

FootSteps

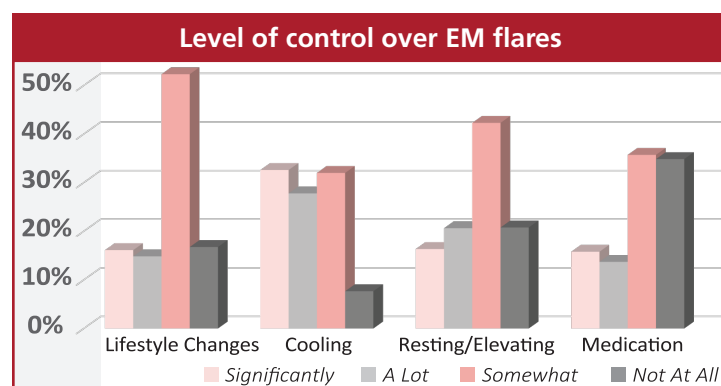
The newsletter for members of The Erythromelalgia Association
FootSteps online: erythromelalgia.org or burningfeet.org

Fall 2021, Vol. 22, No. 1
2021 Survey Results Edition

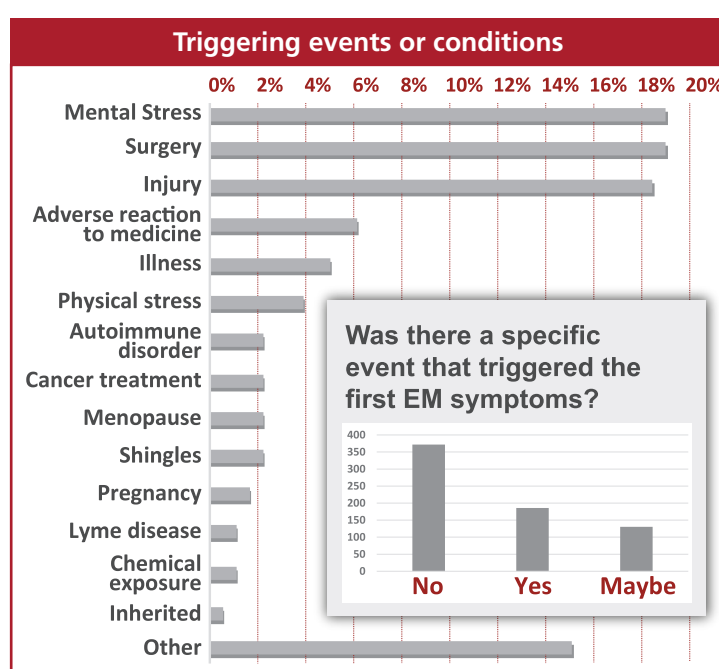
Survey covers EM triggers, symptoms, diagnoses

Of those responding to TEA's January 2021 member survey, the majority (about 60 percent) said a diagnosis of EM took more than a year, and the reason for the delay cited most often was their provider's lack of familiarity with EM. But 87 percent reported their diagnoses of EM were finally made by providers with rheumatologists, dermatologists and neurologists most often recognizing the disorder. This TEA member survey was conducted 100 percent online from January 4 to 22, 2021. A description of the survey with a link to the survey questions was sent by email to the 3,300 TEA registered members. In addition, the description and link were posted on TEA's Facebook page and the Fans of TEA Facebook page. A total of 683 people completed and returned the survey. Respondents (the 683) were 82 percent female and 17 percent male. (More women than men are known to have EM and women are generally more likely to answer surveys.) Of those completing the survey, 75 percent were age 50 or older.

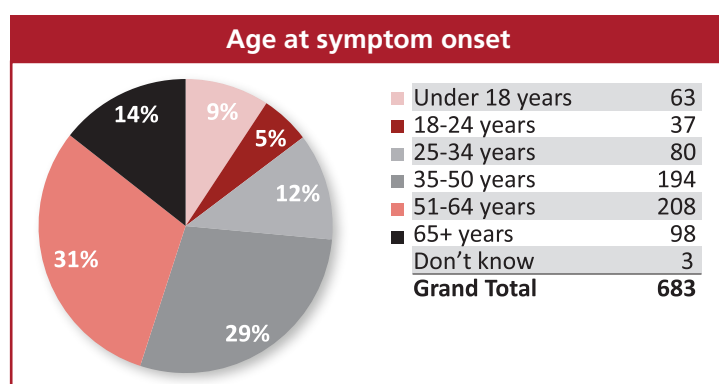
Some of the findings:



Just over 50 percent said they have some level of control over their EM flares through a variety of methods—for more than 30 percent, cooling helps “significantly”.



