



JANUARY/FEBRUARY 2025

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A newsletter for members of Western Neuropathy Association (WNA)

■ EAR SEEDS: WHAT TO KNOW ABOUT THIS ACUPRESSURE THERAPY

Patty Weasler, RN, BSN; *VeryWellHealth.com*; June 23, 2023.

Ear seeds are used as a part of auricular (ear) acupuncture. It is a form of acupressure that targets ear pressure points without using needles. People may use ear seeds to treat or manage the symptoms of several conditions, including addiction and anxiety.

What Are Ear Seeds?

Ear seeds are a tool used in auricular acupuncture, which is the practice of using pressure points on the ear. Auricular acupuncture is a traditional Chinese medicine practiced for about 2,500 years. Acupuncture is used to balance and restore the flow of Qi (or Chi). Qi is the vital life force that moves through pathways in the body, called meridians.

Acupuncture and acupressure follow the theory that there are points on the surface of the body that correlate with internal areas of the body. By targeting these areas, the normal flow of Qi can be restored, and certain conditions can be alleviated. Auricular acupuncture is thought to correct various issues or manage certain conditions by stimulating external points on the ear.

Types of Ear Seeds

Ear seeds used for auricular acupressure can be made from many materials. The most common ones are made from Vaccaria seeds. Other types of ear seeds are made from magnet beads, or other ceramic and metal beads. The ear seeds are attached to the ear's surface with tape.

How Auricular Acupressure (Ear Seeding) Works

Auricular acupressure works by placing ear seeds in various spots on the ear's surface. The ear seeds are secured to the ear with tape. The spots are points of correlation with the body, not meridians. Acupuncture/acupressure restores the flow of Qi, not Qi itself.

Auricular acupressure has been used for various conditions. When it's used for addictions, behavioral health, and emotional trauma, the National Acupuncture Detoxification Association (NADA) protocol is followed.

The NADA protocol includes these five points:

1. **Autonomic point:** This spot calms the nervous system and provides relaxation.
2. **Shen men:** Also called spirit gate, this spot reduces anxiety.
3. **Kidney point:** This area heals internal organs and eases fears.
4. **Liver point:** This area is used for detox, purifying the blood, and minimizing aggression.
5. **Lung point:** Acupressure on this spot improves air movement through the lungs and releases grief.

Health Benefits of Ear Seeding

Ear seeding has been used to address several health conditions and symptoms. These include pain, stress, depression, anxiety, substance addiction, weight loss, insomnia, and emotional trauma.

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PERIPHERAL NEUROPATHY SUPPORT GROUPS VIRTUAL AND IN-PERSON FOR JANUARY / FEBRUARY 2025

*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

JANUARY 15	Santa Cruz, CA Support Group Wednesday, 1 - 2:30pm Pacific Trinity Presbyterian Church, 420 Melrose Avenue, Santa Cruz, CA Host - Mary Ann Leer (831) 477-1239
MEETS ODD MONTHS	
JANUARY CANCELLED	Auburn, CA Peripheral Neuropathy Support Group Monday, 12 noon - 1:30pm Pacific 1212 High Street, Unity of Auburn, Auburn, CA. Hosts-Pam Hart, pamula1@hotmail.com and Cass Capel, capelkbphd@gmail.com
FEBRUARY 3	

VIRTUAL

CONTACT ERIKA	Strategies for Singles with Neuropathy Support Group Host – Erika McDannell, contact Erika for next meeting date
MEETS ODD MONTHS	
JANUARY 8	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
FEBRUARY 12	
JANUARY 11	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
FEBRUARY 8	
JANUARY 15	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 Zoom link
FEBRUARY 19	
JANUARY 15	CIDP and Autoimmune Support Group Wednesday, 3pm - 4pm Pacific / 5pm - 6pm Central / 6pm - 7pm Eastern Host - John Phillips, contact John for Zoom link
FEBRUARY 19	
JANUARY 25	4th Saturday Peripheral Neuropathy Open Discussion Saturday, 11-1pm Pacific / 1pm-3pm Central / 2pm – 4pm Eastern Meeting ID: 851 7949 9276 / Passcode: 159827 Host – John Phillips, contact Katherine for Zoom link
FEBRUARY 22	

Contact emails in the sidebar Board of Directors listing.

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

■ FROM THE PRESIDENT Pam Hart, WNA President

Happy New Year! The start of a new year brings with it a sense of possibility and excitement, along with the opportunity to embrace change. In this spirit, we are entering 2025 with renewed energy, ready to face challenges head-on and celebrate the many changes that lie ahead.

