



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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Are the foods you are eating keeping you in pain?

by: Jesse Cannone, CFT, CPRS

Try An Anti-Inflammatory Diet: It Could Be The Answer To Eliminating Your Pain

When I say "Inflammation", thoughts of painful joints, muscles, swelling and loss of mobility probably comes to mind. But did you know that recent research shows that chronic inflammation in your body can lead to serious disease such as diabetes, heart disease, some cancers, and Alzheimer's disease, to name just a few?

The amount of inflammation in our body varies and is dependent on many circumstances like activity level, amount of sleep or stress in our lives and even the foods we eat. Now what you have to realize is that these factors are all accumulative and as the levels increase the risk for disease increases.

Now early in life these levels can be so low that you would not even know that you have any inflammation in your body and that is because our bodies do a fair job at controlling the inflammation at least for a while, and then one day you wake up and you are in your 40's and something is just not right and then the fear sets in and you think to your self what did I do, what did I do wrong or what can I do right now to help my self.

Well, the first step is to get your C-Reactive Protein levels tested, you will need to ask your Doctor and may even demand to have the test done, all it takes is a blood sample and then have your levels evaluated by your Doctor and even by

a registered dietician to help you formulate a plan of care because our diets can play a large part in achieving optimal health.

If you have pain from inflammation you may choose to take the traditional "medical" path for inflammation such as, Non-steroidal anti-inflammatory drugs (NSAID's), steroids and even joint replacement surgery in severe cases. The good news is that there are more natural ways to fight inflammation, and they do not have the undesirable side effects caused by most typical medical treatments.

What You Eat Makes All The Difference

The food we eat is a critical piece of the puzzle when it comes to controlling inflammation. The average American diet consists of high fat, high sugar, loads of red meat and a frightening amount of processed foods. These are all likely to increase inflammation, not to mention contributing to obesity, yet another high-inflammatory culprit. By switching to an Anti-Inflammatory Diet plan made up of healthy, whole foods, you can actually decrease inflammation and in turn ease the pain and discomfort associated with it.

The first step is to avoid processed foods, foods high in sugar and junk food whenever possible. Instead choose fresh, whole foods including anti-inflammatory varieties like lean proteins, fruits and vegetables. But choose carefully, in fact even some vegetables and pre-packaged "health" foods can

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767 Tower Boulevard
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Board of Directors

*

Jann Heston.....President
155 Delaware Avenue
Lexington, OH 44904
614-583-5720 Fax: 614-737-3784
Email: Nemsn2005@aol.com or
jheston @gmail.com

*

Jinx Engstrom.....VP/Web Administrator
4036 Aldrich Avenue South
Minneapolis, MN 55409
612-825-9135
Email: Jinx.Engstrom@Co.Hennepin.MN.US

*

Ann Flaherty.....Secretary
237 Lear Road
Avon Lake, OH 44012
440-933-6810
Email: aflaherty225@yahoo.com

*

Michael Bird.....Treasurer
219 Twin Lakes Drive
Fredericksburg, VA 22401
540-368-0356
Email: popsies@aol.com

*

Sandy Kintz.....Newsletter Editor
767 Tower Boulevard
Lorain, OH 44052-5213
440-960-5910 Fax: 440-960-0071
Email: NEMSNewseditor@gmail.com

*

Nancy Grant.....Med/Research Director
4308 Alcove Avenue Unit 104
Studio City, CA 91604
818-623-9199
Email: nancy.grant@juno.com

*

Lois Vierk.....Public Relations Director
P.O. Box 4171, Monitor Station
West New York, NJ 07093
201-868-9572 Fax: 201-854-6450
Email: elveevee@aol.com

*

Robin Burkin.....Web Master
203-388-5943
Email: rburkin@adelphia.net

*

Website: www.nemsn.org

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From the Editor...

Dear NEMS Network Members,

Time flies so fast, I can't believe it is time for another newsletter. We here in Ohio, have been needing rain and lo and behold, it is raining a little bit today. Here's hoping it will be enough to help the crops.

I had hoped to hear from some of you with your stories. It helps others to read someone else's story and see that they are not alone. If you can write about your experiences with EMS, please send it on to me. If you are unable to write and want to dictate it to me, that would be alright too. Just give me a call and I can call you back, as my long distance doesn't cost me anything here in the states.

I have recently been going to a pain clinic. The doctor told me the foods I eat have an effect on my pain. I found the article on page one on the internet and it addresses this problem. I hope it helps those of you who

live with chronic pain.

I live up north on Lake Erie and have taken the time to enjoy the lake this year...just sitting and enjoying it. My swimming days are long gone, but I still love sitting by the lake and listening to the waves. It is so soothing to the soul.

