

A Patient's Guide to Erythromelalgia



The Erythromelalgia Association

Our mission

TEA's mission is to empower all those affected by EM to improve their quality of life.

TEA provides education, awareness and community through our website, member services program, newsletter, social media presence and networking programs.

TEA promotes research through relationships with academic researchers, clinicians and pharma companies with interest in EM. TEA also raises funds to support EM research.



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What is erythromelalgia?

Erythromelalgia (EM) is a rare neurovascular condition that most commonly affects the feet, but may also occur in the hands, face, or other parts of the body. The term neurovascular means that both nerves and blood vessels are involved.

The three hallmark symptoms of EM are:

- **Redness:** This skin-color change is caused by excessive blood flow to the affected area. The medical term is *erythema*.
- **Heat:** Skin will feel warm or hot to the touch due to the increased blood flow.
- **Pain:** Discomfort may range from mild tingling to severe burning. For some, it can also involve sensations such as pins and needles or itching.

Additional symptoms may include:

- **Swelling:** The increased blood flow may cause a buildup of fluid in the affected body part. The medical term is *edema*.
- **Change in perspiration:** Some people with EM sweat less in the affected body part. This is called *anhidrosis*. However, other people with EM experience an increase in sweating, which is called *hyperhidrosis*. Both of these symptoms may be caused by problems with the autonomic nervous system (the part of the nervous system that automatically regulates body functions) or damage to small nerve fibers.
- **Purple discoloration** and/or **cold to the touch:** Some people with EM experience cold and/or bluish skin when they are not actively flaring. These symptoms may be related to narrowing of the blood vessels, which is called *vasoconstriction*.

EM flares are most commonly triggered by warmth, physical activity, or stress. People with EM may avoid exercising and taking hot baths or showers and may be unable to wear socks or closed shoes. Some people with EM cannot tolerate having their legs in a dependent position (feet below level of knees and hips) and are more comfortable keeping their feet elevated. Flares may be intermittent or continuous.



How common is EM?

According to a 2008 study conducted by Mayo Clinic in Rochester, Minnesota, EM affects an estimated 1.3 people per 100,000 each year in the United States.^[1] A 2013 study from New Zealand suggests that the incidence of EM may be as high as 15 per 100,000.^[2] EM is considered a rare disease and is listed in the database of the National Organization for Rare Disorders (NORD).

What are the different types of EM?

Primary EM

Primary EM is not caused by an underlying disease. It includes both inherited and idiopathic EM.

- **Inherited EM**

An estimated five^[3] to fifteen percent^[4] of EM cases are hereditary, caused by mutations of the SCN9A gene—and possibly other as-yet-unidentified genes. These mutations affect the way nerves send pain signals to the brain and may also cause the warmth and redness associated with EM.^[5]

- **Idiopathic EM**

Idiopathic cases of EM have no identifiable cause. This is the most common form.

Secondary EM

Cases of EM that are caused by another disease or condition are called secondary EM. The most common causes of secondary EM are:

- **Essential thrombocythemia**, a myeloproliferative blood disorder that causes increased production of platelets^[6]
- **Polycythemia vera**, a myeloproliferative blood disorder that causes an increased production of blood cells, primarily red blood cells^[7]
- **Thrombocytopenia**, a blood disorder that involves a low platelet count^[8]
- **Peripheral neuropathy**, including diabetic neuropathy^[9]
- **Autoimmune diseases**, such as lupus,^[10] vasculitis,^[11] rheumatoid arthritis,^[12] and multiple sclerosis^[13]
- **Nerve damage** due to injuries or other conditions, such as carpal tunnel syndrome, sciatica, and frostbite^[14]

In some cases, when the underlying disease is treated, EM symptoms will improve or resolve completely.

Some medications have been linked to the onset of EM, including calcium-channel blockers,^[15] certain kinds of antidepressants,^[16] and the immunosuppressant cyclosporine.^[17] In some cases, when a person stops taking these medications, his EM symptoms will get better.

Secondary EM has also been linked to toxins such as mercury^[18] and poisonous mushrooms.^[19] Symptoms may go away when the toxin has cleared the body.

How is EM diagnosed?

Finding the right doctor

The first step to diagnosing EM is seeing your primary care doctor. Your doctor may conduct tests for some of the common causes of EM, and she may refer you to a specialist to confirm a suspected diagnosis. Specialists that diagnose and treat EM include neurologists, dermatologists, rheumatologists, and vascular physicians or surgeons.



