

eNcouragement

The Newsletter for the Minnesota Neuropathy Association
Volume XIII– No 1 Winter 2016

*“Providing hope and a better quality of life through educating and connecting members
to medical resources and emerging technologies”*

Meetings in 2016

Saturday, February 27, 2016 - 10:00 am

**Circle of Conversation – see enclosed flyer
at St Michael’s - Bloomington**

No meeting in March – Easter weekend

Thursday, April 28 – 7:00 pm

Family and friends encouraged to attend.

IMPORTANT – read page 9

A Note from MNA

Our newsletters contain a variety of information, and in each article we have identified the source, but the views and opinions of the articles do not necessarily represent the views of MNA, nor do they infer an endorsement of any product or service. They are not intended to replace medical or other professional advice and counsel.

Thank you....

Our thanks to The Foundation for Peripheral Neuropathy (FPN) for permission to reprint the articles that are part of this issue of the MNA newsletter. Some are a bit technical, but still contain valuable information. There are many helpful articles from time to time on their website.

Thank you for your support!

The MNA thanks all of you who have so faithfully sent in your membership contribution each year. Without you, we would not be able to offer the programs, activities, monthly mailings, and newsletters that we have done in the past, and will continue to do. Remember that our Board members are all volunteers; we have no paid staff.

Look at the mailing label on the envelope in which you received this newsletter. The **yellow highlighted area** indicates when the last year you made your contribution (not when it is due). You want to see a 2016 in that highlighted area by the end of this year. Mail your contribution, payable to MNA, in the enclosed envelope to Myron Martin, 8100 Russell Avenue South, #127, Minneapolis, MN 55431. The suggested yearly amount is \$25.00 (or more, if you can). Since we are a 501(c)(3) organization, your contribution is tax deductible. If you feel that your mailing label's date does not reflect your most recent membership contribution, please call Myron Martin, treasurer, 952-941-5372 to verify your information.



MNA continues to look for several members to add to the Board to be in ‘training’ to oversee the Association into the coming years, and for MNA to continue to be an effective support group for our members. If this is of interest to you, please contact any of the Board members.



MNA Handbooks Available

Our MNA Handbook is available for everyone who is a first-time member (i.e. makes a contribution for the first time). It has 70-80 pages of helpful information to help you in dealing with neuropathy. If you are a first-time member, and have not received your copy, please contact Lois Martin (952.941.5372), or loismemartin@gmail.com.

If you have an MNA Handbook from several years ago, and would like to have the updated pages, we have good news for you! If you bring your complete Handbook to one of our meetings, we will exchange it for a new one.

Taken from the Internet. Editor's note: I do not know the person who wrote the article. An ER nurse says this is the best description of a woman having a heart attack that she has ever heard. Please read, pay attention, and SHARE.....

FEMALE HEART ATTACKS

I was aware that female heart attacks are different, but this is the best description I've ever read. Women rarely have the same dramatic symptoms that men have ... you know, the sudden stabbing pain in the chest, the cold sweat, grabbing the chest & dropping to the floor that we see in movies. Here is the story of one woman's experience with a heart attack.

I had a heart attack at about 10:30 PM with NO prior exertion; NO prior emotional trauma that one would suspect might have brought it on. I was sitting all snugly & warm on a cold evening, with my purring cat in my lap, reading an interesting story my friend had sent me, and actually thinking, 'A-A-h, this is the life, all cozy and warm in my soft, cushy Lazy Boy with my feet propped up.

A moment later, I felt that awful sensation of indigestion, when you've been in a hurry and grabbed a bite of sandwich and washed it down with a dash of water, and that hurried bite seems to feel like you've swallowed a golf ball going down the esophagus in slow motion and it is most uncomfortable. You realize you shouldn't have gulped it down so fast and needed to chew it more thoroughly and this time drink a glass of water to hasten its progress down to the stomach. This was my initial sensation--the only trouble was that I hadn't taken a bite of anything since about 5:00 p.m.

After it seemed to subside, the next sensation was like little squeezing motions that seemed to be racing up my SPINE (hind-sight, it was probably my aorta spasms), gaining speed as they continued racing up and under my sternum (breast bone, where one presses rhythmically when administering CPR).

