

VOL. 12, No. 8

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acros

Most of the important things in the world have been accomplished by people who have kept on trying when there seemed to be no help at all.

Dale Carnegie

DAVIS

TUESDAY, OCTOBER 11, 3:30 - 5:00 p.m.

Program: Screening DVD: "Coping with Chronic Neuropathy" featuring Eugene Richardson

Davis Senior Center 646 A Street, Davis, 95616 Contact: Mary Sprifke (530) 756-5102 or Retta Gilbert at (530) 747-0186

WOODLAND

No Meeting - No leader(s)

SACRAMENTO

TUESDAY, OCTOBER 18 - 1:30-3:30

Program: Round-Table Focused Discussion including Stem Cell Research, Earthing Practice, Pain Scale and more

Northminster Presbyterian Church 3235 Pope Avenue Sacramento, CA 95825 Contact: Charles Moore (916) 485-7723

OCTOBER 2016

MEETING RECAPS

DAVIS SEPTEMBER NOTES By Mary Sprifke

When a round table discussion gets going, it can resemble a Ping-Pong game. Hints, stories and suggestions flew by, and my notes are woefully short on capturing it. You just had to be there.

However here are some nuggets:

- Co-Leader Retta Gilbert (researcher par excellence) warned of full-page ads in local papers touting cures for PN. The heart of her point is that a LOT of money is expected and contracts exist and there is no guarantee of relief;
- The organization 'Out of Sight' located in Woodland can be of great help with vision issues. They can be reached at 662-9521;
- With a doctor's certificate, a state program provides a free cell phone through the 'California Lifeline. Web Site is <u>http://www.freegovernmentcellphones.net</u> /states/california-government-cell-phoneproviders
- Beware robot-call product offers. Retta is checking on one to do with a topical painkiller.
- Reservations about Gabapentin kept one member from filling the prescription. The side effects can be serious.

• Drink more water each day. Keep a glass or bottle nearby all the time.



- Looking back at any reasons for feeling better, one named eating fresh food, avoiding sugar and light use of iodized salt. Also using a topical mix of lidocaine and Aspercreme as needed.
- Sometimes symptoms worsen over time and taking extra good care of your feet can make a big difference in overall comfort. Orthotics and cushioning were noted.
- After 15 years of back-related pain, one found that Sutter Health's exercise program located at the Davis hospital basement has supportive staff. With a doctor's referral and at a cost of \$50 per month, site usage is open to independent exercise too. This is essentially a cardiac-based program from 7am-noon.
- One has numb hands resulting from chemotherapy.
- Trying to address multiple symptoms that fall into several medical areas can be extremely stressful. Fibromyalgia and arthritis plus PN have taken lots of patience and perseverance. Added to that are medical coverage issues. The group noted that Health Net Senior Advantage is a Medicare provider.

SACRAMENTO SEPTEMBER NOTES By Charles Moore

Debbie Eernisse, fitness trainer, yoga instructor and balance specialist at the Davis Senior Center, presented an instructional workshop to the Sacramento PN Support Group on September 20, 2016.

Debbie had chosen **"Building Balance"** as a particularly appropriate title for her presentation. She provided an excellent handout with illustrated exercises, in each case providing movements that do

indeed build toward improving balance, so important to PN sufferers who often experience numbness in the feet and legs, as well as creating problems of balance and the danger of falling.

Before turning to the "7 Components of Balance," she had us perform an interesting exercise: we stood on one foot in the center of an imaginary face of a clock on the floor. Standing on the left leg we moved the right foot to different times on the clock face. With each move, we shifted our weight so that both legs bore the weight equally. Debbie said we should feel the weight equally in both buttocks. Clearly, some points on the clock were easier to manage (e.g., 3), while some were more difficult (e.g., 6), which requires reaching in back. We repeated the exercise standing on the right foot and moving the left around the clock face.

The 7 Components of Balance

- 1. Proprioception
- 5. Flexibility
- 2. Vestibular System 6. Reactions
- 3. Vision
- 7. Confidence
- 4. Strength



- A little vocabulary check is in order:
 - "Proprioception" is the sense of the relative position of neighboring parts of the body and strength of effort employed in movement. If one suffers loss of feeling, especially in the feet or legs, one may suffer impaired proprioception.
 - The **"Vestibular System"** is the sensory apparatus of the inner ear that helps the body maintain its postural equilibrium. Loss can lead to vertigo.