If you live outside of larger urban areas, where doctors may not have seen many cases of EM, you may have to travel to a larger city with an academic medical center to get a diagnosis and treatment. Once you have seen a specialist, your primary care doctor will likely be able to help you with the day-to-day management of your EM.

Reaching a diagnosis

There is no specific test for EM. Doctors diagnose EM by observing symptoms and by ruling out any other possible cause of your symptoms. If you are not actively flaring at the time of your appointment, your doctor may be able to reach a diagnosis by asking you questions about your symptoms and looking at photos of a flare in progress. Some doctors may want to witness an actual flare before making an official diagnosis.

In either case, it is important to keep track of your symptoms. You can help your doctor make a diagnosis by keeping a journal of what triggers your flares, the symptoms you experience, and anything that brings you relief. Take these notes, as well as photos of a flare, to share with your doctor.

Identifying or ruling out causes of secondary EM

While there is no specific test for EM, a doctor may order many tests to identify or rule out any possible underlying disease that could be causing your EM symptoms. For example, a complete blood count (CBC) can help diagnose blood disorders, and glucose testing may identify diabetes. Autoimmune diseases may be identified by blood tests for the presence of autoantibodies or by skin biopsies. Neurologists may perform electromyography (EMG) or nerve conduction velocity (NCV) testing to identify nerve damage.

Common conditions associated with EM

Other conditions may coexist with EM, including Raynaud's phenomenon^[20] and perniosis (also called chilblains).^[21] Raynaud's is a condition where fingers or toes turn white or blue in response to cold temperatures or emotional stress. (Some describe EM as the “opposite” of Raynaud's.) Perniosis also occurs on fingers or toes that have been exposed to cold, resulting in inflammation of small blood vessels, which may then lead to painful swelling and blistering of the skin. When a person has both EM and a condition that reacts to cold, it can be a balancing act to manage the two conditions.

Prognosis

In patients followed for approximately a decade, doctors at Mayo Clinic observed that EM symptoms got better, worse, or stayed the same in roughly equal proportions. In about ten percent of those cases, the EM resolved completely.^[22]

Treatments for EM

There is no cure for EM. While it is true that treating an underlying disease may sometimes bring complete relief from EM symptoms, most cases of EM cannot be fully treated. In such cases, treatment focuses on relieving symptoms with medications and other techniques. It frequently takes a period of trial and error before a person with EM finds a treatment plan that works for her.

Symptom relief

Cooling the affected area typically provides some relief for an EM flare.

Safe methods for cooling a flaring body part include:

- **Fan:** direct a fan on the affected area
- **Cool Surface:** rest bare feet on a cool tile or concrete floor
- **Gel Packs:** apply cool (not cold) gel packs to the affected body part
- **Feet Up:** elevate flaring feet



When using a fan or cool gel packs, moderation is key. If used for more than a short period of time, these methods can damage skin and make your symptoms worse.

When experiencing an EM flare, you may be tempted to soak the affected body part in cold water. This is a dangerous practice that can seriously damage the skin and should be avoided.^[23] Even if you try to protect your skin from the water by using plastic bags, the long exposure to cold can lead to nerve damage,^[24] rebound flaring,^[25] and ultimately, a worsening of symptoms. For the same reason, applying ice packs to the skin is also dangerous.

Topical medication

Topical medications are applied directly to the skin and can be effective at reducing EM symptoms, especially for those who cannot tolerate the side effects of oral medications.

Compounded creams

Your doctor may prescribe a topical medication that is specially mixed by a pharmacy, a process that is called compounding. Such medications may be in the form of a cream, gel, or ointment. Mayo Clinic has conducted several studies on the effects of a compounded gel of 1% amitriptyline/0.5% ketamine on EM symptoms. A majority of patients using this gel reported improvement.^[26]

Another Mayo Clinic study tested the effects of 0.2% midodrine cream on EM symptoms and had similarly positive results.^[27] Compounded topical medications may also include other drugs, such as lidocaine, gabapentin, and clonidine.

Capsaicin

Capsaicin cream (Zostrix) has been reported to relieve EM symptoms.^[28] Based on these reports, some doctors treat EM with an 8% capsaicin patch (Qutenza).^[29] The patch is administered with anesthesia for sixty to ninety minutes and helps desensitize the skin's heat receptors, which may be over-sensitized in some cases of EM.^[30] This treatment may provide lasting relief for months or longer.