As with many of you, WNA is making a shift for the new year. We have moved our office from Sacramento to Auburn, CA. We no longer have the Association Resource Center handling our administrative duties. We are keeping our same phone number, upgrading our website and will continue to provide membership services

Change isn't always easy, but it's an essential part of growth. As we adapt to shifting landscapes, we're excited to see how these changes will open doors to new possibilities, fresh perspectives, and innovative ideas. 2025 promises to be a year full of new collaborations and partnerships. We're thrilled about the potential for working alongside passionate individuals, innovative organizations, and like-minded teams who share our values and vision for the future. Together, we will forge new paths, break boundaries, and achieve extraordinary things.

None of this would be possible without the incredible support and dedication of each one of you. Whether you've been with us from the beginning or are joining us for the first time, your involvement is a driving force behind our progress. We look forward to continuing this journey with you, fueled by the excitement and opportunities that 2025 brings.

Here's to a year filled with positive change, boundless enthusiasm, and meaningful achievements. Let's make this year our best one yet!

Cheers,
Pam
pamula1@hotmail.com

EAR SEEDS: WHAT TO KNOW ABOUT THIS ACUPRESSURE THERAPY - Continued from page 1

More research is needed on the health benefits of ear seeding.

Risks and Side Effects of Ear Seeding

Ear seeding carries minimal risks and side effects for most people. People with allergies or sensitivities to tape or adhesives may react when using the tape to adhere to the ear seed. Another risk is that the tape holding the ear seed can loosen, and the seed can fall into the ear canal. Other adverse reactions may include pain, bleeding, infections, dizziness and skin irritation.

How to Use Ear Seeds at Home

When learning how to use ear seeds, it's best to see an acupuncturist to ensure correct seed placement. After seeing an acupuncturist and learning how to apply the ear seeds properly, it is possible to use an at-home application.

Summary

Ear seeds are a form of acupressure that use small seeds or other objects taped to the surface of the ear. The method follows acupuncture theories to restore flow of the body's life force, or Qi, to improve health conditions. Ear seeding has been used for various conditions, including addiction, stress, and anxiety.

Continue reading on **Page 4** about new Board Director Kris Langenfeld's participation in an ear seed study for Chemotherapy Induced Peripheral Neuropathy.

HEALTH CARE CHALLENGES WEBSITES (updated)

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and services can help
in your daily life.

AURICULAR POINT ACUPRESSURE (APA) EXPERIENCE

Kris Langenfeld, WNA Director, Houston, TX

In the Summer of 2022, there was a notice sent out to WNA's support group recruiting people who have chemo-induced peripheral neuropathy (CIPN) for a medical study funded by the National Cancer Institute and jointly conducted by Johns Hopkins and UTHealth/MD Anderson Cancer Center. In addition to CIPN, participants must live within driving distance of the Houston Medical Center for in-person testing.

The study involved measuring the effectiveness of auricular point acupressure (APA) using three different teaching methods:

1. In-person: The professor or research assistant would teach and directly apply the ear seeds to the participant.
2. Virtual: The professor or research assistant would teach via virtual conference how to apply the ear seeds to the participant.
3. Self-guided: The participant would learn how to apply the ear seeds via a phone app.

Before I get too ahead of myself, you may be wondering what APA is.

- **Auricular:** Of or relating to the ear or to the sense of hearing.
- **Point:** A specific spot on the ear, which correlates to a specific area of the body.
- **Acupressure:** Similar to acupuncture, acupressure stimulates the area of the body; however, acupressure uses ear seeds applied with a small adhesive instead of needles.

The study included 240 participants and randomly selected the three teaching methods. I was the 81st participant and assigned to the in-person teaching approach. Yeah! On the first visit, I was introduced to APA and directions for daily treatments.