This fascinating process continued on into my throat and branched out into both jaws. 'AHA!! NOW I stopped puzzling about what was happening -- we all have read and/or heard about pain in the jaws being one of the signals of an MI happening, haven't we? I said aloud to myself and the cat, "Dear God, I think I'm having a heart attack!" I lowered the footrest dumping the cat from my lap, started to take a step and fell on the floor instead. I thought to myself, If this is a heart attack, I shouldn't be walking into the next room where the phone is or anywhere else... but, on the other hand, if I don't, nobody will know that I need help, and if I wait any longer, I may not be able to get up in a moment.

I pulled myself up with the arms of the chair, walked slowly into the next room and dialed the Paramedics. I told her I thought I was having a heart attack due to the pressure building under the sternum and radiating into my jaws. I didn't feel hysterical or afraid, just stating the facts. She said she

was sending the Paramedics over immediately, asked if the front door was near to me, and if so, to unbolt the door and then lie down on the floor where they could see me when they came in.

I unlocked the door and then laid down on the floor as instructed and lost consciousness, as I don't remember the medics coming in, their examination, lifting me onto a gurney or getting me into their ambulance, or hearing the call they made to the ER on the way, but I did briefly awaken when we arrived and saw that the radiologist was already there in his surgical blues and cap, helping the medics pull my stretcher out of the ambulance. He was bending over me asking questions (probably something like 'Have you taken any medications?') but I couldn't make my mind interpret what he was saying, or form an answer, and nodded off again, not waking up until the Cardiologist and partner had already threaded the teeny angiogram balloon up my femoral artery into the aorta and into my heart where they installed 2 side by side stints to hold open my right coronary artery.

I know it sounds like all my thinking and actions at home must have taken at least 20-30 minutes before calling the paramedics, but actually it took perhaps 4-5 minutes before the call, and both the fire station and the hospital are only minutes away from my home, and my cardiologist was already to go to the OR in his scrubs and get going on restarting my heart (which had stopped somewhere between my arrival and the procedure) and installing the stents.

Why have I written all of this to you with so much detail? Because I want all of you who are so important in my life to know what I learned first hand.

1. Be aware that something very different is happening in your body, not the usual men's symptoms but inexplicable things happening (until my sternum and jaws got into the act). It is said that many more women than men die of their first MI (myocardial infarction, i.e. heart attack) because they didn't know they were having one and commonly mistake it as indigestion, take some Maalox or other anti-heartburn preparation and go to bed, hoping they'll feel better in the morning when they wake up...which doesn't happen. My female friends, your symptoms might not be exactly like mine, so I advise you to call the Paramedics if ANYTHING is unpleasantly happening that you've not felt before. It is better to have a 'false alarm' visitation than to risk your life guessing what it might be!

2. Note that I said 'Call the Paramedics.' And if you can, take an aspirin. Ladies, TIME IS OF THE ESSENCE!

Do NOT try to drive yourself to the ER - you are a hazard to others on the road.

Do NOT have your panicked husband who will be speeding and looking anxiously at what's happening with you instead of the road.

Do NOT call your doctor -- he doesn't know where you live and if it's at night you won't reach him anyway, and if it's daytime, his assistants (or answering service) will tell you to call the Paramedics. He doesn't carry the equipment in his car that you need to be saved! The Paramedics do, principally OXYGEN that you need ASAP. Your Doctor will be notified later.

3. Don't assume it couldn't be a heart attack because you have a normal cholesterol count. Research has discovered that a cholesterol-elevated reading is rarely the cause of an MI (unless it's unbelievably high and/or accompanied by high blood pressure). MI's are usually caused by long-term stress and inflammation in the body, which dumps all sorts of deadly hormones into your system to sludge things up in there. Pain in the jaw can wake you from a sound sleep. Let's be careful and be aware. The more we know the better chance we could survive.

A cardiologist says if everyone who sees this post would Share, you can be sure that we'll save at least one life.

MNA Board Members

Questions? Comments? Let your MNA Board know your thoughts and ideas! Contact information:

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"Tell whoever it is that I can't come to the phone because my dog is sleeping on my lap, and if I get up, I will disturb him."

