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SUPPLEMENTS AND HERBS IN THE TREATMENT OF ERYTHROMELALGIA

Dr. Cohen developed severe erythromelalgia (EM) in 1995, when little was known about treating EM. He was disabled for several years but is pain free and highly active today. Dr. Cohen is an adjunct (voluntary) professor at the University of California, San Diego. He has published several medical journal articles on EM.

Erythromelalgia (EM) is a disorder of the neurovascular system, that is, of the mechanisms controlling the activity of nerves and blood vessels. These neurovascular abnormalities typically affect the skin in the feet and legs, sometimes the hands and arms, and occasionally the ears, nose or other areas.

EM has many similarities to migraine disorder, and both disorders can be reactive to a wide range of substances. In migraine, such substances are called triggers. Triggers in EM are usually substances that cause vasodilation, that is, the opening of blood vessels, causing redness, heat and burning pain.

VARIATION IN EM RESPONSE

Vasodilators are substances that cause blood vessels to open. Such substances can be helpful in the treatment of hypertension (high blood pressure), because by opening blood vessels, the pressure within the vascular system drops. These same substances can make EM worse.

Like migraine, EM is a multifactorial disorder, meaning that different people may have different underlying abnormalities in the neurovascular network. This explains why people with EM may respond so differently to the same supplements or medications. Some respond beautifully to magnesium, while others worsen. Some respond well to Cymbalta (duloxetine), but others see no improvement at all. The medical journals offer a dozen cases of major improvement with Effexor (venlafaxine), and many others have obtained no improvement or worsened, as I did.

Omega-3 fatty acids, contained in fish oils or flax oil, promote cardiovascular health in most people. Taking one capsule (1,000 mg of fish oil) does not usually affect people with EM, yet they clearly cause vasodilation and pain in me.

SUPPLEMENTS THAT CAN WORSEN EM

Transdermal Therapy with Amitriptyline and Ketamine

The following substances are known to cause vasodilation and may reduce blood pressure. They may cause difficulty for some with EM. If you decide to use one of these substances for health reasons, do so carefully, starting with a low dose. If you are already on one of them, consider discontinuing it to see if doing so improves your EM. Allow at least a month for it to clear your system.

Arginine	Lycopene
Bioflavonoids	Lysine
Borage Oil	Magnesium
Carnitine	N-Acetylcysteine
Coenzyme Q10	Selenium
Evening Primrose Oil	Taurine
Fish Oil	Vitamin B3 (Niacin)
Flax Oil	Flax Oil
GLA (Gamma Linolenic Acid)	Vitamin E
5HTP	Zinc

Comments on some of these supplements:

Amino Acids: Arginine, Taurine, Lysine

Both arginine and taurine increase levels of nitric oxide in blood vessel cells. Nitric oxide is the primary substance in the vascular system that produces vasodilation. Lysine may mildly increase levels of nitric oxide.

Bioflavonoids

More than 4,000 naturally occurring flavonoids have been identified in nature. They are potent antioxidants and free radical scavengers. Although studies are few, it appears that bioflavonoids can modestly reduce blood pressure, meaning they may cause vasodilation.

Coenzyme Q10

This potent antioxidant has many uses in the human body. Alternative doctors frequently recommend coenzyme Q10 to offset the side effects of cholesterol-lowering drugs such as Lipitor (atorvastatin) and Zocor. Because levels of coenzyme Q10 gradually drop with age, the supplement is also frequently recommended for maintaining cardiovascular health. Studies show that coenzyme Q10 can also reduce blood pressure.

Fish Oil & Flax Oil Capsules

Fish oil and flax oil are high in omega-3 fatty acids. Both supplements increase the level of prostaglandins in cells. Prostaglandins are potent vasodilators.

Gamma Linolenic Acid: GLA, Evening Primrose, Borage Oils

All have been shown to reduce blood pressure. They also can reduce inflammation in arthritis.

5HTP

A derivative of tryptophan, 5HTP causes the body to produce serotonin. This may help some people with EM, especially those who obtain benefit but cannot tolerate the side effects of SSRI/SNRI drugs such as Cymbalta, Effexor, Prozac, Zoloft, etc.

Lycopene

Lycopene is found in tomatoes, grapefruit, watermelon and papaya. Studies have proven that lycopene can reduce blood pressure.

Minerals: Zinc, Selenium

Zinc and selenium are sometimes recommended by alternative doctors for hypertension. Both supplements worsened my EM.

N-Acetylcysteine (NAC)

A potent antioxidant and free radical scavenger, NAC increases levels of nitric oxide, the primary vasodilator in vascular cells.

Niacin

Niacin is a potent vasodilator, so potent that niacin preparations can cause skin flushing from dilation of blood vessels. Prescription niacin preparations often do the same. Even in small doses in multivitamin pills, niacin may cause vasodilation in EM. Some multivitamin preparations contain niacinamide, a less potent derivative of niacin, yet niacinamide may still be a problem for some with EM.

DO ANY SUPPLEMENTS HELP EM?