Only about 30 percent could point to a specific event that may have triggered their first EM symptoms—most often named were mental stress, surgery, or an injury.



EM can first appear at any age. About half (54 percent) reported being under 50 and half were 50 or older.

(Continued on PG 2)

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is published by



The Erythromelalgia Association

erythromelalgia.org
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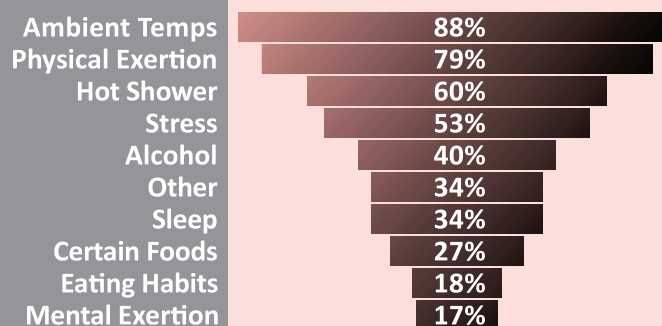
Justin Wedul

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The intent and purpose of this publication is to inform those with EM or their friends and families—not, in any way, to provide medical advice.

EM survey results (Continued from PG 1)

EM symptom triggers



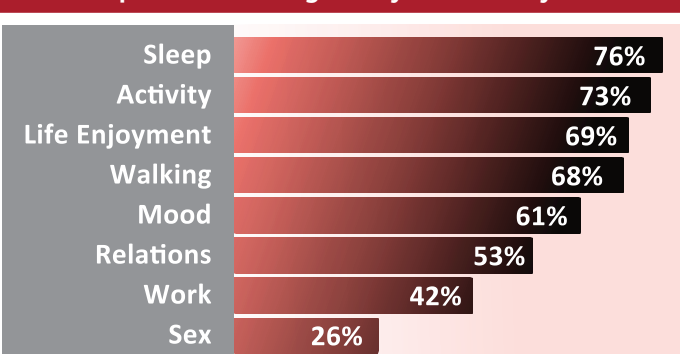
Symptom triggers reported most were hot weather (88 percent), physical exertion (79 percent), and hot showers (60 percent).

Other diagnoses

Disease or condition	# reported
Raynaud's	42
Fibromyalgia	39
Small Fiber Neuropathy	24
Unspecified autoimmune disorders	20
Diabetes	16
Hashimoto's disease	16
Lupus	14
Migraines	14
Dysautonomia	9
Rosacea	8
Polycythemia Vera	6
Lyme	4
Multiple Sclerosis	4

Some 32 percent of respondents reported having another condition along with EM with Raynaud's syndrome being most frequently named.

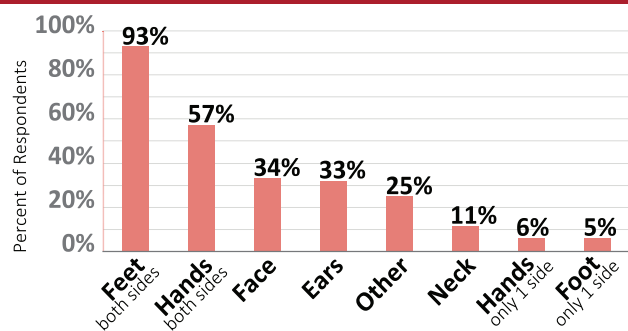
Aspects of life negatively affected by EM



Sleep is negatively affected for three-quarters of respondents. A large majority said walking and activity in general are also limited by EM. Almost 70 percent reported that enjoying life is hampered.