—Charlie Brown

Alternative and Complementary therapies from A to Z – continued from the Fall MNA Newsletter

Healthlight 1-888-395-3040 www.healthlight.us
Some Pners have used this therapy and report it is effective. The means of application can be used in a variety of body locations depending on where the pain is located.

IVIG – Intravenous Immunoglobulin therapy has been used successfully to treat many neuropathic diseases some of which are not specified by FDA. This is a plasma-based product found most useful for PN by patients with Chronic Inflammatory Demyelinating Polyneuropathy (CIDP). ACCREDO Therapeutics and Coram Healthcare are two companies providing this very expensive therapy. This is done under the care of your doctor and by prescription. We need to do all we can to insure that this treatment option is maintained with Medicare funding, as there are strong political pressures to discontinue the service because of

high costs. For more information on this issue, go to www.neuropathyaction.org and www.neuropathy.org

Ivory Soap – While some dismiss this product for PN as an urban myth or quackery nonsense, some people are actually finding that placing a bar of Ivory between the sheets at the foot of the bed actually reduces their night time PN feet distress. (Some have used other soaps.)

Jalapeños and Mineral Oil – rubbed into the skin at a place of pain, functioning as a homemade capsaicin.

Laser Therapy - True laser therapy can be effective. Some call other than lasers, lasers so care must be taken. Avicenna makes many of the lasers that are found effective. If they call it a "low level laser," it likely is infrared light, not a laser.

L-Arginine – This amino acid improves blood vessel functioning, to increase circulation for better distribution of oxygen and nutrients. It is available from health food stores, pharmacies, and on line at Vitacost, Swanson, or other Internet resources.

Leg Cramps – An over the counter preparation by Hylands's that is said to relieve leg cramps. It says it is Nighttime Cramp Relief. It is available at Rite Aid. Other pharmacies or health food stores may have it also.

Lidocaine Patches – These are commonly used for severe pain using very high-powered pain medications and are available only by prescription. There are also a number of over-the-counter pain patches for lesser levels of pain and non-narcotic ingredients.

Lortab – This very strong pain medication combines acetaminophen and hydrocodone and is available by prescription only. It is often used as an alternative for opiate dependency.

Lyrica (pregabalin) – Fairly new FDA approved anticonvulsant for diabetic peripheral neuropathy and shingles pain that is being increasingly prescribed for other neuropathies and fibromyalgia.

Metanx - Metanx is a medical food to address the distinct requirements of diabetic neuropathy and is available by prescription only. It may also work for people with other causes for neuropathy. It is supposed to help with tingling, burning, numbness, and pain. Check it out at Metanx.com or 1-877-321-2652.

Methadone and Morphine – These are two opiate painkillers that have been found helpful for neuropathy. These must be carefully monitored by a doctor.

Motrin – An over the counter pain reliever, particularly for muscle strain, etc.

Neuropathy Support Formula - This product combines B vitamins, Vitamin D, Alpha Lipoic Acid, and some herbs. It uses the newer B1 (thiamine) called benfotiamine and the natural form of Alpha Lipoic Acid - R-Alpha Lipoic Acid. Check it out or order by calling 1-888-840-7142, Fax at 1-888-901-3749 or by mail at NTG, 3855 W. Lorenzo Ste.100, Eagle, ID 83616. Due to it being the natural product, the amount given is less than the 600 per day recommended of the more often used synthetic. It is thought the natural is more potent, but it also could be inconsistent in potency.

Neuragen PN – This FDA registered OTC drug is designed to relieve neuropathic pain. Created with a non-toxic, skin penetrating (transdermal) formula of essential botanical oils, it has been extensively test in clinical trials. Its major ingredient is the essential oil of geranium developed by OriginBioMed, Inc. in Halifax, Nova Scotia, Canada.

Some 70% of patients with post-herpetic neuralgia reported significant pain relief with the use of Neuragen PN. Neuragen PN is available as a clear liquid or as a gel at most chain pharmacies. You may also order this and other natural products directly via (888) 234-7256 or from www.originbiomed.com.

Neuromodulation - Implants in the back that deliver pain medication. Several companies, including Medtronic, have this modality.

