



National EMS Network Newsletter

Points of interest
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- **Your continued donations have kept this Newsletter and NEMSN alive. Please keep those donations coming no matter how large or small. Our thanks.**
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- **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.**
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- **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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Communicating With Your Doctor - A Guide to Doing it Right

(c) 2002 By Becky Sisk

Have you ever come home from a visit to your doctor wondering if you really understood your medical problem or how to take your medications? In the past, doctors were in charge of your care and you were to "follow orders." These days, patients and doctors have an equal responsibility for care. You have a right to information about your condition and treatment and the doctor has a right to an accurate accounting of your history and symptoms.

According to the National Institute on Aging, here is what you can do to communicate better with your doctor:

- * Be completely honest about all of the medications you take, including over-the-counter medications and herbal preparations. If you have more than one doctor, be sure each knows about all of your medications and other treatments, since dangerous interactions among medications are possible.
- * Also be honest about smoking and drinking. Doctors and nurses are accustomed to taking care of people who smoke or drink. They need to know if you have any habits that contribute to disease or interfere with treatment.
- * Your doctor may question you about a topic that you consider embarrassing, such as sexuality, memory loss, incontinence, or problems with your spouse or children. These problems often have an influence on diseases or may be caused by taking certain medications. Your doctor needs to know about them to accurately

diagnose and treat your condition. Also remember that the doctor and staff members are professional people who will protect your privacy.

- * Make a list of your symptoms, special concerns, medical history, and current medications and give the list to the doctor. Doing this at home before your appointment keeps you from leaving out details.
- * Provide the doctor with a brief, to-the-point description of your problem. What are your symptoms? How severe are they? When did they start? What brings them on? How long do they last and what relieves them?
- * If you are concerned about cooperating with the doctor's treatment, say so. Are you worried about the cost involved? Does the treatment conflict with your beliefs and values? Do the possible side effects of a medication bother you to the extent that you are unlikely to take it?

Here are suggestions to help you get the most accurate information and cooperation from the doctor:

- * Ask a friend or family member to come with you. Take notes during your visit, take a tape recorder to record the doctor's instructions, or insist on a written explanation.
- * You have the right to an explanation of your condition that you understand. Important questions to ask are: "What is wrong?" "What is the cause of my condition?" "What are pros ...continued page 6

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A way for you to help NEMSN

What if NEMSN earned a penny every time you searched the Internet? Or how about if a percentage of every purchase you made online went to support our cause? Well, now it can! NEMSN is asking you to support our organization by using this search engine (instead of whatever you are using now, like google.com for example)-please check out:
www.goodsearch.com

GoodSearch.com is a new Yahoo-powered search engine that donates half its advertising revenue, about a penny per search, to the charities its users designate. Use it just as you would any search engine, get quality search results from Yahoo, and watch the donations add up! You can add GoodSearch to your toolbar to make it easier.

GoodShop.com is a new online shopping mall which donates up to 37 percent of each purchase to your favorite cause! Hundreds of great stores including Target, Gap, Best Buy, eBay, Macy's and Barnes & Noble have teamed up with GoodShop and every time you place an order, you'll be supporting your favorite cause.

Go to www.goodsearch.com instead of Google or other search engines, and select "National Eosinophilia Myalgia Syndrome Network" or "NEMSN" as your designated charity, and this wonderful organization, because of its advertising revenue, will donate one cent to NEMSN for each search that you do! It is simple, it works easily and well. A penny for a search may seem like not much, but if just 100 searches total, from all NEMSN supporters across the country, are done in a day, it will mean a DOLLAR A DAY for NEMSN! The

check will be sent monthly to our treasurer, Michael Bird. We are doing our best to be here for you, please be here for NEMSN. And pass the word around to anyone who is supportive.

Editors Note: You can check when you are using the search engine and see what we are earning. Every little bit helps.

Another way to help NEMSN is to visit iGive.com and sign up with NEMSN as your charity of choice.

Established in 1997, iGive.com is an Internet company whose goal is to enable the economic power of individuals to benefit their chosen communities.

iGive.com has tens of thousands of members who have raised over \$1,700,000 for their favorite worthy causes - all at no cost to the members or their causes.

As I said above, every little bit helps, so if you are shopping online, you might as well be earning money for NEMSN.