Mineral Supplements By chance I recently discovered that two types of mineral supplements reduce my EM. One is Cal-Apatite by Metagenics, a top-of-the-line supplement manufacturer. No other company makes Cal-Apatite. The other is Utah Sea Minerals; both the liquid and tablet, were helpful. Years ago, I tried many mineral supplements, and they all worsened my EM. I do not know why I have responded well to these two products. They do contain some magnesium, but as far as I can tell, not enough to explain my response. You can find Cal-Apatite and Utah Sea Minerals via Google.

Phosphatidylcholine (PC)

I cannot remember why I tried this supplement, but I began using it around 2003. It remains one of my mainstays. PC is a key factor in every cell of the body, especially nerve cells. Why it helps my EM, I do not know. I use a specific brand from BodyBio (bodybio.com). No other brand works for me. BodyBio PC is made via a different process than other brands of PC.

Magnesium

Based on surveys, it appears that about one-third of us are helped by magnesium, one-third worsen, and one-third obtain no effect. The good news is that when magnesium works, it can work very well. Magnesium is the body's natural calcium channel blocker. The recommended daily allowance is 400 mg/day. Alternative doctors often recommend 600 or 800 mg/day. Start with a small amount, 100-200 mg/day, and increase gradually. Use high quality magnesium because poor quality can cause diarrhea. My favorite magnesium product is Magnesium Plus Protein (mgplusprotein.com), but it is easier to get magnesium citrate or gluconate or Natural Calm (magnesium citrate crystals in water) from a health food store. Magnesium therapy requires normal kidney function and good hydration, and use in the elderly or dosing above the recommended daily allowance of 400 mg/day requires medical supervision. Alternative doctors (find one at ACAM.org) are usually more knowledgeable about magnesium than mainstream doctors. Under their direction, higher doses of 600-800 mg/day can be used. Other substances with mild calcium channel blocking effects are chromium, high doses of ascorbic acid, and the herb butterbur.

Alpha Lipoic Acid (ALA)

This supplement has been used for decades in Europe and now in America for neuropathies, the type of nerve injuries seen in diabetes. Neuropathies are the underlying problem in most cases of EM. ALA is one of my main supplements. It works for me probably because it has some calcium channel blocking

effect, like magnesium. Anyone helped by magnesium might also obtain benefit with alpha lipoic acid. If magnesium worsened your EM, try ALA carefully.

HERBS

Many herbs and spices are vasodilators, so I have to be careful about using them. Herbs that may have vasodilatory properties include ashwagandha, bay leaf, curcumin, curry, devil's claw, echinacea, ginkgo biloba, hawthorn, maitake mushrooms, nutmeg, Siberian ginseng, skull cap, tumeric, and many, many others.

St. John's wort increases serotonin, just like Prozac (fluoxetine), Zoloft (sertraline) and others. There have been a few reports of benefit with these drugs, so St. John's wort may be worth trying.

The herb butterbur has calcium channel blocking properties, similar in this regard to magnesium (see above). Because calcium channel blocking therapies can help some people with EM, yet worsen others, start with a low dose of butterbur and increase gradually until it is clearly helpful. If your EM worsens, discontinue.

THE 5HTP-SEROTONIN TEST

Serotonin is produced in the body via the pathway tryptophan > 5-hydroxytryptophan (5HTP) > serotonin. If you take 50 or 100mg 5HTP, within an hour or two you may see an improvement or worsening of your EM. If improvement occurs, you can continue taking 5HTP. Doses vary with different supplements but are usually 50 to 300mg per day. You can take 5HTP in divided doses such as 50 or 100mg three times a day. If 5HTP causes sedation, take smaller daytime doses and more at bedtime, or all of it at night. If 5HTP causes redness and pain, as it did for me, it tells you that serotonin producing medications may not work for you or may worsen your EM. Instead you might try two herbs, feverfew and white willow. These herbs are serotonin antagonists: they block the effect of serotonin on blood vessels. I chose them because, through the 5HTP test, I learned that serotonin made my EM worse. I also tried serotonin antagonist drugs, cyproheptadine (Periactin) and pizotifen (Sandomigran, from Canada). Cyproheptadine had minimal effect, but pizotifen was highly beneficial. Feverfew and white willow are moderately effective for me. Interestingly, these substances also help many people by preventing migraines. Please note: white willow contains salacin, a mild aspirin-like substance that can thin the blood: check with your doctor before using it. Do not use white willow if you take any blood thinning medication or other substances including as warfarin, Coumadin, or aspirin.

THE 5HTP-SEROTONIN TEST

When I developed EM in 1995, we were still in the dark regarding treatment. Hardly any doctors had heard of EM. Only a few treatments had been reported, and they rarely worked. Today things are much better. Our understanding and methods have grown considerably, and many people can be helped. Of course, I still sleep with the covers off of my legs and avoid walking in the hot sun, but I rarely have pain and can do most of the things I want. I believe that significant improvement is possible for most people with EM. Find a doctor who can make an accurate diagnosis and is willing to work with you, using this article as a guide. It takes patience to try one treatment after another, but don't give up. Be patient and persistent. For support, contact The Erythromelalgia Association at erythromelalgia.org. This excellent organization is run by volunteers with EM and offers extensive information you will find useful.

NOTE TO READERS: Few studies have been done on EM, so there is a lack of established scientific