Neurontin (gabapentin) – This anti-convulsant is one of the most commonly prescribed medications for neuropathic pain and distress. Dosages may range from 300 to 3600 mg per day or sometimes higher. Some PNers find it very helpful; others find its side effects too difficult for prolonged use. Using topical/transdermal pain relievers can typically reduce one's needs for the larger doses. Many take it just at night to help them sleep. Some recommend that it be taken later in the evening.

Neuropathal - This is a topical pain reliever that contains a number of soothing oils. Contacts: 877-745-9990 or support@neuropathal.com

Occupational Therapy - Occupational therapists are experts in understanding the relationships among physical, psychological, and social aspects of illness, injury, and aging. They help in ability to perform daily tasks that promote independence like cooking, cleaning, bathing, dressing, and social participation as well as advising in fall prevention. Occupational Therapists have a variety of helping gadgets to make daily life easier.

Peppermint Lotion – Cooling and soothing for neuropathic distress. The often-used Dr. Scholl's Peppermint Foot & Leg Lotion version is available at most pharmacies.

Peripheral nerve decompression surgery (AKA tarsal tunnel surgery) – This involves releasing compressed or pinched nerves in the foot that can lessen and/or or alleviate neuropathic pain caused by nerve entrapments in the foot or behind the knee thus allowing the nerves to regenerate. It has been most effectively used with persons with diabetic neuropathy and some other forms of neuropathy. A thorough exam can probably determine its effectiveness. Some podiatrists, plastic, and orthopedic surgeons offer this treatment alternative.

Physical Therapy – A variety of physical therapies can be helpful for some neuropathy conditions, particularly in relation to restoring balance and relieving neuro-muscular disorder pain and distress. Most HMOs and other medical coverage will cover a

limited number and type of therapies if a prescription is given. Your doctor or clinic will have some to recommend.

Rebuilder – This is a self-administered, drug free, in-home treatment for neuropathy and chronic pain. It is said to arrest the progression, reduce pain and numbness, improve sleep and walk further with greater confidence. You can contact Rebuilder Medical, Inc. at 636 Treeline Drive, Charlestown, WV 25414 (866) 725-2202 fax: (304) 725- 4915 or via email at <http://www.rebuildermedical.com> for information and order arrangements.

Reflexology – Reflexology is a science that deals with the principle that there are reflex areas on the feet and hands that correspond with all the glands, organs and parts of the body. It is an art of stress reduction using the thumb and fingers on a client's feet in a specific way. Check with your clinic for a referral.

Reiki – This is an ancient energy approach to spiritual and physical healing, with or without “hands on” methods. The yellow pages will include listings of Reiki practitioners, usually among massage therapists.

SalonPas – Over the counter patch for pain. Found at most pharmacies and grocery stores. COSTCO has them for around \$7 for 120 patches!

Socks – Some people find it helpful to wear socks to bed so the sensation of the covers on the feet is dulled.

Shoes – Find a good shoe store that will consult with you and fit you well. If you are wearing an orthotic, be sure to take it with you to be sure it fits well in your shoe choice. Properly fitting shoes are essential for those with neuropathic distress in their feet and/or with leg and back pain problems. Most communities will have specialty shoe stores.

Sore No More - This blend of plant extracts has a topical anesthetic effect depresses cutaneous sensory receptors, relieving muscle aches, soreness and neuropathic distress, with its cooling and soothing combination of herbs and extracts. It has a light amount of capsaicin. A long lasting 8 oz. jar costs \$13.95, with \$6 in shipping and handling. Orders can be placed by calling 1-800-842-6622 in Moab, Utah.

Sports Cream – Available at drug stores - deep rub for pain

Tea Tree Oil – This soothing lotion can help calm neuropathic distress.

Tai Chi – This simple movement exercise system is favored by many with peripheral neuropathy as it helps to develop and maintain proper balance. Clinical trial studies at the Louisiana State University have shown that it also helps in restoring sensation in previously numb feet. Tai Chi classes are available at public community/senior centers and in private fitness settings.