Lorain is built on the Black River which flows into lake Erie. It seems every week we have some sort of festival happening on the banks of the river.

It's nice to take the time to visit them and taste the many different foods offered. All too soon summer will be gone, the water will be frozen over and I will be hibernating in the house and not going out unless I have to.

I hope you are all enjoying the summer weather and feeling a little better than we do in the winter when the sun is gone.

Sincerely,

Sandy Kintz

Poets or writers wanted...

We are still looking for items for the newsletter to help take our minds off of our disease. We do not want religious items or items in bad taste that contains graphic language, violence, sexual encounters etc.....but we would like inspirational items, humorous items, items about having a chronic disease, and so on.....especially humorous things might be a hit. If you would like to send us your poems or small essays, etc., you may send them to the newsletter editor at the following addresses.

Sandy Kintz
767 Tower Boulevard
Lorain, OH 44052-5213
or NEMSNewseditor@gmail.com

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 Network 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 Network 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 Network 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.

Request for contact...

Any EMS survivors with MS out there?

My husband and I are EMS survivors - I have it, and he cares for me. I'm 67 years old, diagnosed with EMS in 1990, and am one of the 1550 listed with EMS with the CDC in Atlanta.

Having suffered the usual debilitating effects of EMS for nearly 20 years, my neurologist now thinks I have M.S. after finding "white matter" in a brain MRI. Has anyone out there been diagnosed with both, and how did they determine a diagnosis of M.S.? My doctor wants me to have a spinal tap which I hear is no fun and perhaps dangerous.

Please get in touch; my e-mail is omargconrad@hotmail.com

Thanks so much,

Dorallyn Conrad

Dear NEMSN Members,

I have rare good news about EMS and my health. This May my doctor diagnosed damage to a specific part of my central nervous system. The great thing is that he also could tell me how to work on the problem to improve how I feel and function. Sorry I'm not able to describe this quickly, so please bear with me.

For quite a few years I've been getting through life by going once a week to my osteopathic doctor, who specializes in cranial sacral therapy (a gentle hands-on treatment that relieves my pain and makes me temporarily stronger), and by swimming three times a week. My EMS background is in the "personal story" section of NEMSN's website, www.nemsn.org, and more about osteopathic doctors can be found at www.cranialacademy.org. By maintaining this treatment and exercise regimen for the last nine years, I've had ups and downs but basically I've stayed on a plateau as far as my health is concerned.

At some point in the last few years my swimming began to improve with all the practice I get. My swimming strokes have never been better and my laps have been getting faster. However at the same time, my walking was getting more and more difficult. My lower back/hips/leg pain kept

getting worse as my spine from top to bottom kept clenching up more and more. Periodically I would try to walk around the track where, pre-EMS, I used to jog, but I couldn't even comfortably walk around once anymore. I could often barely stand up out of a chair without painfully hoisting myself up with my arms. I was getting clumsier and clumsier. Standing or sitting on a hard surface drained my energy and got extremely painful within seconds.

The combination of swimming getting stronger and walking getting weaker began to bewilder me. In May I asked my osteopath what he thought. So he told me to walk around the room, and he also observed how I was standing. Then he understood what has been going on. My proprioceptive system, which is part of the central nervous system, had been damaged and has not been working well. The proprioceptive system includes specific parts of the brain plus nervous system structures in the spine and neck, arms, legs and feet. As I understand it, this system senses where your body is in space and the relationship of your body to what's around it, including the floor or ground, for example. There are explanations online at Wikipedia and elsewhere. Proprioception tells the body which muscles to use and how much strength is needed to accomplish tasks like walking, for example. Proprioception is not conscious. Some professionals call proprioception a "sense".

My doctor explained that because my proprioception has been impaired, I have been using my vision to compensate. Eyes can provide a lot of data and they can keep me from falling over. But they can't tell my body which muscles to use to do something, or how much strength needs to be exerted by each individual muscle. Accomplishing a task can put very distorted kinds of physical demands on the body if proprioception is malfunctioning. I have been walking flatfooted without bending my feet. I have been walking very stiffly, taking a lot of stress into my pelvis and lower back, and these body parts are not built to take all this physical stress. I've been standing with my weight over the front of my feet instead of standing with the weight over the heels, and this makes my spine clench up more and more. I've been hardly ever experiencing relaxation anywhere in my spine all these years, except when my osteopath works on me. And then that relaxation fades away into the clenched up state again. A result of all of

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Request for Contact

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this has been much, much pain and general body weakness.