Lidocaine and menthol

Some people with EM have found relief using lidocaine patches (Lidoderm).^[31] Another option is a menthol product like Biofreeze gel or spray, which can induce a sensation of cooling.

Oral medication

A number of medications are effective for reducing flares or relieving the pain experienced during flares. However, a medication that works for one person with EM may not work for another. With the help of a doctor, and through trial and error, many people are able to find a drug (or combination of drugs) that helps to relieve symptoms and make EM flares less frequent and less painful.

The following are medications that have been shown to help relieve EM symptoms for some people, either alone or in combination with other drugs.

Aspirin

Aspirin is very effective in treating EM associated with blood disorders like essential thrombocythemia and polycythemia vera because aspirin acts as a blood thinner.^[32] To help with diagnosis, your doctor may prescribe aspirin first, to see how your EM reacts to it. When EM responds well to

aspirin—and in many cases, symptoms will completely resolve—the EM is likely caused by a certain kind of blood disorder called a myeloproliferative disorder. Your doctor may then refer you to a hematologist (blood specialist) for further diagnosis and treatment.

Anticonvulsants

Anticonvulsants, such as gabapentin (Neurontin)^[33] and pregabalin (Lyrica),^[34] may help relieve EM symptoms by reducing nerve activity and altering the way the body perceives pain. These medications are often used as a first-line treatment for EM, as well as for neuropathy (nerve damage), a condition often associated with EM.

Antidepressants

Antidepressants are also used to treat symptoms of EM and neuropathy, though it is not fully understood how they work. The most common antidepressants used for treating EM include duloxetine (Cymbalta), venlafaxine (Effexor),^[35] amitriptyline (Elavil),^[36] and nortriptyline (Pamelor). Doctors may also prescribe sertraline (Zoloft),^[37] fluoxetine (Prozac), or paroxetine (Paxil). It is important to note that your doctor is not prescribing antidepressants because he thinks you are depressed—even though these drugs were originally developed to treat depression—but because they have been shown to actually reduce EM symptoms in some patients. These medications can also help with sleep, which can be difficult for people suffering from EM pain.

Sodium-channel blockers

Sodium-channel blockers can reduce EM pain by blocking sodium-channel activity. Drugs in this category include carbamazepine (Tegretol),^[38] an anticonvulsant that also acts as a sodium-channel blocker, and mexiletine (Mexitil).^[39]





Cardiovascular drugs

Other medications work by altering the way blood flows through your vessels. Vasodilators, which relax or “open up” your blood vessels, include the calcium-channel blockers diltiazem (Cardizem) and nifedipine (Procardia) and the alpha blockers alfuzosin (Uroxatral) and phenoxybenzamine (Dibenzyline). These drugs may be useful for people whose EM is caused by poor blood flow in the body’s smallest blood vessels.^[40] On the other hand, beta blockers, such as propranolol (Inderal),^[41] atenolol (Tenormin), and metoprolol (Lopressor), may provide relief when EM symptoms are caused by too much blood flow to the extremities. Clonidine (Catapres) and midodrine (ProAmatine)^[42] are two drugs in a class called alpha agonists that also reduce blood flow to the extremities.

Narcotic pain medications

Doctors may also prescribe narcotic (also called opioid) pain medications for managing the pain associated with EM. These medications generally do not prevent flares but can reduce the pain experienced during a flare. Some doctors may require you to work with a pain specialist or other expert in the use of narcotics if you are using these medications regularly to treat your EM.

Supplements

Some nutritional supplements may be used to treat EM symptoms. For example, magnesium is a calcium-channel blocker and vasodilator that has been helpful for many EM patients.^[43] Another supplement, alpha lipoic acid, has been used for decades for nerve injuries like those present in some people with EM.^[44] Those whose EM benefits from antidepressant medications may find improvement with 5HTP, an amino acid that increases production of serotonin.^[45] Any supplement should be treated like a prescription medication and discussed with your doctor before adding it to your treatment.

Other medications

Some people with EM have experienced improved symptoms with antihistamines like cyproheptadine (Periactin),^[46] cetirizine (Zyrtec),^[47] and diphenhydramine (Benadryl). Others have found relief with migraine drugs like pizotifen (Sandomigran)^[48] and the triptans rizatriptan (Maxalt) and zolmitriptan (Zomig).^[49]

Other drugs that have been reported to help EM symptoms in at least one patient include clonazepam (Klonopin),^[50] prednisone,^[51] misoprostol (Cytotec),^[52] and cyclosporine (Sandimmune).^[53]

Surgical and other procedures

In rare cases, your doctor may recommend intravenous (IV) infusions or surgery when other forms of relief do not work.