TENS – Transcutaneous Electrical Nerve Stimulator – These are commonly used and are the basis of some other equipment presented for neuropathy. It provides electric shocks to a specific area and can be moved to where the pain is located. Other equipment may be described as “like a TENS unit.”

Tiger Balm – soothing balm

Tonic Water – This has enough quinine to help with leg cramps/muscle spasms. If you are prone to cramping, you might consider trying a 1/4 or 1/2 cup of tonic water each evening.

Topricin Foot Therapy Cream – This says rapid foot pain relief. People in at least one of our groups have found that it helps. It says it helps foot, arch, heel, and ankle pain. It is available in drug stores.

Vicodin and Norco – These can help with neuropathic pain. They must be used with care under a doctor's prescription.

Tylenol – This common, over the counter medication is generally used in reducing some pains.

Vicks Vapor Rub – Massaging one's feet with Vicks, particularly at night, soothes neuropathic pain and distress in one's feet and legs. It is also excellent for softening your toenails and diminishing common toe nail problems.

Voltaren Gel (diclofenac sodium topical gel) 1% by prescription. It is a topical gel that does seem to lower pain levels in the area where it is applied. Especially good for arthritis. Several report it helped their neuropathy, too.

Walking – Walking is an excellent general exercise for almost anyone without specific medical conditions that would preclude walking. Walking can reduce pain. (Water walking is an excellent alternative even for those with back or leg problems who find walking too problematic.) Properly fitting walking shoes are essential for avoiding injuries. Consulting with your doctor and a fitness coach can help you establish a walking program appropriate for your physical conditions,

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## Presenters' notes

Periodically we receive requests for information that a speaker presents when members are unable to attend a meeting. If a presenter uses a handout or power point that is informative, we share that with our members when we send our monthly flyer. We also encourage our speakers to write an article for our newsletter. We do not have any way of doing a video or audio recording of our speakers.

*Note: See excerpts of Dr Scott's October presentation on page 8*

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## How Restless Leg Syndrome/Willis-Ekbom Disease is Diagnosed

Doctors look for these five diagnostic criteria:

1. the urge to move the legs, which is usually, but not always, accompanied by uncomfortable and unpleasant sensations
2. the urge to move the legs and the accompanying sensations start or worsen during rest or inactivity
3. the urge and sensations are partially or totally relieved by movement such as walking or stretching
4. the urge and sensations only occur, or are worse in the evening or at night
5. the first four symptoms cannot be attributed to another medical condition such as leg cramps, positional discomfort, muscle pain, swelling of the legs, blood pooling in the leg veins, or habitual foot tapping.

Four risk factors:

1. Age: this syndrome affects 10% of people 65 and older, compared with only 5% of the general population
2. Sex: women are more likely to experience the condition than men, but the sex connection seems to be tied to pregnancy. If a woman has never been pregnant, her risk is the same as a man's.
3. Low iron: diminished iron in the brain is implicated in the syndrome
4. Family history: people with a family history of the disease are at greater risk.

For more information: [Willis-Ekbom Disease Foundation:rls.org](http://Willis-Ekbom Disease Foundation:rls.org)

*From Neurology Now – June/July 2015 issue*

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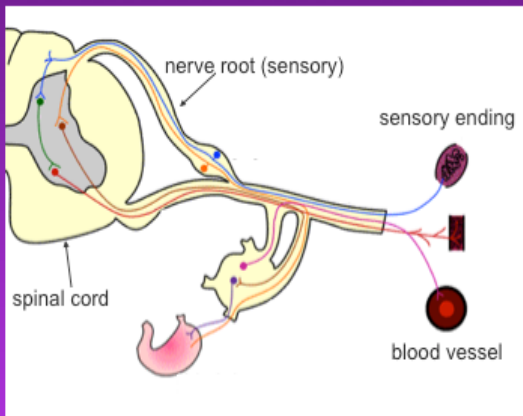
TOP 15 “PERKS” OF GETTING OLDER...