As we moved through the 7 Components of Balance, Debbie provided some typical movements or exercises that helped to develop each component. For example, under Proprioception, she urged walking, walking backwards, and walking as if on a balance beam.

Activating the vestibular system would involve using a rocking chair, dancing, and imitating a maypole by swinging the upper body around so that the arms were raised a bit.

Vision required standing on one leg, marching in place, and tracking one's thumb as far to the right and as far to the left as possible.

Strength is best developed by moving *quickly* from sitting to standing and *slowly* from standing to sitting. Modified push-ups against a wall or kitchen cabinet were also useful.

Flexibility involved exercises including calf stretching with a strap, seated rotation of the upper body for thoracic spine mobility and leg-swings forward and back.

Reaction made use of heel drop, stomping, hopping and jumping.

Confidence involved all the **7 Components of balance** and the "Super Hero Stance" (with a Supermanlike illustration).

Feedback from the group members indicated that this was a most successful workshop. I observed that all 20 members participated in the various exercises, realizing the value of fall prevention in our PN lives.

Now it is up to us to make use of Debbie's valuable approach toward building balance.

Correction to "Foot Care Resources in Woodland"

All About You Salon 91 W. Main Street Woodland, CA 95695 Teresa Wells 530-661-1912, cell: 530-304-7746

Pro Cut Salon 1861 Gibson Road Woodland CA 95695 530-662-1565 A reader reports both shops are no longer doing foot care.

We suggest using a local podiatrist to ensure competent care.



How Smart is Your Right Foot?

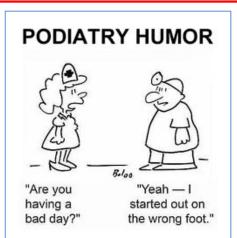
This is so frustrating! Give it a go This is so funny/weird that it will boggle your mind. And if you are anywhere near as stubborn as I am, you will keep trying at least a few more times to see if you can outsmart your foot, but you can't.

1) While sitting at your desk, lift your right foot off the floor and make clockwise circles.

2) Now, while doing this, draw the number '6' in the air with your right hand.

3) Your foot will change direction. I told you so. And, there's nothing you can do about it! Go ahead: KEEP TRYING ALL YOU WANT.

Have a great day.





It's To Laugh . . .

Excerpted from *Neurology Today* Magazine, June-July 2016 (pp. 30-33) From the article entitled "*Brain Health* - *Balancing Act*" By Amy Paturel, MS, MPH

"... Poor balance isn't inevitable. Even with a diagnosed neuro-degenerative condition, you can improve it. ... A computerized, dynamic posturography test (assesses) ability to balance under various conditions. ... Results showed (the patient's) eyes were doing 85 percent of the work of the vestibular system – normally, sensors in the inner ear, feet, limbs, and even the brainstem share the load."

A patient's postural sway and movement speed can be checked using accelerometers. Small changes can be measured that may not be seen in a 30-second standing examination. "The worse your balance is, the more cognitive attention it requires," says Mark Gudesblatt, MD, medical director of South Shore Neurologic Associates in Islip, NY.

Brain circuits may become 'overloaded' so to improve balance, practice dual tasking which increases brain response speed. Sports such as dancing or tennis where movement varies, and can be sudden, keep us thinking quickly.

"Other studies suggest another activity that involves dual tasking – tai chi – is especially effective for improving balance. ... In 2005, researchers discovered that our ability to move through the environment is directly related to the ability to learn and remember. 'If you can't multitask or process information, or if you don't have a sufficient attention span, you can't adapt quickly enough to a changing environment, and that's a huge risk factor for falling,' explains Dr. Gudesblatt. In fact, one key warning sign that you're at increased risk of falling is if you tend to stop walking when you start talking.

That's where working with a qualified trainer, one who is experienced with neurologic disorders, makes a dramatic difference. 'If you're experiencing neuropathy and you have no feeling in your feet, a trainer can help you focus on balance and gait training ... says Dr. Gudesblat.

6 Steps to Better Balance



1. STAND ON ONE FOOT. Hold on to a sturdy chair that won't move, or stand next to a wall and put your hand on it for support, and lift one foot. Then try standing on one foot without holding the chair. As you feel steadier, try closing your eyes. Then repeat with the other foot.