IV infusions

Some people with EM experience relief from lidocaine infusions, especially those with EM that is caused by overactive sodium channels.^[54] Sodium nitroprusside helps open up constricted blood vessels and may benefit children and adolescents,^[55] though this treatment has not been proven effective in adults.^[56] Iloprost infusions also help to improve circulation and may be useful for patients whose EM is caused by excessive vasoconstriction.^[57]

Nerve blocks

Epidurals^[58] and sympathetic nerve blocks^[59] are two types of nerve-block procedures that have been used to treat EM. In these procedures, an anesthetic such as lidocaine is injected into the space around the spinal cord (for an epidural) or into certain nerves (for a sympathetic block) and can help block pain signals. If a sympathetic block is successful in providing pain relief, then a sympathectomy—an irreversible procedure in which nerves are surgically destroyed—may be considered.^[60]

Surgical implants

Implanted devices like a spinal-cord stimulator^[61] or an intrathecal drug-delivery pump (sometimes called a “pain pump”) may help relieve the pain associated with an EM flare. There has been a case report of ziconotide (Prialt) delivered via an intrathecal pump relieving both pain and swelling in a patient with EM.^[62]

Unconventional treatments

Some less common treatments have also been reported to help EM symptoms. A recent report indicates that certain laser treatments can alleviate EM symptoms in some people.^[63] Hyperbaric oxygen therapy, a treatment that involves lying in a pressurized oxygen chamber, has been reported as successfully treating EM in one case.^[64] Another case report documents improvement of EM symptoms after the patient received a series of Botox injections.^[65] Because treatments like these have not been well studied and may be invasive or expensive, it is unlikely your doctor will recommend them, except in cases where all other treatments have failed.



Mind-body therapies

Practiced mental processes can also lessen EM symptoms. The principle behind mind-body therapies is that the mind and body are connected and that your thoughts can affect the way your body feels. The aim of these therapies is to reduce the negative effects of stress and pain—through practicing relaxation, reframing unhealthy emotions, and training the mind to focus on the body—so that positive, healthful changes may occur. Cognitive Behavioral Therapy (CBT), biofeedback, and hypnosis are three techniques that have been reported to help treat the symptoms of EM.

- **CBT** is a form of therapy that helps you learn how to manage negative thoughts. While the technique may not directly affect EM symptoms, it can help a person cope by controlling his perception of pain.^[66]
- **Biofeedback** teaches a person to gain conscious control over certain body processes by receiving real-time feedback via computer monitors. This may allow a person with EM to exercise some control over bodily functions that impact, or are impacted by, EM symptoms, including heart rate and blood flow.^[67]
- **Hypnotherapy** allows the patient to enter a state of deep relaxation, during which the practitioner can guide her toward altering her experience of painful EM symptoms.^[68]

Mental therapies can be just as important as medical therapies in learning to live fully with a chronic-pain condition like EM. You will likely need to make use of both in order to best manage your symptoms.

Coping with EM

Lifestyle modification

In addition to relieving painful symptoms, coping with EM also involves taking measures to prevent flares from occurring. To do this, you must first identify what triggers an EM flare for you, and then limit or modify those activities or situations. By recognizing your triggers and learning methods of adapting, it is possible for you to continue many of your normal activities.

The following are some tips on how to handle four of the most common EM triggers: exercise, bathing, eating certain foods, and sleep.

- **Exercise:** Exercise increases blood flow and body warmth. Because this is likely to trigger a flare of EM symptoms, it may be challenging for many individuals with EM to stay active. For some, EM flares and swelling in the feet may make walking or running difficult. Instead, swimming can be a good option, because it is not weight-bearing and the cool water temperature may minimize flaring. Gentler exercises such as some types of yoga and Pilates also keep your body temperature lower and may allow your feet to remain elevated. For outdoor activities, take advantage of cooler temperatures in the early morning or evening. No matter what type of exercise works best for you, keeping your indoor environment cool and breaking up your exercise routine into shorter sections can make any program more manageable. Despite the temporary discomfort, there is no evidence that exercise will worsen your condition. To the contrary, doctors believe that adhering to an exercise program—even a moderate one—improves your overall health and can help manage stress and pain levels.
- **Bathing:** Most people with EM have had to make adjustments to their bathing routine, such as lowering the water temperature, bathing less frequently, showering instead of bathing in a tub, changing the time of day they bathe (many people with EM experience worse flares in the evening), or keeping a door or window open to cool the bathroom. When even lukewarm water is enough to provoke a flare, other options include running cool water into a bathtub to stand in while showering or sitting on a shower stool in order to keep your feet out of the warm water.
- **Foods:** Some people find that certain foods will provoke or worsen an EM flare. Spicy foods and alcohol are common triggers. If you think that your EM symptoms are affected by the foods you eat, you can experiment by removing one type of food at a time and keeping a diary to track any potential link between foods and flaring. If food-triggered flares require you to make any major changes to your diet, it is important to discuss these changes with your doctor to ensure that you are still getting proper nutrition.