1. Kidnappers are not interested in you.
2. In a hostage situation you are likely to be released first.
3. No one expects you to run - - - anywhere.
4. You can wear your robe until you feel like getting dressed.
5. People no longer view you as a hypochondriac.
6. Things you buy now, won't wear out.
7. You can eat dinner at 4:00 pm and get the early-bird-special.
8. There is nothing left to learn the hard way.
9. You no longer think of speed limits as a challenge.
10. You quit trying to hold your stomach in, no matter who walks into the room
11. You sing along with elevator music and remember all the words.
12. Your investment in health insurance is finally starting to pay off.
13. Your secrets are safe with your friends because they can't remember them either
14. Your supply of brain cells is finally down to a manageable size.
15. Your joints are more accurate meteorologists than the TV weatherman.

An overview of Neuropathy: it is what it is, but it is not what ain't

Excerpts from October MNA PowerPoint presentation by Leland C Scott, M.D. PhD

Peripheral Nervous System

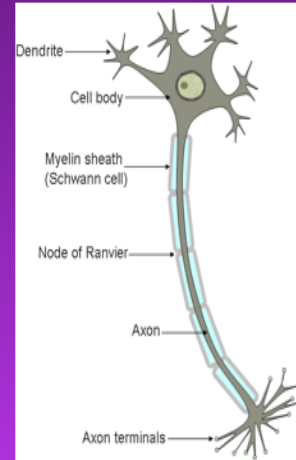


Peripheral Nervous System

Motor Neuron

Axon (*wire*)

Myelin (*insulation*)



Neuropathy is a symptom of an underlying condition. Effective treatment requires treatment of the underlying condition, not just treatment of the symptoms.

Neuropathy damage: acquired or hereditary?

Hereditary

- Charcot Marie Tooth
- SMA
- Krabbe disease
- HPNN
- Hereditary SFN
- Celiac disease
- Erythromelalgia

- Fabry Disease
- Porphyria
- HPNN

Acquired

- Diabetes mellitus
- B6 toxicity
- Guillain-Barre' (AIDP)
- Multifocal motor neuropathy
- Amyloidosis
- MAG antibody
- Hepatitis C virus infection
- B-12 Deficiency
- CIDP
- Polio/leprosy

Not all numbness is neuropathy – other causes of numbness:

- Stroke
- Multiple sclerosis
- Spinal cord damage: cervical or thoracic stenosis/myelopathy
- Nerve root impingement: cervical, thoracic, or lumbar radiculopathy
- Carple tunnel syndrome
- Tarsal tunnel syndrome

Why don't I have pain? Neuropathy can cause numbness, weakness, tingling, imbalance/incoordination, cramps, and pain, or any combination. Many forms of neuropathy don't cause pain. Very chronic, slowly progressive nerve damage is more likely to cause numbness or weakness without any discomfort or tingling.

Not all foot pain is neuropathy:

- Neuropathic pain—minimal morning pain, minimal pain walking, pain worse with feet up, pain bad in bed and worse if feet are elevated.
- Orthopedic pain—pain in 'first step' upon arising, pain worse with walking, pain improved off feet, pain generally best in bed and better with feet elevated

Evaluation of neuropathy—nothing is irrelevant

History and examination:

- thorough history with family history
- medical problems
- medications
- physical exam including motor, sensory, and reflexes

Laboratory testing:

Blood test, genetic test, EMG/NCS, MRI imaging, nerve biopsy.

Treatment— Symptomatic medication

1. antiepileptics: Neurontin, Tegretol, Dilantin, Lyrica, Topamax, Trileptal
2. Tricyclic antidepressants: Amitriptyline, Nortriptyline, Imipramine
3. SSRI's: Lexapro
4. Atypicals: Cymbalta
5. Narcotic analgesics
6. Topical compound medication

Get your Reward!

(by Michael Boland, Board Member)

For the past decade, the Minnesota Neuropathy Association has been providing hope and a better quality life by educating and connecting members to medical resources and emerging technologies, but it wasn't always that way. When Al Porte began the Association 20 years ago, there weren't a whole lot of medical resources to which you could be connected. In fact for many people with neuropathy, it took several doctors and many years just to get a diagnosis, and with the diagnosis came the inevitable doctor's prescription, "Neuropathy won't kill you, here's some pain medication, take it and don't bother coming back." "And, oh by-the-way, the medication will make you fat, sleepy and you'll forget where you put your keys, sorry."