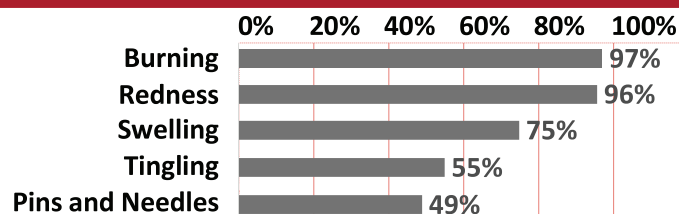
EM survey results (Continued from PG 2)

EM flare location



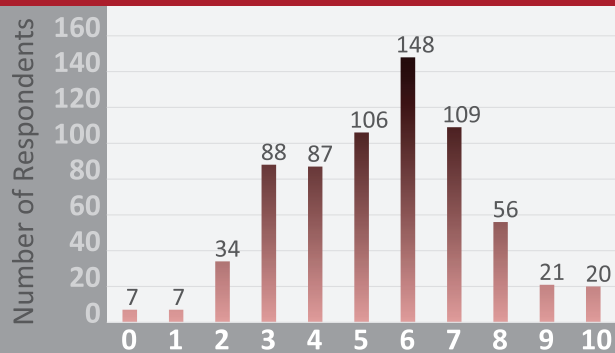
EM comes in flares—93 percent said their flares affect the feet; 57 percent the hands and 34 percent their face.

Pain descriptions during EM flare



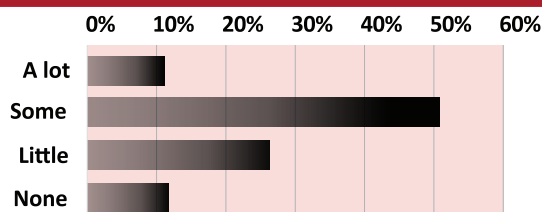
EM pain was described as burning by 97 percent with redness (96 percent). Swelling was mentioned by 75 percent.

Typical EM pain on a scale of 0-10, 10=most severe



On a scale of 1 to 10, typical EM pain is moderately severe—from 5 to 7.

Level of control reported over EM flare



Half reported they have “some” level of control over EM flares, but about 26 percent said they have “little”.

Medication most reported using and effect

Medication Name	Medication Class	IMPROVEMENT				
		A Lot	Some	Little	None	Worse
Aspirin	NSAID	6	9	3	49	
Gabapentin Neurontin	Anticonvulsant and nerve pain	3	7		24	
Pregabalin Lyrica	Nerve pain	1	2	1	14	1
Duloxetine Cymbalta	Anticonvulsant and nerve pain		1	1	8	3
Venlafaxine Effexor*	Anticonvulsant and nerve pain	1	3	1	2	1
Amytriptyline Elavil, Endep	Tricyclic antidepressant		1	1	5	
Mexiletine	Antiarrhythmic	1			4	
Amlodipine Norvasc	Calcium Channel Blocker		3		1	2
Nifedipine	Calcium Channel Blocker		1		2	1

*a.k.a. serotonin-norepinephrine reuptake inhibitor (SNRI)

Aspirin was the most frequently attempted medication for EM pain—less than 3 percent had some improvement. In addition to the most reported medications, about 35 other drugs have been tried by the respondents. One found that the drug diltiazem helped. Another got a lot of help from prednisone. TEA survey results continue to show that different people react differently to various medications and very few get significant improvement from any single drug.

Alternative treatment data

Treatment Name	Improvement	
	YES	NO
Acupuncture	17	108
Biofeedback	3	1
CBD	7	13
Compression Stockings	5	0
Lidocaine	5	3
Marijuana	3	5
Meditation	5	4
Nerve Block	1	7
THC	4	2

*Not shown: numerous treatments reported by only one or two participants such as homeopathic tinctures, Epsom salts, Botox and TENS unit

In addition to medications, alternative treatments have been tried by respondents with very limited success in reducing EM pain. However, acupuncture showed a level of improvement equal to aspirin. For full survey results, go to www.erythromelalgia.org/resources/#member-survey or go to our home page at www.burningfeet.org, then go to Resources in the menu and scroll down and click on Erythromelalgia Surveys.



The Erythromelalgia Association

200 Old Castle Lane,
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Share your story about how EM has affected your life. Send a head shot and your story (350 words or less) to memberservices@burningfeet.org or mail to 200 Old Castle Lane, Wallingford, PA, 19086.



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TEA FootSteps

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EM Yahoo Group now Google

The long-standing EM Yahoo Group has a new home on the Google Groups platform, according to Meg Edelson. Anyone with EM can join the new EM Google Group at groups.google.com/g/erythromelalgia-em.

The Yahoo Group had been in existence since 1999 and was begun by the same group of people with EM who founded TEA. It has been a resource for many with EM and a platform for sharing symptoms of EM and learning about treatments.

Raising Awareness.

Raising Research Funds.

Raising Hope.

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