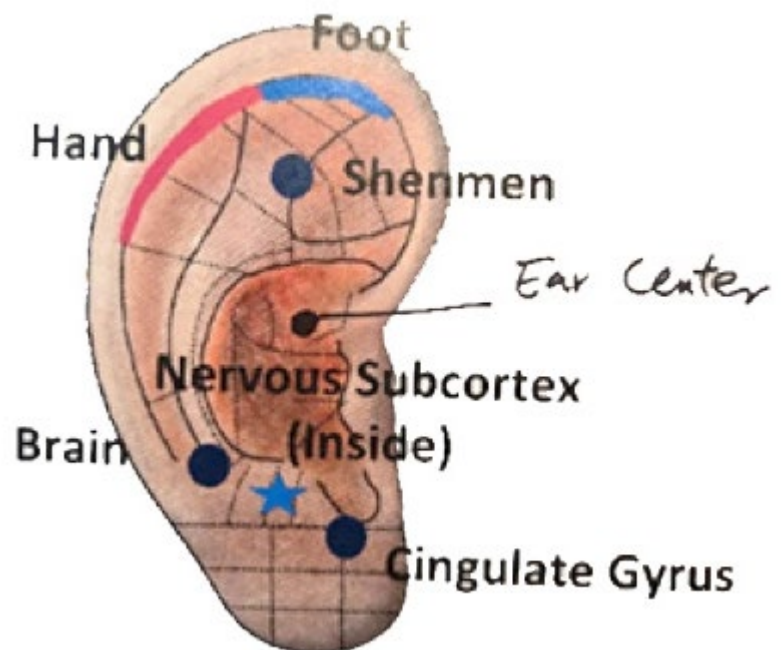
Think of the ear representing an upside-down fetus; the earlobe is the head, and the top of the ear includes the hands and feet. To stimulate the points, press each seed until feeling tenderness (not pain!) and keep pressed while moving up and down (not side to side). Press for two seconds, release for two seconds, re-press for two seconds, etc. Repeat for each point on both ears.

The seeds should be pressed at least three sessions per day. The seeds can be pressed on both ears at the same time or separately; I chose separately. In addition, there is no specific order to press the seeds. I found it easier to start with the ear lobe and move towards the top of the ear.

There are various protocols for how long to leave the seeds on the ears and how long to let the ears rest. In this study, the ear seeds were left on for five days and given a rest for two days.

While APA can be used for many conditions (e.g., anxiety, weight loss, insomnia), the points that are specifically for peripheral neuropathy are:

- Foot
- Hand
- Shen men
- Ear Center
- Nervous Subcortex
- Brain
- Cingulate Gyrus



I noticed a positive difference immediately after the first time the ear seeds were applied. I could feel individual carpet fibers under feet. Prior to the ear seed application, it felt like I was walking on pillows; it was hard to detect the substrate under my feet. On the way home, I could feel my toes in my shoes. This lasted about 15 minutes into the drive.

– Continued on page 5

WELCOME TO KRIS LANGENFELD, NEW EXECUTIVE BOARD DIRECTOR

Kris was diagnosed with Chemo-Induced Peripheral Neuropathy (CIPN) in July 2020. After a 3-month flare up in June 2021, she realized she needed to devote more time to understanding and managing CIPN. One day Kris stumbled upon the WNA website and asked to join the Zoom support group call. What she learned in that first meeting in September 2021 was more than the advice she received from her neurologist the previous year. Forever grateful for the help, guidance and support of WNA, Kris was elected to the Board of Directors in November 2024 to help other PN sufferers also lead a better quality of life.

TIDBITS FROM NOVEMBER 23, 2024 VIRTUAL SUPPORT GROUP Katherine Stenzel, Editor

- For those using wheelchairs, search for “Exercises from a wheelchair” on your iPad, tablet, smart phone or computer to find physical activity you can do while seated. My search turned up a list of easy stretches and lifts along with many YouTube videos.
- Barefoot shoes are a minimal material shoe that has a thinner sole. Many of the support group attendees use these with one person saying they made her feel more secure when active. SKECHERS and MERRELL were popular brands mentioned in the discussion.
- R-Alpha Lipoic Acid can cause your urine to have a different smell – as one attendee discovered.
- Peripheral Neuropathy is a mental health journey as well as a physical journey - and it is okay to have those mental feelings of anxiety.

AURICULAR POINT ACUPRESSURE (APA) EXPERIENCE - Continued from page 4

For the following week, I noticed additional improvements in my sensory and motor skills. During minute eight of a treadmill walk, I could feel my toes bending at the joint. So, I increased my speed from 3.5 mph to 4 mph. No numbness or tingling, which would have been felt in the past. I increased the speed more, to 5 mph. Still no numbness. Feeling a little confident, I ran for one minute, walked for one and a half minutes, for a total of 30 minutes. I was able to replicate this the next day. However, this was short-lived due to a fall and fracturing my foot.

During the second week of APA, positive progression continued. The bottom of my left big toe was itchy for the first time in a very long time. Another improvement was in my typing skills. They had been declining; both in sensory and motor skills. The improvements were noticed on phone and laptop. My fingers were hitting the intended letter. And at a faster rate.

By the third week I could point my toes on my left foot, my grip was more defined, and I could use a manual can opener again. In the first month of the study, the professor applied the ear seeds once a week. After that fourth week, it was up to me to apply the ear seeds weekly for the following three months (the duration of the study). With such positive results, two years later I continue to use APA therapy.