In large part due to Al's dogged determined, and endless hours on the Internet, he would find new innovative things that "might" work for people with neuropathy. One of those things was an electronic stimulator that turned out to be my key to a life, the way I like to live it. It took me from the painful neuropathy shuffle back to the athlete I was before the disease destroyed my life. When Al asked me to join the Board and help others find relief, I was honored.

Over the next few years, and thanks in large part, the outbreak of diabetes, new innovative medicines and technologies were created for those suffering from neuropathy. It wasn't long before drug companies and medical device manufacturers were coming to us to test and demonstrate their new products. I can't tell you how satisfying it was to watch people meeting after meeting, struggling, shuffle in, and then, after one special meeting they would simply walk out. What was also impressive, is how many hands created little work, a few hours a month, 3 or 4 sometimes six hours spent to get such a fantastic payoff. It eventually became not work, but reward.

Now in its 20th year, the neuropathy association has reached a critical juncture. With so much happening both in the drug and medical device industry, as well as in the alternative medicine industry, it is more important than ever that the Minnesota Neuropathy Association live up to its Mission of providing hope and a better quality of life by educating and connecting members to medical resources and emerging technologies.

To make this happen, the Board needs you, to volunteer a few hours a month. We will provide the help and mentorship needed to make sure that you are successful. We're not asking for a lifetime commitment, but just the amount of time it takes for you to make a big impact on the Association and its members. With more than 300 members, it is more important than ever that we continue to seek out and find new technologies and resources that may provide our fellow members (or yourself) with relief.

You can be the one that opens the door, that turns the key, that provides that one solution to someone that allows them to live the life they so desperately want. And, all you have to do, is give us a few hours a month; not hours of work, the hours of reward!

We are very much looking forward to working with you! Please contact Lois Martin at 952-941-5372 or Michael Boland at 612-751-5800 to have your questions answered.

An Irish Blessing

May you always have work for your hands to do. May your pockets hold always a coin or two. May the sun shine bright on your windowpane. May the rainbow be certain to follow each rain. May the hand of a friend always be near you. And may God fill your heart with gladness to cheer. May you live as long as you want, and never want as long as you live.



HELP FOR THE CAREGIVER

Beware of burnout

Overstressed caregivers are vulnerable to depression and other health problems. Protect yourself with these tips.

Recognize red flags: if you start yelling at the person you're caring for, or worse, become neglectful or abusive, that's a clear sign the plan needs to change immediately. Another red flag: you start resenting your care giving duties. Don't feel ashamed by it, instead, recognize it as a sign that you are overwhelmed and may need help.

Ask for help earlier: if you're feeling more negative than positive about your situation, it's time to reach out for more support. Wait too long and you'll have no breathing room to think about getting help. That's what happened to Maggie, the longtime caregiver for her younger brother, who has progressive multiple sclerosis. Once you got overwhelmed, it stressed her out to imagine hiring help. Waiting to ask for help until there is an emergency or you're at the point where you're thinking, "there's no way I'm going to get through this day and get everything done" makes it that much harder.

Start small: reach out to a care manager. You can find one at eldercare.gov who can be hired at an hourly rate to assess your situation and let you know what services are available to you.

Listen to loved ones: If family members or friends express concerns about how you're coping, hear them out. They may have perspective on your situation that you can't see. Of course, there's a difference between showing concern and offering unsolicited advice. Most people are fixers, and they may want to give advice. The bottom line: trying to keep an open mind and not shrug off someone's doubts if, in your gut, you suspect those doubts might be valid.

Join a support group: it's so important to have conversations with people in similar situations. It helps normalize your own experience and reactions so you don't feel guilty about your emotions.

Talk to a Medicare counselor: the Medicare counseling program is a great resource for free, unbiased advice about your insurance benefits, options, and rights. Professionals know how to navigate these waters, and once they take over, that frees you up to deal with your emotions.

Consider talk therapy: if you're struggling with anxiety or depression, talk to your primary care doctor. Your physician can refer you to a mental health professional who can provide more intensive support and treatment than a support group or telephone counseling. Therapists can help you cope with feelings of guilt or sadness and, if possible, help you reduce your care giving demands.

From Neurology Now: October/November 2015 issue