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. NEMSN 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 NEMSN 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 NEMSN 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.

Stress Management Tips

By Becky Sisk,, PhD, RN (c) 2003

Stress is a natural part of life. *Eustress*, or normal stress, helps us face challenges and solve problems, but *distress* can lead to chronic health problems and inability to cope. Physiologically, stress is a protective mechanism. When stressed, your body produces adrenalin, readying the person for “fight or flight.” You want to have some adrenalin available but you do not want it elevated all the time. Stressors as challenges that come into a person's life. Stressors can be positive or negative. For example, examinations cause students some negative feelings, but they are positive in that they eventually lead to accomplishment of a goal.

What are some mechanisms for handling stress? Here are some suggestions:

- Take care of your physical needs:
 - o If you have not had a physical exam lately, get one. Medical conditions such as anemia, thyroid disease, or hormone imbalances can make stress more stressful.
 - o Provide yourself a balance between sleep, rest, and activity.
 - o Avoid “pick-me-ups,” such as caffeine, nicotine, or sugar. Caffeine and nicotine increase your pulse and blood pressure, leading to more stress. Sugar intake provokes increased insulin production and shakiness.
 - o If you have trouble sleeping, get up, read a book, or try warm milk. Warm milk enhances the endorphins (natural highs) in your brain!
 - o Try natural highs to combat stress. For example, eating vegetables improves the absorption of L-Tryptophan, an amino acid that is important for the production of serotonin. Serotonin is a soother that allows you to sleep.
 - o Eat well balanced meals, including breakfast. Take a multivitamin daily if you have not been eating well.
 - o If you have allergies, avoid what you know triggers your particular allergies.
- o Be active—exercise.
- o Rest and relax by dancing, listening to music, reading, crafting.
- o Avoid downers, such as tranquilizers, alcohol, and pot. Do not stop prescription meds without talking to your doctor.
- Take life one day at a time – “This is the day the Lord has made.” Write a list of what makes you thankful.
- Simplify your life and prioritize. How hard do you *have* to work? Is work a substitute for real living?
- Manage your time wisely and prioritize your activities. Keep a “to do” list.
- In situations you can't control, use "secondary control."
 - o Seek help from someone who can help you control the situation, such as a counselor.
 - o Determine how important the situation is to you. Is this situation important enough for you to invest your precious resources?
 - o In some situations, try acceptance and prayer.
- Here are some techniques for handling stress.
 - o Take 2-3 deep breaths, exhaling through your mouth and relaxing your jaw and shoulders while exhaling. Imagine warmth flowing down your arms and legs while you exhale. Let your shoulder muscles droop, smile, and say something silly, like “happy” or “ummmm”.
 - o Try progressive muscle relaxation, consciously tightening, then relaxing in muscle groups. Imagine the tension flowing out of your body while you do this.
 - o Stretch your body, then relax, stretching neck, back, arms, and legs progressively.
 - o Use prayer and meditation, with qualified clergy if necessary.
 - o Use cognitive techniques, such as positive self-talk, thought stopping; positive language. Control what you can and accept what you can't. Live adventurously--

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Stress Management Tips *(continued from page 3)*

By Becky Sisk,, PhD, RN (c) 2003

- o try something new.
- o Use mental imagery: think about a nice memory, a favorite place.
- o Try yoga, which soothes your nervous system, improves respiration, and reduces anxiety.
- o Walk! Exercise and take deep breaths while doing so.
- o Take a warm bath...by candlelight...with music playing.
- o Try a new tea (chamomile tea is supposed to be soothing).
- Do *something* – *Make changes, step out of your boundaries*:
 - o Lighten your load. It is okay to say “no” if someone wants help or a commitment from you, e.g. social or voluntary obligations.
 - o Try to avoid making any big changes in your life, like moving or remodeling or going back to school, when you are under stress.
 - o Think about whether you really need to be a “workaholic.” Working for more than 40 hours a week is a stressor...every situation does not call for you to be competitive
 - o Seek out positive people and positive social or voluntary groups.
 - o Seek help from a counselor or support group.
 - o Work to educate others or influence legislators if your stressor is something from which you've learned lessons.
 - o Keep a journal:
 - What are you most thankful for?
 - Happy memories/positive affirmations.
 - Three things you have accomplished this year.
 - Five things you are thankful for this year.
 - Goals for the next year.
 - o Call a friend you haven't visited with for

awhile.

