



Mast Cell Activation Syndrome (or Disorder), MCAS or MCAD

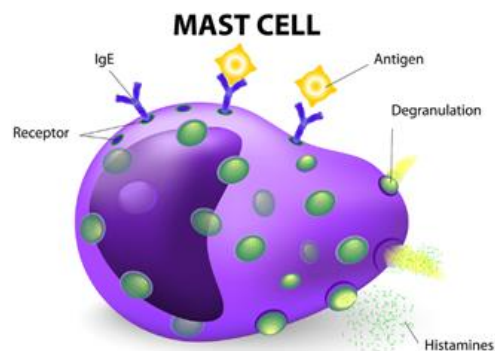
Good Health Physical Therapy and Wellness
Goodhealthphysicaltherapy.com

You are Strong and Courageous

You are strong and courageous. How do we know? If you are reading this, you have likely been facing one or many health challenges for some time. And you have been doing your best to live and function each day. That takes strength and courage. We are here to listen to you and to support you in your healing journey. In particular, we hope to support you being even more empowered to get your symptoms under control, to know the best ways to manage the health challenges and to get back to doing what you want to and need to be able to do for all the life you deserve. This is one of a series of patient education handouts – the Strong and Courageous Series – aimed at helping you to learn more about your condition, learn the controllable triggers of flareups, and learn the steps you can take to claim back your power and your ability to function.

Mast Cell Activation Syndrome, Overview

Mast cells are part of the body's defense system. They exist in almost every area of the body including the lungs, blood vessels, skin, gut, muscles and nervous system. They serve to keep us healthy and repair the body by releasing chemicals, called mediators, by a process called degranulation. These mediators start inflammation and healing when there is a wound, injury or antigen (foreign body) such as dirt, a bacteria or a virus.



Some Mast Cell Mediators

Histamine
Prostaglandin
Platelet Activating Factor
Cytokines
Thromboxane
Tryptase
Lukotriene

Mast Cell Activation Syndrome (MCAS), also sometimes called Mast Cell Activation Disorder (MCAD), is a condition in which the mast cells too easily release their mediators often in response to some kind of trigger. This causes inflammation and pain (as well as other symptoms, see below) in multiple areas of the body.

MCAS is NOT the same as Mastocytosis in which there are too many mast cells. We mention this because some physicians will think you are talking about Mastocytosis when you ask about MCAS.

MCAS is very commonly associated with hypermobility spectrum disorder (HSD) and hypermobile Ehlers Danlos Syndrome (hEDS), and also associated with a nervous system condition called Postural Orthostatic Tachycardia Syndrome (POTS). POTS causes abnormal changes in heart rate and blood pressure especially with position changes like going from lying to sitting or sitting to standing, and with prolonged standing for more than a short time. Between 66 and 89% of patients with hEDS have been shown to have some symptoms of MCAS.

The reasons for the connection between HSD/hEDS and MCAS and between POTS and MCAS are not well understood. But these connections are a good example of the many functions and physiologic processes going on in connective tissue. Many of the Mast Cells of the body are in connective tissue.

Some Common Symptoms

As you will see in a section below, one of the 3 criteria for the diagnosis of MCAS is that there be symptoms affecting two or more systems of the body. Some of the systems of the body affected by MCAS may include stomach/ gut, eyes, heart/ circulation, skin, bladder, lungs/ breathing, liver, brain/ nerves, blood.

There is a danger in giving a list of symptoms for an inflammatory condition which can affect as many areas as MCAS. That danger is that a list can suggest new worries for patients. The following list is intended for information NOT for self-diagnosis. We know you are wise and will remember that each symptom below can have other causes.

Constitutional – fatigue, temperature sensitivity, sweats, chills, decreased appetite, weight gain or loss, chemical sensitivities	GI System – diarrhea, constipation, nausea, vomiting, bloating, difficulty swallowing, abdominal pain, bad absorption. Diabetes
Teeth – deterioration of teeth and gums despite good hygiene	Immunological – increased vulnerability to infections, autoimmunity, poor healing
Eyes/ Ears – blurred vision, dry eyes, twitching lids, ringing, hearing loss	Liver/ Gall Bladder – abnormal liver tests; gallbladder inflammation
Nose/ Mouth – Nose bleeds, congestion, post-nasal drip, chronic sinus irritation or infections. Burning mouth, sores, white patches, abnormal color or texture	Reproductive/ Urinary – painful urination, frequent urination, incontinence, bladder pain, chronic kidney disease, cystitis, vaginal inflammation, endometriosis, painful intercourse, painful periods, decreased libido
Thyroid -- Hypothyroidism, hyperthyroidism	Musculoskeletal – joint pain, bone pain, thinning of the bones, muscle pain, tendinitis
Lungs/ Breathing – Sore throat, hoarseness, chronic cough, laryngitis, wheezing, shortness of breath, obstructive sleep apnea, sensitivity to smells and odors.	Lymph System – enlarged lymph nodes, inflamed spleen
Heart/ Circulation – chest pain, palpitations, high blood pressure, high cholesterol, POTS, Raynaud’s disease	Nervous System/ Brain – numbness, tingling, muscle weakness, seizures, low muscle tone or too much muscle tone, headaches, memory deficits, brain fog; changes in taste, hearing, smell, vision; sleep disorders/ insomnia, restless leg syndrome
Blood – changes in blood tests with too many or too few of different cell types	Skin -- rashes, sores, small red spots, hives, hair loss, brittle finger nails, warts, skin tags

Diagnosis

Hypermobility (HSD) and Ehlers Danlos Syndrome (EDS) are not the only conditions which can lead to symptoms of Mast Cell Activation Syndrome. There are different categories of diseases associated with Mast Cells, and a number of possible causes. Mast cell disease can be primary, meaning the problem is due to a malfunction or problem the Mast Cells themselves, or secondary to conditions other than HSD.EDS such as allergies, cancer or autoimmune conditions. Finally, mast cell disease can be “idiopathic” – a medical terms meaning that the exact cause of the disorder is not known. The MCAS disorder connected with HSD.EDS is idiopathic. As we have already noted, the reason for the connection between HSD.EDS and MCAS is not fully understood.

