-tier testing for others). Patients who test positive for hepatitis C should undergo further testing for cryoglobulinemia, which can present with painful small fiber neuropathy.

Serum and urine immunoelectrophoresis

Paraproteinemia, with causes ranging from monoclonal gammopathy of uncertain significance to multiple myeloma, has been associated with small fiber neuropathy. An abnormal serum or urine immunoelectrophoresis test warrants further investigation and possibly referral to a hematology-oncology specialist.

SECOND-TIER TESTING

Less common treatable causes of small fiber neuropathy may also be evaluated.

Copper, vitamin B1 (thiamine), or vitamin B6 (pyridoxine) deficiency testing

Although vitamin B6 toxicity may also result in neuropathy due to its toxic effect on the dorsal root ganglia, the mildly elevated vitamin B6 levels often found in patients being evaluated for neuropathy are unlikely to be the primary cause of symptoms. Many laboratories require fasting samples for accurate vitamin B6 levels.

Angiotensin-converting enzyme levels for sarcoidosis

Small fiber neuropathy is common in sarcoidosis, occurring in more than 30% of patients with systemic disease. However, screening for sarcoidosis by measuring serum levels is often falsely positive and is not cost-effective. In a study of 195 patients with idiopathic small fiber neuropathy, 44% had an elevated serum level, but no evidence of sarcoidosis was seen on further testing, which included computed tomography of the chest in 29 patients. Thus, this test is best used for patients with evidence of systemic disease.

Amyloid testing for amyloidosis

Fat pad or bone marrow biopsy should be considered in the appropriate clinical setting.

Paraneoplastic autoantibody panel for occult cancer

Such testing may also be considered if clinically warranted. However, if a patient is found to have low positive titers of paraneoplastic antibodies and suspicion is low for an occult cancer (eg, no weight loss or early satiety), repeat confirmatory testing at another laboratory should be done before embarking on an extensive search for malignancy.

Ganglionic acetylcholine receptor antibody testing for autoimmune autonomic ganglionopathy

This should be ordered for patients with prominent autonomic dysfunction. The antibody test can be ordered separately or as part of an autoantibody panel. The antibody may indicate a primary immune-mediated process or a paraneoplastic disease.

GENETIC MUTATION TESTING

Recent discoveries of gene mutations leading to peripheral nerve hyperexcitability of voltage-gated sodium channels have elucidated a hereditary cause of small fiber neuropathy in nearly 30% of cases that were once thought to be idiopathic. Genetic testing for mutations in SCN9A and SCN10 (which code for the Nav1.7 and Nav1.8 sodium channels, respectively) is commercially available and may be considered for those with a family history of neuropathic pain in the feet or for young, otherwise healthy patients.

Fabry disease is an X-linked lysosomal disorder characterized by angiokeratomas, cardiac and renal impairment, and small fiber neuropathy. Treatment is now available, but screening is not cost-efficient and should only be pursued in patients with other symptoms of the disease.

– Continued on page 7

7 FOODS THAT MAY HELP FIGHT NEUROPATHY NIVA Health; retrieved February 19, 2024

Researchers and doctors have long held the connection between neuropathy and diet, in that a healthy diet may prevent or slow down the progression of neuropathy. Neuropathy is most often associated with diabetes, but it can also be due to metabolic conditions, infections, and exposure to toxins. Nerves need nutrients for their continued health, which is why a treatment for neuropathy could be dietary changes and a partnership with a nutritionist or dietitian.