Luckily for me, my doctor could recommend treatment for the diagnosed condition. The treatment is aimed largely at jumpstarting my proprioceptive system by taking vision out of the loop since it doesn't belong there. The first thing my osteopath did was to hold onto my shoulders and have me walk a few steps in his office *with my eyes closed*. With my doctor's coaching, I learned that day to feel the floor with my feet, instead of depending on my eyes to know where I was in relation to the floor. I learned to bend my foot with each step. As I learned to "see" with my feet, I could feel that my hips were starting to swing back and forth as I walked and do the work that they are meant to do. Not the pelvis or lower back, but the hips. I could feel various muscles in my legs working in ways that had been unfamiliar to me for a long time. For the first time in years it felt good to take steps.

My assignment was then to walk each day at home just a few steps at a time with my eyes closed. Again, right away I could feel my hips begin working, swaying from side to side as they are meant to while I walk. Also with my eyes closed I could feel how the foot bends when I walk heel-toe, not flatfooted. The foot as it bends, "tells" the many walking muscles to engage, and exactly when and to what extent. Bending the foot while walking increases agility.

Since this time in May, I am walking more and more. Now I go to the track a few times a week during non-busy hours. I walk around the track twice, with my eyes closed as much as possible. For ten steps or so at a time I cut out the visual input and let my proprioceptive system function as it was meant to. When I stand still I consciously put my weight over my heels and in so doing I can often let my spine unclench itself and relax. Walking and standing like this continues to feel good. As I practice more, good habits are slowly becoming more automatic in regular life.

The bottom line is, the more relaxation I can find for my pelvis, lower back, spine, and body in general, the more my pain goes down and the stronger I feel.

It is by no means a straight line to improvement. For the first week I was quite dizzy, for example. Dizziness now

comes and goes but has basically subsided. As I begin walking more naturally all the time, not just when I am on the track, I want to do more and more things. So I strain muscles that I haven't used much in quite a while. I sometimes overdo it and as a result I go through a lot of pain and weakness. I then have to stop everything and rest for a day or even a few days. I have to use a lot of conscious energy all day long in order to notice how I am using my body. Many times a day I find that my spine is clenched up. Then I have to consciously change how I am standing or holding my shoulders, and let my spine unclench. You could say my treatment is a way of life.

But the wonderful news here is that the pain in my lower body is greatly reduced. Just to guess, I'd say it's only about a quarter of what it was three months ago. I can walk much better than before so that means I can do more things. I often have a lot more energy than I used to and my stamina for normal life activities is greater. My legs and feet are not so clumsy because I'm gaining agility in my lower body. I sleep better and I am dreaming again after not being able to remember dreams for years.

This is a work in progress. I continue swimming; I continue walking at the track with my eyes closed. I intend to work more now on upper body. I still have a lot of pain in my neck/arms/shoulders, and also clumsiness in my arms and hands. I hope to find more relief for these things, too.

I write this letter just to let you know of some very unexpected improvement in EMS symptoms that has come my way. I'm interested to know if anyone else has had a similar experience or if anything here rings a bell for anyone.

Best wishes to all,
Lois Vierk
elveevee@aol.com

NEMSN Disclaimer: Consult your own physician(s) for your own medical condition(s). Lois is NEMSN's Public Relations Director and she is writing this as an EMS patient and not as a NEMSN Board member. Her letter is about her own condition and she is not advising our readers on treatment or actions they should try. If you have had any of the same experiences, she would love to hear from you at the above e-mail address.

Are the foods you are eating keeping you in pain?

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work against you. Use this quick list of the best and worst foods in controlling inflammation:

Anti-inflammatory foods

Atlantic Salmon- (wild)
Fresh whole fruits, vegetables
Bright multi-colored vegetables
Green tea
Water
Olive oil
Lean poultry
Nuts, legumes and seeds
Dark green leafy vegetables
Old fashioned oatmeal
Spices, especially Turmeric and Ginger

Pro-inflammatory foods

Sugar, from any source
Processed foods
French Fries
Fast Foods
White bread
Pasta
Ice Cream
Cheddar Cheeses
Snack Foods
Oils such as vegetable and corn
Soda, caffeine and alcohol

In addition to these dietary changes it is also recommended that you:

- **Maintain a healthy weight** - There is no question that "Eating Healthy" is not easy now days, either at home or at a restaurant. But you must at least start to do these three things. Decrease your sugars, Decrease your hydrogenated oils and increase your daily intake of fiber to 35 grams. That is a ton of fiber but just try, you may hit it, you may not, the point is try to.

- **Get better sleep** – 7 to 9 hours is

mandatory for optimal health and the one thing that most people do not know is that quality sleep is the key to controlling systemic inflammation.

- **Relax more often to lower stress levels** – Find time for yourself, morning, noon and night and focus on your breathing and clear the clutter in your mind, learn to stay focused on the most important tasks in your life.

