



# National EMS Network Newsletter

## Points of interest

- **Your continued donations have kept this Newsletter and NEMSN alive. Please keep those donations coming no matter how large or small. Our thanks.**
- **We do appreciate all the letters to the Editor and hope that you keep writing. We look forward to your letters and comments.**
- **We are interested in your story. Please take the time to write it and send to us for our newsletter.**
- **If you have not seen our web site yet, it's improved and holds a lot of information.**
- **CHECK OUT WWW.NEMSN.ORG**

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## What Works?

*Reporting Today on Nancy Grant and Yoga*  
by Lois Vierk

Welcome to *What Works?* -- a new column, a new place to share experiences about what works to help relieve EMS symptoms. If there are things you do, routines you follow, treatments you take, etc. that help you, please get in touch so we can write it up here. Reading about what is good for you may help someone else find a way to ease the pain or get through the day better. Let us know.

Of course it's true that what's good for one person may not be appropriate or helpful for another, and NEMSN does not recommend anything in particular for a given individual. However, if you've found something that works to help you, please send us a letter (NEMSN, c/o Lois Vierk, P.O. Box Monitor 4171, West New York, New Jersey 07093) or an email (elveevee@aol.com). If it's too much for you to write out, let me telephone you, we can talk it over, and I will write a draft of your story. My phone number is 201-868-9572.

This forum will not focus on medicines or the like. You're welcome to write to us about this topic too, but send it as a Letter to Editor. *What Works?* will not be a place to advertise a particular product of any sort, though it's fine to mention products that you use.

We're pleased to start out *What Works?* by bringing you what Nancy Grant has to say about practicing yoga and how this helps some of her EMS symptoms.

For Nancy Grant, EMS gives her "bone pain" which she describes as pain residing deep within the bone and experiences as radiating outward through the entire body. This pain is accompanied by profound fatigue. Because the bone pain and fatigue are felt as enveloping the entire body, Nancy used to regard this pain as muscle pain. But this pain is not muscle pain, in the sense that Nancy does not experience tenderness in her muscles or pain when trigger points are pressed. However, the pain may be related to the connective tissue that attaches the muscles and tendons to the bone. Typically Nancy initially feels this pain in the extremities of her legs and arms and then the pain moves up her limbs.

In her early years with EMS, in conjunction with pharmaceutical and traditional western therapeutic modalities, Nancy received some relief from

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**From The Editor**

I want to remind our readers. We have passed our 20 year mark and you are not alone. We are all the faces of EMS and our members like to hear your stories to help them know they, too, are not alone.

One of our officers, Nancy Grant, has been interviewed for this newsletter on what works for her to cope with this disease. If you would like to share your story or tell us how you are coping with EMS, please write to me by e-mail or by regular mail or you may call Lois Vierk and an arrangement will be made for you to be interviewed.

Again, you are not alone. Many of us are getting sicker as we age, but we are still survivors and fighting to have a half-way normal life.

Sandy



Please remember to use GoodSearch.com, GoodShop.com and iGive.com when surfing the web. Use GoodSearch when searching the web and GoodShop and iGive when making purchases online. Type in NEMS as your charity. So far, since signing NEMS up on these sites, we have earned \$62.40 on iGive, \$43.68 on GoodSearch and \$268.61 on GoodShop. This money adds up, so please use these sites when possible.

**Caution: Current L-Tryptophan Contacts**

Tryptophan is legally back on the market in many forms. NEMS reports that recently several different people have contacted us and have told of adverse reactions which they attribute to L-Tryptophan supplements, 5-HTP supplements (which are chemically similar to L-T), or other L-Tryptophan-containing products, since the beginning of this year. Our Medical Advisory Panel has been monitoring the situation and has asked to be informed if any new cases come along. If you know of anyone who has become sick from taking a product containing L-Tryptophan or 5-HTP, tell them to save the product and contact NEMS.

*Mission Statement*

**The National Eosinophilia-Myalgia Syndrome Network, Inc., is a non-profit organization dedicated to helping EMS survivors and their families by offering educational information and peer support. NEMS is also committed to encouraging research to improve treatment for L-tryptophan-induced EMS and to increasing awareness of the cause and effects of the disease.**

**DISCLAIMER**

The NEMS does not engage in the practice of medicine or law & does not claim to have legal or medical knowledge. All persons should seek the advice of their own lawyers & medical professionals. Opinions expressed by individual writers herein are those of the writers and not necessarily those of the NEMS Board of Directors or its committee or subcommittee heads, nor of the Editor. Information is intended merely to inform readers. Drugs & treatments & legal issues should be discussed with readers' own physicians & attorneys.