- **Sleep:** EM flares are frequently worse at night, as sleep itself can be a trigger for some people. In preparation for sleep, the brain signals the body to cool down by directing blood flow away from the core, causing the extremities to become warmer.^[69] EM sufferers may be unable to tolerate bed sheets on the affected area and may find some relief by using a fan or portable air conditioning unit. People with EM may also take their EM medications or sleep aids at bedtime.

EM in the workplace

Having EM can present challenges in the workplace, especially if your job is likely to trigger flares (such as one that requires you to be on your feet or exposed to warmer temperatures).

Because of the various conditions that trigger flares, people with EM frequently require special accommodations in the workplace. In the United States, federal law requires that your employer make reasonable accommodations for you, so that you can continue to work despite EM. A “reasonable accommodation” is a change to your duties or workplace that your employer can make to better enable you to perform your job, without causing the employer undue hardship. This may include providing air conditioning or a fan in your workspace, providing a way for you to elevate your feet under your desk, or allowing you to spend more time sitting than standing. Such accommodations can also include altering the duties of your job, changing your hours, granting a period of leave, or allowing you to telecommute from home. Your doctor can help explain the accommodations you need by writing a letter to your supervisor.

If there is no way for you to perform your current job, even with accommodations, you may consider finding a different position that would allow you to manage your EM while still working. For example, a hospital nurse with EM who can no longer be on his feet all day may find that he is better able to work in a doctor's office, perhaps answering patients' questions via telephone.

In cases where EM prevents individuals from remaining employed at all in positions for which they are qualified, they may be able to seek short-term or long-term disability benefits, either through an insurance policy or government program.

Children with EM

EM most commonly affects adults but can occasionally be present in children. Though treatments prescribed for children may differ from those recommended for adults, many of the same lifestyle modifications can be applied.

For example, a child with EM may be more comfortable wearing sandals instead of closed shoes. You can bathe your child in the morning when EM tends to be less active. Likewise, consider scheduling outdoor activities in the morning or evening when the weather may be cooler. Hot cars can trigger flares, so run your car's air conditioning to cool the car before your child gets in. If your home is not air-conditioned, you may want to install a portable air conditioner in your child's bedroom to make sure she can sleep comfortably and to give her a cool place to retreat to when other rooms are warm.

Do not use cold water or ice packs to cool a flare, because they can cause skin damage and rebound flaring. Directing a fan on the affected area is a safer method for cooling flares.

There are many ways in which you can make life easier for your child. The following tips have been provided by parents of children with EM.

- Explain the condition to your child's school, and communicate any special needs he may have. These may include limiting Physical Education participation, taking breaks during exams if the EM affects his hands, or allowing him to complete schoolwork at home when absent.



- Identify activities and sports, such as swimming, that are less likely to exacerbate your child's symptoms.
- Make every effort you can to keep your child from feeling isolated. Try to identify any local spots—such as restaurants, movie theaters, or shopping malls—that are adequately air-conditioned, and plan your child's social activities there. If this is not feasible, invite her friends over to your home whenever possible.
- Consider counseling for your child with a professional who specializes in children with chronic illnesses.

Most importantly, help your child focus on all that he can do rather than dwell on the condition and its possible limitations. By providing your child with unconditional love and support, and concentrating on the positive, you can enable your child to have a full and happy life despite having EM.

Communicating with family and friends

EM affects not just you, the patient, but also those who are closest to you. It may sometimes seem as though family and friends cannot comprehend what it is like to have EM. Loved ones, therefore, may need help understanding what is going on in your body.

Here are some suggestions on how to explain EM to them.