2. WALK HEEL-TO-TOE. Position the heel of one foot just in front of the toes of the other foot for each step, as though you're walking on a tightrope.

3. LIFT YOUR ARMS. Raise your arms out to our sides at shoulder height, then choose a spot on the wall and focus on it to stay steady as you walk.

4. USE YOUR HEAD. Turn your head from side to side while walking in a straight line. Every couple of steps, look at something on the left and keep it in focus, then look at something on the right and keep it in focus.

5. KICK BACK. Hold on to a chair or stand next to a wall and put your hand on it for support, then slowly lift and extend one leg straight back without bending your knee or pointing your toe. Hold the position for one second then repeat 10-15 times with each leg.

6. LIFT TO THE SIDE. Hold on to a chair or stand next to a wall and put your hand on it for support, then slowly lift one leg straight out to the side with our toes facing forward. Hold the position for one second then repeat 10-15 times with each leg (p.33).



Self-Care + Coping Skills

From the Foundation for Peripheral Neuropathy

The following suggestions can help you manage peripheral neuropathy:

Take care of your feet, especially if you have diabetes. Check your feet daily for signs of blisters, cuts or calluses. Tight shoes and socks can worsen pain and tingling and may lead to sores that won't heal. Wear soft, loose cotton socks and padded shoes. You can use a semicircular hoop, which is available in medical supply stores, to keep bed covers off hot or sensitive feet.

Quit smoking. Cigarette smoking can affect circulation, increasing the risk of foot problems and possibly amputation.

Eat healthy meals. If you're at high risk of neuropathy or have a chronic medical condition, healthy eating is especially important. Emphasize low-fat meats and dairy products and include lots of fruits, vegetables and whole grains in your diet. Drink alcohol in moderation.

Massage. Massage your hands and feet, or have someone massage them for you. Massage helps improve circulation, stimulates nerves and may temporarily relieve pain.

Avoid prolonged pressure. Don't keep your knees crossed or lean on your elbows for long periods of time. Doing so may cause new nerve damage.

Skills for Coping With Peripheral

Neuropathy. Living with chronic pain or disability presents daily challenges. Some of these suggestions may make it easier for you to cope:

Set priorities. Decide which tasks you need to do on a given day, such as paying bills or shopping for groceries, and which can wait until another time. Stay active, but don't overdo.

Get out of the house. When you have severe pain, it's natural to want to be alone. But this only makes it easier to focus on your pain.

Instead, visit a friend, go to a movie or take a walk.

Seek and accept support. It isn't a sign of weakness to ask for or accept help when you need it. In addition to support from family and friends, consider joining a chronic pain support group. Although support groups aren't for everyone, they can be good places to hear about coping techniques or treatments that have worked for others. You'll also meet people who understand what you're going through. To find a support group in your community, check with your doctor, a nurse or the county health department.

Prepare for challenging situations. If

something especially stressful is coming up in your life, such as a move or a new job, knowing what you have to do ahead of time can help you cope.

Talk to a counselor or therapist. Insomnia, depression and impotence are possible complications of peripheral neuropathy. If you experience any of these, you may find it helpful to talk to a counselor or therapist in addition to your primary care doctor. There are treatments that can help.

How to Sleep With Neuropathy. Sleep is an essential part of living—sleep helps us avoid major health problems and it is essential to our mental and physical performance. It affects our mood and stress and anxiety levels. Unfortunately, sleep disturbance or insomnia is often a side effect of neuropathy pain. It is a common complaint among people with living with chronic pain.

It's no surprise that about 70 percent of pain patients, including those suffering from PN, back pain, headaches, arthritis and fibromyalgia, report they have trouble sleeping according to the Journal of Pain Medicine. Pain can interfere with sleep due to a combination of issues. The list includes discomfort, reduced activity levels, anxiety, worry, depression and use of medications such as codeine that relieve pain but disturb sleep.