## What Works?

*Reporting Today on Nancy Grant and Yoga by Lois Vierk, (continued from page 1)*

massage if administered by the right practitioner. If the masseuse or masseur manipulated the painful area correctly, the pain would shoot to an altogether different part of her body. This "referred pain," often felt in the head with a throbbing intensity, would provide relief for the original site of pain and the body in general. Massage was not covered by Nancy's medical insurance, so this therapeutic modality became a "treat" when she could afford the cost, rather than a regular intervention "treatment".

Nancy eventually turned to yoga, a type of exercise and discipline that she finds "helps the body, mind and spirit". It was not the first time in Nancy's life that she had found benefit and satisfaction from physical exercise that in some way linked body and brain. As a girl she had loved studying ballet. She developed an awareness of and relationship with her own physicality by practicing ballet. She describes starting "a dialog" with her body at that time.

So years later, after being disabled with EMS, she found similar qualities in and benefits from practicing yoga. With yoga Nancy finds a way of developing a relationship between mind and body. The exercise itself is good for her. Stretching, for example, helps ease the pain noticeably.

Nancy finds physical relaxation and pain relief from "basic and restorative yoga". She finds Iyengar Yoga (a type of yoga that works with prolonged poses and the breath) particularly helpful. She describes doing yoga poses which invert the body with shoulder stands, head stands and other positions that place the heart above the head and facilitate the flow of blood with less effort to the brain. Often this type of yoga is done in the evening. It is peaceful. Nancy also finds working with her teachers and with her fellow students in the yoga community to be inspiring and calming.

In studying the type of yoga that Nancy finds

helpful, a person learns to have the awareness to mentally go inside the body and to let the muscles go, to let the joints move, and to let physical tension leave the body. Nancy says she is just becoming able to achieve this in small ways. However, she feels that in the future, with consistent practice of yoga, she will be able to achieve greater and greater physical comfort with less and less physical body tension.

Disclaimer of NEMSN: Consult your own physician(s) for your own medical condition(s).

Comment from Nancy:

I was interviewed by Lois for this story. I could not have

done it without her. I found the interview to be a delightful and thought provoking experience. If you have a story that others might find helpful, but don't have the strength to write it, I highly recommend contacting Lois for an interview.

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Nancy takes classes at YogaWorks in Los Angeles. She requested assistance from the studio for an article to accompany this story. The following online materials on yoga and health were suggested by YogaWorks and reviewed by Nancy:

[http://www.yogajournal.com/for\\_teachers/2581](http://www.yogajournal.com/for_teachers/2581)  
[http://www.yogajournal.com/for\\_teachers/2551](http://www.yogajournal.com/for_teachers/2551)  
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<http://www.healthywomen.org/content/article/help-heal-yourself-yoga>  
<http://www.mothenature.com/Library/Bookshelf/Books/21/54.cfm>  
[http://www.yogabound.com/yoga/art\\_yoga\\_works.htm](http://www.yogabound.com/yoga/art_yoga_works.htm)

The first of these articles is reprinted on Page 6

## Yoga Therapy for Rare or Undiagnosed Medical Conditions

Even when the doctors aren't sure what's going on, you can find yogic tools to help your students.

By Timothy McCall, M.D.

Modern medicine and yoga have different ways of deciding on treatment. In conventional medicine, whenever possible, we try to make a diagnosis first. Once the diagnosis is made, appropriate therapies can be prescribed—ideally ones that don't just ameliorate symptoms but that get at the underlying cause. This isn't always possible, of course, but that's the theory.

In therapeutic yoga, we learn to observe individual students with care and attention and then formulate a plan of action based on what we see. Indeed, two students might have the identical medical diagnosis—say, breast cancer—but a teacher might recommend very different approaches based on their overall fitness, other medical conditions, energy levels, time available to practice, prior yoga experience, and a host of other factors. And good teachers also learn to modify their students' regimens depending on what else is going on in their lives. Whatever your long-term plan, you might need to temporarily alter your approach if your student has just sprained an ankle, has come down with a cold, or is going through an unusually stressful period.