I entered this study a skeptic. Like most of us, I have tried many treatments with no improvements. One of the treatments I tried was acupuncture. I saw an acupuncturist once a week for eight weeks. It made some of my symptoms worse and others unchanged. So, I went into this with very low expectations. But the APA has ended up being a great additional tool for managing my peripheral neuropathy symptoms.

Interested in trying this therapy?

Kris bought her ear seed kit from Amazon after her involvement in the study:

<https://www.amazon.com/gp/product/B01HXPJ76G/>

Another kit with good reviews:

<https://www.amazon.com/gp/product/B0B4Z157W1>

The kits include seeds, tweezers, ear probes and an e-book. The e-book has instructions and placement of seeds for a lot of medical issues - except PN. For PN, use the chart of the ear in Kris's article on page 4 which was given to her during the peripheral neuropathy ear seed study.

■ ANTICIPATORY GRIEF - SYMPTOMS AND HOW TO COPE

Mental Health; *ClevelandClinic.org*; April 9, 2024

(Editor – I adapted this article to patients suffering from peripheral neuropathy)

Grief. We'll all experience it at some point. But there may be times in your life when you're expecting to feel grief years or months before it even happens. Known as anticipatory grief, it's a coping mechanism to help us prepare for a loss like receiving a new diagnosis of peripheral neuropathy or the disability that could occur with the progression of peripheral neuropathy.

What Is Anticipatory Grief?

"It's a collection of symptoms — cognitive, behavioral, emotional — that we experience in anticipation of an impending loss," explains Dr. Josell. "We most commonly associate anticipatory grief with somebody who is very ill or dying — either one's own impending death or a loved one. But it can also be in reference to other types of losses such as an illness or a forced job change."

How is anticipatory grief different from traditional or conventional grief? Conventional grief happens after the loss — it's a reaction to the loss, whereas anticipatory grief is considering what is to come. It's thinking about what's going to happen as opposed to reacting to something that has already happened.

Anticipatory grief can have benefits. It can help prepare somebody for the grief when it actually happens. Anticipatory grief can help you face your fears rather than avoid them, with the hope that you can navigate your grief when the loss occurs.

Symptoms Of Anticipatory Grief

Anticipatory grief is like a snowflake — no two people's symptoms are exactly the same. Common anticipatory grief symptoms include:

- Overwhelming emotions such as sadness, anger and loneliness.
- Difficulty sleeping.
- Loss of appetite.
- Difficulty concentrating.
- Being preoccupied and replaying different scenarios in your head.
- Withdrawal from others.

How To Deal With Anticipatory Grief

Dr. Josell says it's important to start off by normalizing the experience of anticipatory grief. "It's normal for people to anticipate loss and to have a reaction to an impending negative experience," she says. Here's how to cope with anticipatory grief:

- **Talk about what you're going through.** Don't hesitate to share and talk with other people about what you're feeling. "When we think that we're unique and the only person who's ever experienced something, it makes everything worse," says Dr. Josell. "Talking with other people who have been through a similar experience or have had similar kinds of symptoms can be very helpful." *(Editor – attend peripheral neuropathy support groups to share what you are experiencing. Many of us have had the same experiences.)*
- **Feel your emotions.** You may have been taught to ignore your emotions — don't let people see you cry or become upset. But that's not a healthy way to deal with your emotions, says Dr. Josell. "We get the message to push those emotions down, that they're not good, they're not healthy," she explains. "But what happens is your emotions burst out another way." Your emotions can manifest in overeating or even turning to alcohol and drugs. So, feel what you feel. "When we let ourselves feel it, those emotions tend to dissipate a lot more quickly than if we try to hold them back or ignore them."
- **Take care of yourself.** Practice self-care often. "When we're not in a good place, we stop taking care of ourselves," notes Dr. Josell. "Make sure you focus on sleep and a healthy diet, while making an effort to move your body, drink plenty of water and being around other people that make you happy."
- **Education yourself.** Learn about this disease. This will help you understand what is happening to you by knowing what the words mean that are used to describe peripheral neuropathy. Use our website at www.pnhelp.org to learn about neuropathy symptoms, peripheral nerves, and conventional and alternative treatments. *(bullet point added by Editor)*

It's important to remember that grief — whether anticipatory or traditional — is normal. If you love someone or are happy to have something in your life, you are going to experience a loss, i.e. grief, when it is missing. You may feel sad, angry and depressed even thinking about that loss. Following the above advice will give you some control over your grief.

