
Many years ago, when I was disabled by the severe pain of erythromelalgia, I used to watch in horror as my feet began to throb and my toes would swell and turn bright red every late afternoon. I had to brace myself, because the pain was always worst from that time into the night. However, by the next morning, around 7 AM, my feet would turn cooler, the swelling in the toes lessened, and the skin looked fairly normal again.

This phenomenon occurs in many of us with EM. People who contact me for a consultation invariably ask about this pattern of their disease. My answer is that these changes are a reflection of the activity of the autonomic nervous system.

The Autonomic nervous System

Blood vessel activity is controlled by the autonomic nervous system, which in turn is controlled by lower levels of the brain (medulla oblongata and lower brainstem). The autonomic nervous system (ANS) is designed to work silently and independently of the conscious brain. Our conscious brains have enough to think about in our dealings with work, people, chores, responsibilities and life in general. Imagine if we actually had to direct how to digest our food, control blood flow throughout our body, synchronize our breathing, adjust how much we sweat, coordinate the muscles when chewing, swallowing and working, and constantly adjusting the lens of our eyes when we focus and accommodate for light -- and a thousand other simultaneous functions. The ANS handles these functions for us, maintaining physiological balance twenty-four/seven.

The ANS consists of two systems: the sympathetic and parasympathetic nervous systems. These two operating systems act independently as they balance the functions of the ANS. In general, the sympathetic system is the activating system, whereas the parasympathetic system is the resting and restorative system. These two systems play a distinct role in the symptoms of EM.

The Sympathetic System
Characteristically, the sympathetic nervous system turns on between 5 and 7 in the morning. The sympathetic system readies the body for daily activity. From the moment we rise, we become bodies in motion, grooming and then working until late afternoon. To accomplish this, the sympathetic nervous system increases the heart rate, breathing rate, cortisol levels -- and tightens the blood vessels. This tightening is not noticeable to most people, nor was it to us before we developed EM. But now, with EM, we can readily see the difference when the sympathetic nervous system activates. Except in severe cases, our EM improves.

The Parasympathetic System

As the day wears on, the sympathetic tone gradually winds down, relinquishing its control to the parasympathetic system. The heart rate drops, the breathing rate slows, and the blood vessels begin to open. These changes are subtle and usually go unnoticed in healthy people. Yet as these changes occur, people with EM readily notice that their symptoms are worsening. In healthy people, the vasodilation that occurs during the parasympathetic mode is usually small, but in us the difference can be huge. In EM, the vascular system overreacts to any degree of vasodilation. EM is a condition in which the normal control mechanism of blood vessel activity is severely damaged. At mild temperatures such as 60 or 70 degrees, our blood vessels open as widely as if it were 110 degrees. Similarly, the slight vasodilation caused by parasympathetic activation is huge in us. We can see it and feel it.

Even in a cold room, people with moderate or severe EM still experience a worsening of their condition as the autonomic nervous system shifts from sympathetic to parasympathetic mode in the late afternoon or evening. However, as the severity of EM gets worse and worse, the excessive vasodilation can become constant. There is so much vasodilation that even in the morning and early afternoon, when the sympathetic system should be dominant and the blood vessels constricted, the intense vasodilation of severe EM overrides everything else. At this point, EM symptoms dominate twenty-four hours a day. This is a tough place to be. I was in this place 1996-99.

Over the years, I have learned to space my therapies (2 medications, 3 supplements) according to the biorhythm of my EM. I am able to use less in the morning, and I gradually increase my dosages in the afternoon and evening. I take larger doses before bedtime. Early on, when my EM was less severe, I could take magnesium every four hours, and this was sufficient. But when my EM turned worsened about ten years ago, and I had to find additional remedies to control the EM.

Today, my EM reflects the typical daily biorhythm. The blood vessels continue to open in the late afternoon, but I can control it now with my therapies. Flaring does occur in some evenings, but it is mild and painless.

If your EM displays a biorhythm as I have described, you may also the able to tailor your treatment regimen so that a greater part of your therapy is used later in the day and at night, and a lesser amount upon awakening and up to around 3-4 PM.

With the articles I have posted here at MedicationSense.com and other sources of information available at TEA (The Erythromelalgia Association), I hope you can achieve control of your EM and cessation of your pain. NOTE TO READERS: Few studies have been done on EM, so there is a lack of established scientific fact about EM and its treatment. This article reflects my knowledge and personal experience with EM, and is meant to provide information for use by you and your doctor. This information should not be considered as a substitute for the medical advice of your doctor, nor is it meant to encourage the diagnosis or treatment of any illness, disease, or other medical problem without your doctor's direction. Readers should not make any changes in drugs, doses, or any other aspects of their treatment unless directed by their doctor. Finally, after many years of disability from EM in the 1990s, Dr. Cohen is now highly active with no pain, but because people with EM vary greatly in what helps them, he makes no
claim that his methods and suggestions will benefit anyone else. Dr. Cohen is an Associate (Voluntary) Professor of Preventive Medicine and Psychiatry at the University of California, San Diego, one of the top 20 universities in America. His work in the area of preventing medication side effects has been widely published and is recognized nationally. If you would like Dr. Cohen’s input on your EM, he is available for office or telephone consultations. He charges a fee for his time, just as he charges people with other medical conditions who come to his office or consult with him from around the world. For information, contact Leslie at 858-345-1760 or schle@att.net. Dr. Cohen’s Publications on Erythromelalgia:


Also consider joining The Erythromelalgia Association (TEA), an excellent resource for information, published articles, and support for people with EM as well as for their families, friends and health care professionals. Readers can obtain information about membership and resources at www.erythromelalgia.org.

Dr. Cohen is an Associate (Voluntary) Professor of Preventive Medicine and Psychiatry at the University of California, San Diego, one of the top 20 universities in America. His work in the area of preventing medication side effects has been widely published and is recognized nationally. If you would like Dr. Cohen’s input on your EM, he is available for office or telephone consultations. He charges a fee for his time, just as he charges people with other medical conditions who come to his office or consult with him from around the world. For information, contact Leslie at 858-345-1760 or schle@att.net.

NOTE TO READERS: The purpose of this E-Letter is solely informational and educational. The information herein should not be considered to be a substitute for the direct medical advice of your doctor, nor is it meant to encourage the diagnosis or treatment of any illness, disease, or other medical problem by laypersons. If you are under a physician’s care for any condition, he or she can advise you whether the information in this E-Letter is suitable for you. Readers should not make any changes in drugs, doses, or any other aspects of their medical treatment unless specifically directed to do so by their own doctors.

If you find this article informative, please tell your friends, family members, colleagues, and doctors about www.MedicationSense.com and the free MedicationSense E-Newsletter.

Copyright, Jay S. Cohen, M.D. All rights reserved. Readers have permission to copy and disseminate all or part of these articles if it is clearly identified as the work of: Jay S. Cohen, M.D., the MedicationSense E-Newsletter, www.MedicationSense.com. You may not use this work for commercial purposes.