- o Play with a child; re-read your favorite children's book; act silly.
- o Get your nails done, get a manicure. Guys – get a massage.
- o Go to a free festival or concert or craft sale or art show or ...

Here are some websites featuring stress management:

Indiana University Health Centre [Stress Management page](#)

[International Stress Management Association](#) - From the UK, a registered charity with a multi-disciplinary professional membership, existing to inform on the prevention and reduction of human stress, setting professional standards.

[Stress Management: A Review of Principles](#), by Wesley E. Sime, PhD, MPH, Professor, Department of Health and Human Performance, University of Nebraska, Lincoln

[Stress Management and Relaxation Central](#) from Future-health.org

[Stress Virtual Library](#) from the University of Florida - Links to articles and resources related to stress.

Becky Sisk is the owner and webmaster of NurseScribe, <http://www.eNurseScribe.com/>.

This article is for information use only and is not medical advice. Please consult your physician if you are concerned with the condition of your eyes or other medical conditions.

REQUEST FOR CONTACT

Sandy, Does anyone know of a good doctor in Sacramento or Davis, California, who has other EMS patients? I am having a hard time finding a physician who can even relate to the complexity of this illness. I have Secure Horizons/Medicare, but will go outside my insurance if necessary. 916-454-3949. Thank you sincerely for all of your good work. Sonya

Summer

Summer is here
I thought I'd feel better
with sunshine and flowers,
I'm really no quitter.

Warm sun on my face
I hardly could wait,
but somehow a difference
does not to me make

I'm tired, I'm cranky
pain every day.
is it EMS
that makes me this way?

I remember when I
a difference could make.
Work all day
and still bake a cake.

I dream of a cure
to give my life back,
to give me the strength,
no fun would I lack.

I'd travel, I'd read,
I'd clean and I'd cook.
I'd sing and I'd write
by the side of a brook.

T'would be nice to forget
for even a minute,
do all these things
and life, just live it.

But that won't happen
must hope for the best,
enjoy what I have
and put up with the rest.

...SGK 2008

QUESTIONS FOR THE MEDICAL ADVISORY PANEL

We at NEMSN are so happy to have our new Medical Advisory Panel in place to answer questions from EMS patients and their families. We thank the doctors for their time and expertise in giving answers to our questions. The following questions were e-mailed to NEMSN. If you would like to have your questions submitted to our panel, please e-mail them to: NEMSNnewseditor@gmail.com or mail them to:

*Sandy Kintz
767 Tower Boulevard
Lorain, OH 44052-5213*

Q: Early in EMS you wrote that you felt that EMS was similar to TOS and that there might be common etiological factors. I know some research has been done in this area over the years and a few conclusions drawn or further elucidated. Do you still believe that EMS and TOS have any common etiological factors - or anything in common?

A: There are intriguing connections between toxic oil syndrome and EMS, but the specific link has not been proven. Both toxic oil and LT made by Showa Denko contained many trace contaminants. However, there is one connection that looks very suspicious. In 1992, Drs. Mayeno and Gleich at the Mayo Clinic [found] that a chemical called PAA was associated with implicated LT, and this was closely related to another chemical (called PAP) found in toxic oil samples. They later showed that PAP could be transformed into PAA by human liver tissue. Other researchers have shown that both PAA and PAP are broken down to a potentially hazardous metabolite (4-

aminophenol) in liver tissue, and other toxic (but short-lived) byproducts may be produced as part of this chemical cascade. However, how or if this metabolite is the actual trigger of EMS has not been determined.

Edward Belongia, M.D.

Q: You were active in early research into EMS especially in the Minnesota area, I think. Can you briefly summarize what you learned back then, and do you hold the same opinions today about what you learned then? (who got EMS, how they got it, what might have caused it, role of genetic engineering, etc.)

A: I was actively involved in the Minnesota investigation that implicated LT made by Showa Denko. The full report was published in the Aug 9, 1990 issue of the New England Journal of Medicine. Briefly, we found that changes in the manufacturing procedures at the company were strongly associated with production of LT that triggered EMS. Several changes were made, including reduced use of powdered carbon for purification, and use of a new genetically modified strain of bacteria that produced the LT. Because all these changes happened at more or less the same time, it was not possible to say for sure which one was most important. I think the epidemiology investigation was very well done, and the major findings were supported by other investigations across the country.