Most experts recommend a range of seven to nine hours of sleep per night for adults, regardless of age or gender. This may seem impossible to people with chronic pain, but there are steps you can take to improve your sleep, which may lead to less pain and lower levels of depression and anxiety. First, talk with your

Following are tips for improving your sleep:

- Reduce your caffeine intake, especially in the afternoons
- Quit smoking
- Limit and/or omit alcohol consumption
- Limit naps to less than one hour, preferably less
- Don't stay in bed too long—spending time in bed without sleeping leads to more shallow sleep



- Adhere to a regular daily schedule including going to bed and getting up at the same time
- Maintain a regular exercise program. Be sure to complete exercise several hours before bedtime
- Make sure your bed is comfortable. You should have enough room to stretch and turn comfortably. Experiment with different levels of mattress firmness, foam or egg crate toppers, and pillows that provide more support
- Keep your room cool. The temperature of your bedroom also affects sleep. Most people sleep best in a slightly cool room

doctor to see if there are medications that may lessen your sleep disturbance. You should also check with your doctor to make sure your current medications aren't causing some of your sleep disturbance.

Beyond medication, there are several things you can do yourself to improve your sleep. Here are some methods to try and help you fall asleep more quickly, help you sleep more deeply, help you stay asleep, and ultimately help keep you healthy.

(around 65° F or 18° C) with adequate ventilation. A bedroom that is too hot or too cold can interfere with quality sleep.

- Turn off your TV and computer -- many people use the television to fall asleep or relax at the end of the day. Not only does the light suppress melatonin production, but television can actually stimulate the mind, rather than relaxing it.
- Don't watch the clock turn your alarm clock around so that it is not facing you
- Keep a note pad and pencil by your bed to write down any thoughts that may wake you up at night so you can put them to rest.
- Refrain from taking a hot bath or shower right before bed; the body needs to cool a degree before getting into deep sleep
- Try listening to relaxing soft music or audio books instead, or practicing relaxation exercises.
- Visualize a peaceful, restful place. Close your eyes and imagine a place or activity that is calming and peaceful for you. Concentrate on how relaxed this place or activity makes you feel.

Some patients find comfort from a pillow between their legs that keeps their knees from touching. And there's an added benefit: A pillow between your legs at night will prevent your upper leg from pulling your spine out of alignment and reduces stress on your hips and lower back.

It may take three to four weeks of trying these techniques before you begin to see an improvement in your sleep. During the first two weeks, your sleep may actually worsen before it improves, but improved sleep may lead to less pain intensity and improved mood.

UPCOMING MEETINGS

Davis

2nd Tuesday, November 8, 3:30-5:00 (Mary Sprifke (530-756-5102) Davis Senior Center 246 A Street, Davis

Sacramento

3rd Tuesday, November 15, 1:30-3:00 Charles Moore (916-485-7723) Northminster Presbyterian Church 3235 Pope Avenue, Sacramento



The mission of the Yolo Neuropathy Groups is to ensure that through information, empowerment and mutual support, all may have hope and that no person will face their peripheral neuropathy alone.

Woodland

Cancelled, pending new leadership

RESOURCES:

- 1. Norman Latov M.D., Ph.D. Peripheral Neuropathy: When the Numbness, Weakness and Pain Won't Stop
- 2. Harry J. Gould, III, M.D., and Ph.D. Understanding Pain: What It Is, Why it Happens and How It's Managed
- 3. Alexander McLellan N.D. and Marc Spitz D.P.M. The Numb Foot Book check Amazon.com -- Out of Print
- 4. Mims Cushing & Norman Latov, MD You CAN Cope With Peripheral Neuropathy 365 Days a Year
- 5. John Senneff Numb Toes and Aching Soles: Coping with Peripheral Neuropathy
- 6.John Senneff Numb Toes and Other Woes: More of Peripheral Neuropathy
- 7. John Senneff Nutrients for Neuropathy: How to use natural supplements to treat the severe pain of PN
- The Foundation for Peripheral Neuropathy- <u>www.foundationforpn.org</u> (a national organization)
- Western Neuropathy Association (WNA) (formerly PCNA) <u>www.pnhelp.org</u> or toll-free (877) 662-6298
- www.diabetes.org
- www.neuropathysupportnetwork.org
- Neuropathy Journal at <u>www.neuropathyjournal.org</u>
- Eugene B Richardson MDiv, MSM, EdM, MS, Patient Educator in the DVD "Coping with Chronic Neuropathy"

To send PN News to others or if you no longer wish to receive this newsletter, please contact (530) 756-5102.

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