The following seven foods may help fight neuropathy and improve the symptoms in hands/arms and feet/legs:

- **Fruits.** Fruits contain antioxidants that help fight nerve damage and control inflammation. Try to have a serving of fruit daily. Raspberries, blackberries, blueberries, cranberries, cherries, grapes, and oranges are all beneficial to the nerves. Not only do they help prevent nerve damage, but they can also facilitate healing of nerve damage – especially grapes and berries, which contain resveratrol, which protects the body against internal damage.
- **Vegetables.** Just like fruits, vegetables are rich in antioxidants, vitamins, and minerals. Broccoli, Brussels sprouts, spinach, and kale contain alpha-lipoic acid, an antioxidant that can prevent nerve damage and improve nerve function. Potatoes and yams contain alpha-lipoic acid and phytonutrients to fight inflammation, so these should also be part of your diet.
- **Whole grains.** For carbohydrates, choose whole grains such as brown rice, oatmeal, quinoa, buckwheat, millet, and sprouted grain bread. The outer shell of the grain, which is maintained in whole grains, contains important B vitamins that are important for brain and nerve health.
- **Nuts.** Nuts are another rich source of vitamin B. Almonds, cashews, walnuts, and sunflower seeds are also rich in fiber, which keeps you full longer and prevents overeating.
- **Legumes.** Magnesium is necessary for restoring nerve function, and it aids in nerve regeneration. Legumes such as black beans, lima beans, pinto beans, chickpeas, fava beans, and lentils naturally contain magnesium.
- **Omega-3-rich foods.** Fish oil has been found to restore the condition of damaged nerves due to the omega-3 found in it. Omega-3 foods such as salmon, tuna, cod, herring, sardines, mackerel, flaxseeds, and chia seeds help improve blood sugar regulation and control inflammation.
- **Lean proteins.** Meat products contain vitamin B-12, which is essential for a healthy nervous system, improves the transmission of nerve impulses, and promotes nerve healing. Incorporate poultry, such as chicken and turkey, into your nerve-friendly diet.

OFFICE APPROACH TO SMALL FIBER NEUROPATHY – PART 2: SEROLOGIC TESTING - Continued from page 6

OTHER POSSIBLE CAUSES

Guillain-Barré syndrome

A Guillain-Barré syndrome variant has been reported that is characterized by ascending limb paresthesias and cerebrospinal fluid albuminocytologic dissociation in the setting of preserved deep tendon reflexes and normal findings on EMG. The clinical course is similar to that of typical Guillain-Barré syndrome, in that symptoms follow an upper respiratory or gastrointestinal tract infection, reach their nadir at 4 weeks, and then gradually improve. Some patients respond to intravenous immune globulin.

Vaccine-associated

Postvaccination small fiber neuropathy has also been reported. The nature of the association is unclear.

Parkinson disease

Small fiber neuropathy is associated with Parkinson disease. It is attributed to a number of proposed factors, including neurodegeneration that occurs parallel to central nervous system decline, as well as intestinal malabsorption with resultant vitamin deficiency.

Rapid glycemic lowering

Aggressive treatment of diabetes, defined as at least a 2-point reduction of serum hemoglobin A1c level over 3 months, may result in acute small fiber neuropathy. It manifests as severe distal extremity pain and dysautonomia.

In a retrospective study, 104 (10.9%) of 954 patients presenting to a tertiary diabetic clinic developed treatment-induced diabetic neuropathy with symptoms occurring within 8 weeks of rapid glycemic control. The severity of neuropathy correlated with the degree and rate of glycemic lowering. The condition was reversible in some cases.

PART 3 – TREATMENT, July Issue, will conclude the series



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IN THIS ISSUE

As with the May issue, the main article in this issue is the Office Approach To Small Fiber Neuropathy by the *Cleveland Journal of Medicine*, with this issue containing Part 2 on Serological Testing. This article is more complex as it details different tests for use in determining causes of neuropathy. While you may not understand every word, you will be able to understand the meaning enough to discuss with your doctor. Printing out the Table on page 5 would be an aid for that conversation.

The front-page article has suggestions for how to manage the emotions associated with neuropathy, specifically neuropathic pain. Stress is a big factor and that seems to be a vicious cycle. We have pain, we are stressed about the pain, and that stress makes the pain worse. Breathing to a specific routine can help as well as progressive muscle relaxation. And remember that coming to our support groups can help by being around others that understand your neuropathy situation.

Page 7 lists foods that can help improve neuropathy symptoms. I kept on looking for chocolate but couldn't find it listed.

May these give you Hope.

..Katherine

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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.

Tax ID # 68-0476041

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

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