- Try to find analogies that they can relate to, for example, holding a hand or foot over an open flame or having a bad sunburn.
- Familiarize them with the pain scale (0 being no pain, 10 being the worst pain imaginable), so that you can communicate to them how you are feeling.
- Explain what triggers your EM and what adjustments they can make for you, such as agreeing to a cooler environment in your home or modifying shared outdoor activities so you can avoid the sun.
- Let them know in specific terms how they can help you. If you have trouble finding the words, showing them this patient's guide is a good place to start.

Sometimes severe EM can be so disabling that a loved one must take on the role of caregiver. This can be difficult for both individuals. The person

with EM must deal not only with the pain but also the loss of independence. The caregiver may feel burdened by additional work or experience negative emotions. In these situations, it is important that your caregiver have support of her own, so that your relationship can thrive despite the tough circumstances. Your doctor may be able to recommend support resources for you and your caregiver.

Mental-health support

Depression and anxiety often arise in people with chronic conditions, especially ones that cause pain and discomfort. A mental-health professional may be able to help you deal with the psychological challenges of EM, including coping with day-to-day pain, adjusting to changes in your life, managing relationships with loved ones, making medical decisions, and even grieving the losses that you may have experienced due to EM. Therapists—including psychologists, licensed clinical social workers, and other licensed therapists—who specialize in chronic pain and illness may be best suited to handle your specific needs, but any therapist with whom you feel comfortable can provide invaluable support.

If you are housebound or on a fixed income and have difficulty getting to see a therapist regularly, an increasing number of therapists provide services online, through video conferencing. Also, reading books on pain and stress management may be useful.

The following books have been recommended by pain psychologists.

- Managing Pain Before It Manages You by Margaret A. Caudill, MD
- The Chronic Pain Solution by James N. Dillard, MD
- Feeling Good by David D. Burns, MD

Online support groups

In coping with your EM, you may be faced with feelings of isolation, particularly if you are limited in what you can do. It is important to remember that you are not alone—even though EM is a rare condition, there are thousands of people experiencing the same symptoms as you. Even if you

are able to maintain an active social life, online groups allow you to interact with others who can relate to your experiences with EM. Members may share treatments that have worked for them, offer tips on how to deal with EM-related challenges, and generally inspire each other to keep going in the face of a chronic, painful condition.

You can find active groups by searching online.

Adjusting to a new normal

EM is undeniably life-changing. Having to make significant changes to your normal routine can be challenging at best and, at worst, traumatic. The challenge going forward is to figure out how to get the most out of life despite EM. It is all about coming to terms with your condition and creating a new “normal.” Instead of focusing on what you cannot do, concentrate your energy on things you can do.

Managing EM takes patience and perseverance. Only a few people are lucky enough to stumble upon their optimal treatment on the first try. Through trial and error, you and your doctor will eventually figure out what works best for you. Although there is currently no cure for EM, it is possible to find ways to manage and improve your symptoms. Advances in research related to EM and its treatment happen every year. *There is hope!*



Looking ahead to the future

In addition to providing information and support to people with EM, TEA continues to encourage and fund research into effective treatments for all types of EM. Though EM is rare and has not been extensively studied, research into its causes, mechanisms, and treatments continues in both academic and commercial settings. At present, there is a growing interest in developing EM treatments, due in part to the belief that a drug designed to treat EM pain could work for many other kinds of pain as well. For the most up-to-date information on advances in EM research and treatments, visit TEA's website at <http://www.erythromelalgia.org>.



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Additional Resources



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- A list of doctors who are familiar with EM, recommended by TEA's members

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Ms. Beaton serves on TEA's Board of Directors and proposed that TEA develop this guide. She conceptualized the content and managed the writing and design, dedicating many volunteer hours to this project. She is an environmental attorney in San Francisco, California. Ms. Beaton was diagnosed with EM in 2013.

Ms. Crawford has contributed to TEA's mission by drafting this guide. Formerly a contemporary dancer and Pilates instructor, Ms. Crawford is now a freelance writer and author of two books, *Flavors of Friuli: A Culinary Journey through Northeastern Italy* and *Balance on the Ball: Exercises Inspired by the Teachings of Joseph Pilates*. She lives in San Francisco, California, and was diagnosed with EM in 2011.

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Erythromelalgia

/ ī·rī·thrō·mēl'älj(ē)ə /

noun

a rare disease with painful, red flare-ups
primarily affecting hands and feet

*This guidebook is a free publication
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