

Rare disorder keeps woman off her feet

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THE NEWS JOURNAL
01/24/2006

It doesn't matter whether she's at a grocery store, eating dinner or watching her sons at karate practice.

When Beth Coimbra feels the need to doff her shoes and plant her feet on a cool tile floor, it's going to happen.

It's not matter of creature comfort, nor is the 42-year-old Wallingford, Pa., resident oblivious to social norms. Coimbra has a rare disorder known as erythromelalgia that makes her extremely sensitive to temperature changes. If she doesn't manage her feet temperature, Coimbra soon finds herself dealing with severe redness and a burning pain that can leave her unable to walk.

Hence, when she starts feeling the heat, vanity goes by the wayside, along with her shoes.

"Little kids will come up to me screaming, 'Mommy, look! Her feet are so red!' " she said.

Coimbra was diagnosed seven years ago after she went to her primary care doctor for what she thought was a persistent case of athlete's foot. Nine months after being referred to a dermatologist, her condition was identified.

When the seriousness of the condition first struck, Coimbra was tucking her children into bed. Without warning, pain swept over her feet and she was literally floored on her way back to her room.

"The pain was so bad, I was crawling around," she said. "I couldn't even stand. I had no idea what was going on."

Like many erythromelalgia sufferers, Coimbra is now a connoisseur of cooling devices. She has big ones for lounging on the couch, medium ones for her computer desk and small portable ones for anywhere else she may go. Though she rarely uses them anymore, Coimbra also has a stockpile of gel cooling



THE NEWS JOURNAL/FRED COMEGYS
Beth Coimbra, with her children Adam (left) and Jordan, suffers from erythromelalgia, a rare disorder that causes intense heat and pain in her feet.

pads.

Shoe selection is particularly frustrating for Coimbra. Much to her disappointment, high heels are just not an option anymore, because they cause blood to rush to the front of her feet. Most of the year, Coimbra wears thong-style sandals to maximize ventilation. In the winter months, she wears close-toed shoes without backs that she can quickly slip on and off.

While awareness of the condition is growing, most doctors still aren't prepared to treat patients with erythromelalgia, said Dr. Ramesh Adiraju of the Revascularization and Clinical Autonomic Research Institute at Lower Bucks Hospital in Bristol, Pa.

"The medical community really doesn't know much about this yet," he said. "They do know the clinical condition, but they don't know how to treat it."

Though sometimes referred to as a neurological condition, erythromelalgia is actually a disorder of the autonomic nervous system, Adiraju said. This part of the nervous system regulates involuntary bodily functions, including the constriction of blood vessels like the capillaries that are vital to circulation and temperature control.

"It took awhile, but over a couple of years we were able to work around with the medications that I used to treat autonomic dysfunction," he said. "Once we got that under control, [Coimbra's] erythromelalgia symptoms, the frequency of her pain and her activity level significantly improved."

By necessity, Coimbra is a Weather Channel fanatic. There are only so many days when she can enjoy herself outdoors. Too hot and she'll instantly feel the burn. Too cold, and the sudden spike in temperature when she comes back indoors will do the same.

Trips to the beach are limited to one-day affairs. Coimbra spends most of her time under an umbrella. When she does get up to take a stroll, she stays near the water in case she

needs to cool off her feet.

Though she knows better, Coimbra occasionally indulges herself by dunking her feet in a cold water bath at home. It's the ultimate in instant gratification for her symptoms, but it leads to pain after she removes her feet from the water. Ice packs also aren't recommended for the same reason.

Coimbra's condition has affected the entire family. All-day outdoor activities are rare now. And random encounters with acquaintances sometimes have to be cut short because Coimbra can only spend so much time on her feet in a given day.

"It's totally not ignorable. Everything has to stop and I have to have relief," she said. "You have to, otherwise it's like you're coming out of your skin."

Still, in some respects, Coimbra's limitations are a blessing in disguise, she said. Her condition has forced her to slow down her life, giving her more time to spend with her sons, 13-year-old Adam and 10-year-old Jordan.

During the milder seasons, she can manage the occasional bike ride with them. When she can't, they're fine with staying in and playing cards. Long road trips north to Canada and Maine take the place of extended beach vacations.

"It gives us a chance to just be near one another," Adam said.

Soon after being diagnosed, Coimbra was told by one of her doctors that she -- like anyone with a rare disease -- would have to be as active as any health professional in seeking a cure.

"They told me, 'This is rare, and for any rare disease you can't give up,' " she said. " 'This is your job now. You are your own advocate.' "

She has become that and more. Coimbra recently was appointed president of the Erythromelalgia Association and is a board member for the National Organization for Rare

Disorders. She gives her time to these groups while continuing to work part time as an accountant.

Careful preparation and knowing her limits help Coimbra make it through most days. She also uses an antidepressant called Cymbalta that seems to help with her pain. But there is one thing Coimbra and her husband, Firmino, would like to address.

The current family car was purchased just months before Coimbra started feeling the effects of erythromelalgia. While shopping around for the vehicle, her husband touted the marvel of dual-zone climate control, which allows each occupant to adjust the temperature to his or her liking.

Ironically, it was Coimbra who insisted it was a frivolous expense.

"I said that was pushing it," she said. "Now he's always freezing because I'm constantly using the air conditioner. You know our next car will have it."

ABOUT ERYTHROMELALGIA

Erythromelalgia is a rare condition that can cause severe redness, fevered skin and intense burning pain in all parts of the body, most frequently the feet and hands, but also in the face, ears, limbs and torso. The disease varies significantly from case to case. In some individuals, symptoms present themselves gradually, and the condition remains relatively mild for years. In others, the disease may appear suddenly, spreading and becoming severe over weeks.

The specific cause of erythromelalgia remains unknown. However, the condition is thought to result from abnormalities in the systems that control the constriction and dilation of certain blood vessels, which can affect blood flow to the extremities. Erythromelalgia may be a primary condition or linked to various underlying disorders.

Treatment is aimed at avoiding situations that can bring about symptoms, such as prolonged outdoor activities in hot temperatures. Medication also can be used to manage pain.

Source: The Erythromelalgia Association

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