### The Yogic Diagnosis

In yoga therapy, we aren't treating the diagnosis so much as we're treating the student with the diagnosis. Even in instances when tests are inconclusive and the doctors can't explain your student's symptoms, there still may be yogic tools that will help. You might notice, for example, that a particular student doesn't breathe well but instead takes quick, erratic breaths mostly into the upper chest. Teaching such a student slow, deep, mindful breathing might improve her well-being and potentially benefit a wide variety of medical conditions.

Similarly, you might observe dysfunctional pos-

tural habits, muscle tightness or weakness, difficulty with balance, or a lack of "felt sense" (poor proprioception), all of which could be helped by various yogic tools, particularly asana. Other students, you might conclude, could benefit from a regular restorative practice, guided visualizations, or seated meditation (in fact, research on mindfulness meditation suggests that it helps patients largely independent of diagnosis).

### Energetic Imbalances

One advantage of some traditional medical approaches such as Ayurveda and Chinese medicine is that they can detect imbalances before they manifest in full-blown disease. Thus practitioners can often provide effective treatment even when no precise Western diagnosis can be made. Airhead's system of looking at imbalances of *vata*, *pitta*, and *kapha* can be particularly useful for yoga teachers, due to Ayurveda's and yoga's shared history and philosophical basis.

Consider an illustrative case: A yoga therapist I know was asked by a local hospital to see a woman with schizophrenia. Even though she's an experienced teacher and therapist, she'd never treated anyone with that condition before and had never read anything about how to approach such a student with yoga. With some trepidation, she agreed to see what she could do.

When the woman arrived for her first appointment, the teacher could see that she was fidgety, had difficulty paying attention, and that her gaze was moving all over the room. Based on these and other clues, the teacher concluded that the student was showing signs of *vata* derangement. She prescribed a regimen to try to ground the student using standing poses and

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## Yoga Therapy for Rare or Undiagnosed Medical Conditions

Even when the doctors aren't sure what's going on, you can find yogic tools to help your students.

By Timothy McCall, M.D. (*continued from page 4*)

other yogic tools, and they proved so helpful that now the hospital is referring several other schizophrenics to her. Some of these other schizophrenics, by the way, appear to have a *vata* imbalance and some don't, so she's adjusted her approach accordingly.

### When the Diagnosis Isn't Known

While it's possible to help a student without knowing precisely what the student has, it still can be useful to know his or her diagnosis. For one thing, it can help you anticipate and avoid potential contraindications. So if you know that a student has diabetes, you'd be sure to have him cleared by an eye doctor before you allowed him to do inverted poses such as Sirsasana (Headstand) and

Sarvagāsana (Shoulderstand), since this student runs a higher risk of a retinal hemorrhage. When the diagnosis is unknown, all you can do is base your approach on what you observe and what your students report to you when they try the practices you suggest—always erring on the side of caution.

In the case of rare medical diagnoses, learn what you can from medical reference books, the Internet, or the students themselves (who sometimes are extremely well informed). Some conditions are rare enough that even physicians may not know much. When you don't know the cause of your students' symptoms, encourage them to follow up with their doctors to be sure something serious, and potentially treatable, isn't being missed. Often symptoms either disappear over time or progress to the point that a diagnosis can be made. Either way, in the meantime, your student will have been benefiting from yoga.

Dr. Timothy McCall is a board-certified internist, Yoga Journal's Medical Editor, and the author

of *Yoga as Medicine: The Yogic Prescription for Health and Healing* (Bantam). He can be found on the Web at [www.DrMcCall.com](http://www.DrMcCall.com).

His web site contains more than 100 free articles, interviews, podcasts, etc. on a variety of topics that may be of interest to many of our members. If you visit his site, please thank him for giving us permission for reprint.

## Special Thanks

A very special thanks to Merzbach Law Offices, P.C., a law firm in Albany, NY which has recently generously consulted with NEMSN *pro bono*. Legal questions occasionally arise as NEMSN supports its members.

### HELP WANTED: POSITIONS OPEN NOW:

NEMSN's Board of Directors has 3 vacancies. The 6 current members of the Board are eager to fill these vacancies --- immediately! We hope you are eager to lend your experience and commitment to our mutual cause.

No previous experience necessary.

Monthly phone conference calls and occasional shared tasks make it easy to communicate and carry out NEMSN's mission.