- **Exercise on a regular basis** – Everyone always asks me what is the best exercise to do and all I can say is "Do something you like to do, granted you can tolerate it. Shoot for 15 to 20 minutes 3 times a week.

- **Demand to have you CRP levels tested** – This simple blood test is the best indicator of the level of systemic inflammation in your body. It is recommended that you have the levels evaluated by an certified health care provider to take the most appropriate action for you and your condition.

So if you are in pain and you are going to make a conscious choice to help your self get better than...

Making these changes to your diet and lifestyle will most certainly improve your overall health and help reduce the pain from inflammation. If you would like more information about reducing inflammation naturally and effectively visit the link below to learn more.

<http://www.losethebackpain.com>



To NEMSN Members from the Board of Directors

We really do need you! Please consider helping in any way you are able.

Our Board of Directors is currently short two members. Besides that, most of us on the board are EMS patients. So while we have lots of ideas for wonderful projects to better serve our membership, the spirit is willing but the body all too often gives out.

Do you have the interest and energy to get involved with NEMSN? Would you like to be considered for a board position? Would you like to volunteer in any other way? Would you like to just give us your ideas? NEMSN welcomes anything you have to say. Again, please consider helping us in any way you are able.

"Friends Supporting Friends"

FDA Issues Dietary Supplements Final Rule

For Immediate Release - June 22, 2007

Consumer Inquiries: 888-INFO-FDA

The U.S. Food and Drug Administration today announced a final rule establishing regulations to require current good manufacturing practices (cGMP) for dietary supplements. The rule ensures that dietary supplements are produced in a quality manner, do not contain contaminants or impurities, and are accurately labeled.

"This rule helps to ensure the quality of dietary supplements so that consumers can be confident that the products they purchase contain what is on the label," said Commissioner of Food and Drugs Andrew C. von Eschenbach, M.D. "In addition, as a result of recent amendments to the Federal Food, Drug, and Cosmetic Act, by the end of the year, industry will be required to report all serious dietary supplement related adverse events to FDA."

The regulations establish the cGMP needed to ensure quality throughout the manufacturing, packaging, labeling, and storing of dietary supplements. The final rule includes requirements for establishing quality control procedures, designing and constructing manufacturing plants, and testing ingredients and the finished product. It also includes requirements for recordkeeping and handling consumer product complaints.

"The final rule will help ensure that dietary supplements are manufactured with controls that result in a consistent product free of contamination, with accurate labeling," said Robert E. Brackett, Ph.D., director of FDA's Center for Food Safety and Applied Nutrition.

Under the final rule, manufacturers are required to evaluate the identity, purity, strength, and composition of their dietary supplements. If dietary supplements contain contaminants or do not contain the dietary ingredient they are represented to contain, FDA would consider those products to be adulterated or misbranded.

The aim of the final rule is to prevent inclusion of the wrong ingredients, too much or too little of a dietary ingredient, contamination by substances such as natural toxins, bacteria, pesticides, glass, lead and other heavy metals, as well as improper packaging and labeling.

The final rule includes flexible requirements that can evolve with improvements in scientific methods used for verifying identity, purity strength, and composition of dietary supplements.

As a companion document, FDA also is issuing an interim final rule that outlines a petition process for manufacturers to request an exemption to the cGMP requirement for 100 percent identity testing of specific dietary ingredients used in the processing of dietary supplements.

Under the interim final rule the manufacturer may be exempted from the dietary ingredient identity testing requirement if it can provide sufficient documentation that the reduced frequency of testing requested would still ensure the identity of the dietary ingredient. FDA is soliciting comment from the public on the interim final rule. There will be a 90-day comment period, ending on September 24, 2007. Comments may be addressed to the Division of Dockets Management Branch at www.fda.gov/dockets/ecomments.

The final CGMP and the interim final rule are effective August 24, 2007. To limit any disruption for dietary supplements produced by small businesses, the rule has a three-year phase-in for small businesses. Companies with more than 500 employees have until June 2008 to comply, companies with less than 500 employees have until June 2009 to comply, and companies with fewer than 20 employees have until June 2010 to comply with the regulations.

Backgrounder: <http://www.cfsan.fda.gov/~dms/dscgmps7.html>

Fact Sheet: <http://www.cfsan.fda.gov/~dms/dscgmps6.html>

To see a consumer article called "Final Rule Promotes Safe Use of Dietary Supplements," visit <http://www.fda.gov/consumer/updates/dietarysupps062207.html>.

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May 11, 2007 through August ____, 2007

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NEMSN Contribution Form

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_____ \$15 _____ \$25 _____ \$50 _____ \$100 _____ \$250 _____ \$500 \$ _____ Other

Make checks payable to NEMSN or National EMS Network. Gifts are tax-deductible to the extent allowed by law. Thank you for your help.

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