■ UREMIC NEUROPATHY: A SYSTEMIC CONSEQUENCE OF KIDNEY DYSFUNCTION

Glenn Ribotsky, WNA Secretary

Certainly, people with neuropathy are alive to the possibility of their neuropathies are the result of a toxic exposure, either accidental, as in the case of being exposed to organic solvents or heavy metals over time, or as a side effect of medical treatments, such as those cases that result from chemotherapy or other drug regimens (i.e., statins or the “flox” categories of antibiotics). But there is also the possibility of suffering nerve damage from exposure to those toxic metabolic wastes that the body itself makes, wastes that are normally filtered out by the liver, and, most importantly, by the kidneys. When kidney function wanes, waste products build up in the bloodstream and the nerves are often among the first organ systems to notice the effects. This is referred to as uremic neuropathy (after urea, the prime waste product of protein metabolism in humans and other mammals, which is normally excreted in urine).

Uremic neuropathy is commonly experienced by a substantial number of people who have reached later stage kidney disease, meaning they need dialysis or transplant, although in some cases symptoms may occur earlier in the process of reducing kidney function. Various literature reviews indicate that by the time end state disease is reached, nearly all will experience some degree of neuropathic symptomology. Typically onset is relatively slow, length-dependent, and involves primarily sensory symptoms of paresthesia and pain, with breakdown in the axonal fibers leading to secondary myelin breakdown, although in advanced cases motor symptoms may become prominent. Timely dialysis or transplant may arrest the symptoms by removing the toxic metabolic products regularly and may even allow for some recovery; unfortunately, delays in diagnosis of kidney disease are common and symptoms may progress and be attributed to other causes or labelled idiopathic before the kidney dysfunction is confirmed. Additionally, those with kidney disease quite commonly have other metabolic issues also associated with neuropathy that may have directly caused kidney dysfunction, such as diabetes, or which have developed in tandem with it, making teasing out an exact diagnosis difficult.

The usual tests serological and nerve conduction studies for neuropathy are involved in trying to confirm uremic neuropathy and rule out other causes; elevations in blood urea nitrogen (BUN) and serum creatinine levels, as well as reduced estimated glomerular filtration rates (eGFR), raise suspicion that the neuropathy may be uremic in nature, especially in the absence of elevated blood sugar/hemoglobin A1C levels which would point to a diabetic genesis. C-reactive protein levels - a measure of inflammation - are also often elevated, though this is true for many vascular and metabolic conditions and is not specific enough to be diagnostic.

While dialysis may slow down the progression of the neuropathy or result in symptoms plateauing, most literature points to kidney transplantation as the only avenue that can fully arrest the process and allow for some regeneration of nerves and improvement in symptoms. Given the difficulty and expense of kidney transplant, it is much more advantageous to closely monitor kidney function parameters in patients and to try to arrest the process of kidney disease itself, especially that caused by metabolic syndrome and obesity as opposed to genetic and toxic causes of kidney dysfunction. The use of GLP-1 drugs may be promising in this regard, assuming they become inexpensive enough to be used widely.

By far the biggest difficulty in detecting the possibility of uremic neuropathy remains lack of access to physicians who are familiar with signs of insidious kidney disease; patients, especially those who have other indications of blood sugar dysregulation, obesity, or cardiovascular symptoms are well advised to have their kidney function regularly checked and to broach the subject during their appointments.

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PERIPHERAL NEUROPATHY VIRTUAL SUPPORT GROUP QUOTES THAT KEEP ON GIVING!

“We have to keep making adjustments to our life.”

“We are all an experiment of one.”

“Rest is rust, motion is lotion.”

“One foot in front of the other until it hurts.” – Alternative – “One foot in front of the other even though it hurts.”



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IN THIS ISSUE

Dear Readers and welcome to 2025!

This double issue is heavy on the topic of Acupressure Therapy, which is different from acupuncture treatments as it uses tiny seeds to activate pressure points. The **front page article** is a general description of the technique with its benefits for the entire body. Then turn to **page 5** for WNA member Kris Langenfeld's (and our newest Executive Board member!) experience with ear seeds in a clinical trial for those with Chemotherapy-Induced Peripheral Neuropathy. She explains the protocol used for ear seeds with peripheral neuropathy and how she felt the benefits almost immediately! At the end of the article is an Amazon link to the ear seed kit she bought after the study which continues to help manage her symptoms.

Grief is a common reaction to loss. **Anticipatory grief is a coping technique that many of us don't realize we use.** When we think about how our life may or will change with neuropathy, anticipatory grief helps us cope with those changes by considering in advance the consequences. **Page 6** lists four ways to deal with this normal response of considering the future.

May these give you Hope.

..Katherine

klstenzel@hotmail.com



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WNA Headquarters: info@pnhelp.org

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.

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

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