Don't hesitate. Express your interest NOW. Call or email Michael Bird, NEMSN's Treasurer, at 540-368-0356 or [wiltshire-bird@gmail.com](mailto:wiltshire-bird@gmail.com) to get more information.

## The Pain Chronicles

by Melanie Thernstrom

*An Online Interview with the Author*

NEMSN recommends a link online which will let you listen to a recorded radio show on your computer as a podcast. You can also read the summary below. The subject is a book on chronic pain by an author who is herself afflicted. Here is the link:

<http://www.wnyc.org/shows/lo pate/2010/nov/09/pain-chronicles/>

The radio program is "The Leonard Lopate Show" broadcast on New York's WNYC radio on November 9, 2010. The program host interviews Melanie Thernstrom, author of *The Pain Chronicles: Cures, Myths, Mysteries, Prayers, Diaries, Brain Scans, Healing, and the Science of Suffering*.

In this half-hour show, Melanie Thernstrom talks about pain throughout the ages, from ancient Babylonian pain-banishing spells to modern brain imaging. She describes her quest to reveal the mysterious nature of pain itself. In her book she reflects on her own battle with chronic pain, discusses the latest medical research, and gives insights on coping with pain from science, history, religion, philosophy, anthropology, literature, and art.

During the interview, Ms. Thernstrom elaborates on chronic pain and, to quote the program host, "what causes it, what cures it, and why some people can never be rid of it." She states that chronic pain is qualitatively different from acute pain. Chronic pain is like a fire alarm that keeps going off although there is no fire.

Chronic pain is a pathology of the nervous system. Chronic pain creates physical changes in the brain and spinal chord. Brain pathways are able to change; they are not hard-wired. The longer you have pain, the more the nervous system revs up and becomes ever more efficient at producing yet more pain. The longer

you have pain, the deeper the level of the neurons that are affected. An apt analogy for what is physically happening in the body is that of a flowing river which is cutting into a landscape. The longer the river flows, the deeper it cuts. Many primary care physicians and other specialists don't understand this about pain, though pain specialist doctors do.

The author has a form of arthritis, which came on after an athletic injury that never healed. From that time on, her pain has been unrelenting. Before researching her book she thought of her own chronic pain as a personal failure, something she was bringing on herself because of a bad attitude. Finally though, the understanding that her ongoing physical pain is the result of a real nervous system pathology has eased her psychic pain. There is something physically real that is causing her pain. It is not a personal failure.

What sort of advice does the author have for others of us with chronic pain? First of all, she says to be as clear as possible at explaining to a doctor exactly what it is that you feel and experience. Do not be vague and do not let yourself be talked into anything that is not true.

The interviewer asks if opiates are always the best medicine for chronic pain. Ms. Thernstrom says no, that opiates are just one tool that can be used. There are also anti-inflammatories, physical therapies, and anti-depressants. Each person's case is different and each case must be assessed individually.

Many doctors will see only the effects of pain, such as depression, sleeplessness, etc., and not the fact that the patient is in fact suffering greatly physically. Unfortunately, often the patient himself/herself gets blamed for pain by the doctor.

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# Donor Honor Roll

May 16, 2010 through August 2011

**Editor's Note:** A person's name will be listed every time they donate. Thank you for your continued support.

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## **Doctor Recommendations Needed**

NEMSN needs to update its list of physicians who can diagnose EMS and treat symptoms. Please let us know of any doctor you recommend. The list will not be published but will be made available to any EMS patient who contacts us about finding a physician. We're looking for doctors in the US and anywhere else in the world. Currently we have a specific request to find a doctor in Atlanta, GA.

Please get in touch by emailing Sandy at [NEMSNnewseditor@gmail.com](mailto:NEMSNnewseditor@gmail.com), by telephoning Lois at 201-868-9572, or by sending a letter to NEMSN, 767 Tower Boulevard, Lorain, OH 44052.

Thank you.

NEMSN Board of Directors

## **The Pain Chronicles**

*Continued from page 6*

The author states from her own experience that "if pain is the first thing in your consciousness it drives you crazy. If it's the seventh thing, you can deal with it." She points to the fact that you need to find relief from the pain in some way, and you need to find a constructive way of dealing with the pain intellectually and emotionally. She advises finding a board-certified pain specialist if your own doctor is not tuned in to your needs.

The author touches on the subject of methods of physical relief from pain. She states that some kinds of physical therapies and treatments can be a cure or produce improvement because, unlike medications, they actually can physically change the body itself.