Edward Belongia, M.D.

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

NEMSN Connections may be just the thing for you.

Would you like to belong to an online email group of NEMSN members who receive monthly information? If so, maybe NEMSN Connections is for you. Members receive the monthly membership list so that they can see the interests (medical and non-medical) of members, states of many members, and even country, since three members are from Canada. If you wish, you can write to another member about a common interest or medical problem. Some members want email pen pals.

Members have the opportunity to ask questions about their medical problems of other members as well as the chance to share helpful tips with other members.

The NEMSN board sends information and announcements each issue. Usually, this consists of medical articles that are of interest to many with EMS. As well, group coordinator Faith Rumph updates the group on happenings.

For the ladies - and men if they cook (or their wives or others with an interest in cooking) - great recipes are part of the sharing monthly. Several members have expertise in this area and have shared recipes including award-winning ones.

Faith sends out the information monthly except in the summer she combines July and August into one issue. If you'd like a sample issue and more information on how to join, please contact Faith: faith_rumph@yahoo.com

Note from the Board of Directors:
Faith Rumph has decided not to join the board for personal reasons. We are very sorry she will not be joining us at this time. Faith has worked tirelessly in the past and continues to do so, helping people with EMS issues.

Communicating With Your Doctor - A Guide to Doing it Right

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and cons of treatment options?"
"How do I know if I need to call you or come back to see you?"

* If you do not understand the doctor's explanation, say so. If the doctor has gone on to the next patient, ask the nurse to provide an explanation for you or provide you with pamphlets about your condition.

* Make sure you understand the action and side effects of any prescribed medication. Find out how often to take the pill, whether you can take it during a meal, and any other special instructions. If you get to the pharmacy to fill the prescription and realize that you still do not understand how to take it, ask the pharmacist for help. Pharmacists are expert at patient teaching, particularly about medications. If you get home and still do not understand what is wrong with you or how to cooperate with treatment, call the doctor's office and talk to the doctor or nurse.

* Ask the doctor for thorough explanations of the preparation for laboratory tests, x-rays, and other procedures. Results are more accurate, and the test does not need to be repeated, when you are appropriately prepared.

* Get acquainted with your insurance plan and how to access care. Some doctors' offices are set up to help you with insurance matters, but not all. Bring your insurance card and any forms that may be necessary, and be prepared to make a co-payment, usually about \$10.00.

* Remember that even the best doctor cannot cure everything. You must do your part, too, by following these tips and taking responsibility for your own health.

Editor's Note: This article is reprinted with permission. Becky Sisk is the owner and webmaster of NurseScribe,

<http://www.enursescribe.com/>.

Prevent Falls in People Over 65

In the United States, one of every three persons aged 65 years and older falls each year. Among older adults, falls are the leading cause of injuries, hospital admissions for trauma, and deaths due to injury. In 1999, about 10,097 seniors died of fall-related injuries. Fractures are the most serious health consequence of falls. Approximately 250,000 hip fractures, the most serious fracture, occur each year among people over age 65.

Many of these falls and resulting injuries can be prevented. Strategies to prevent falls among older adults include exercises to improve strength, balance, and flexibility; reviews of medications that may affect balance; and home modifications that reduce fall hazards such as installing grab bars, improving lighting, and removing items that may cause tripping.

Excerpted from the CDC Injuries Among Older Adults at ...
<http://www.cdc.gov/aging/info.htm>

Donor Honor Roll

March 1, 2008 through June 13, 2008

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Senior class of Mother of Mercy High School in memory of Harry Schulte.

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Please mail your check in the courtesy reply envelope to the Treasurer, Michael Bird. If you lose the envelope, mail in your own envelope to this address: Michael Bird, Treasurer, 219 Twinlakes Drive, Fredericksburg, VA 22401

NEMSN Contribution Form

Here is my gift to support the work of NEMSN:

_____ \$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.

Name _____ Address _____

City/State _____ Zip _____ - _____ Phone _____ - _____ - _____

- Check here if this is a NEW address and enter your previous zip code: _____ - _____
- Check here if you desire a card acknowledging your gift to be sent to you or another. Be sure to include the mailing address.

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