Diagnosis must be done by a knowledgeable medical provider who can consider the following: medical history, other signs and symptoms, physical examination and tests. For a formal diagnosis, three criteria must be met.

- The patient has recurring or chronic symptoms of MCAS affecting two or more body systems which are bad enough to need treatment and other major possible causes have been ruled out (such as pheochromocytoma, low thyroid, low testosterone, eosinophilic disorder).
- There has been a blood test showing a high level of a Mast Cell mediator (tryptase) within two hours of a flare up or a urine test showing high levels of one or more mediators (n-methyl histamine, prostaglandin D2, 110 prostaglandin f20).
- The patient has some relief from symptoms in response to medications that suppress mast cell mediator chemicals. (See below)

Treatment Overview

There are four general aspects to the treatment of MCAS. First, education. As we say repeatedly in this series of patient handouts, knowledge is power. So, everything you can do to inform yourself about the condition is positive. One useful resource is the website of The Mast Cell Disease Society:

<https://tmsforacure.org/>

The other three aspects of MCAS treatment are: medication & supplements, trigger awareness plus avoidance, and, for some patients, diet.

Medications & Supplements

The first line of defense in MCAS is medication to limit or block the effect of mast cell mediators.

- Medications used to block histamines: hydroxyzine, doxepin, diphenhydramine, loratadine, fexofenadine, cetirizine, ranitidine, cimetidine, famotidine.
- Medications used to block leukotrienes: monteleukast, zileuton, ketotifen.
- Medications used to block cytokines: low-dose naltrexone.

Another first line of defense is medications which stabilize the Mast Cells so that they do not release their mediators so easily. These medications may include: cromolyn sodium and ketotifen.

Some of the medications listed above are available over the counter. It is always important to work with your physician rather than attempting to self-medicate. Many medications have interactions and can cause problems in combinations.

There are also a number of supplements used by naturopathic physicians to inhibit mediators and/ or stabilize the mast cell. Some of these are: quercetin, Vitamin C, bromelain, flavonoids, resveratrol, melatonin, cannabinoids, curcumin. Here too, it is important to work with your naturopathic physician to get the most effective form and dosage of the supplement and to avoid interactions.

Common Triggers

Patients with MCAS are susceptible to a number of different types of triggers. Which triggers affect any individual is by itself very individual. It will take self-observation and awareness for you to determine which affect you. Below is a list of common triggers which can affect patients with MCAS. The purpose of this list is information. Information properly used should be empowering. However, improperly used can simply serve to make you afraid of you world. If you find this list empowering, use it. If looking at the list of possible triggers raises your fear levels, skip it for now.

Obviously, once your triggers are known, part of your treatment will be to try to avoid them. Laundry detergents can be changed, cleaning agents switched for other products and sometimes a mask worn.

<p>Environmental Strong odors. examples: gasoline, perfume Cleaning agents Laundry detergent Mold Dust Venom such as insect or snake bites Poison ivy, poison oak Pesticides Amalgam fillings Rapid temperature changes Changes in barometric pressure Sun exposure</p>	<p>Physical/ Emotional Psychological or emotional stress Strong emotions Self-negativity Extreme mental exertion High sexual arousal Caffeine Physical overexertion Physical stimuli such as vibration, friction, shock or impact Menstrual cycle changes Infection</p>
<p>Dietary Fruits and vegetables with higher levels of pesticides Alcohol Tomatoes Chocolate Spinach Fermented foods Citrus Preservatives Individual food sensitivities.</p>	<p>Medications Antibiotics: Cefuroxime, Vancomycin Anticonvulsants: Carbamazepine, Topiramate Cardiovascular drugs: ACE inhibitors, beta adrenoceptor antagonists Intravenous narcotics: Methohexital, Phenobarbital, Thiopental Local anesthetic: Lidocaine, Articaine, Tetracaine, Procaine Opioids: Meperidine, Morphine, codeine Acidic NSAIDS such as Ibuprofen Nerve medicines: Icatibant, Cetrorelix, Sermorelin, Octreotide, Leuprolide, Bupropion Plasma substitutes: Hydroxyethyl starch, gelatin Muscle relaxants: Atracurium, Miva curium, Rocuronium X-ray contrast materials</p>

Dietary Approach

The first step in identifying dietary triggers is to start keeping a food journal. Write down everything you put in your mouth every day and make notes about how you feel. Initially, you might pay special attention to how you feel after eating any of the foods listed in the section above. Foods that are individual triggers for you may not show up on the first intake.

Sometimes foods have an active ingredient which for you is a trigger, but which must build up in your blood stream. For example, suppose that chocolate is a trigger for you. And imagine that on a Sunday afternoon, you eat a piece of chocolate. You feel ok. Then on Monday you have another piece of chocolate and still feel ok. But on Tuesday when you have a third, you immediately start having an inflammatory reaction. This would be because the chemicals in the chocolate which you are sensitive to built up in your blood stream until the reaction was triggered. On another week if you allowed 4-5 days between small doses of chocolate, you might not have a reaction. Or if you ate a large amount in one sitting, you could have a reaction right away.

If you suspect that you have dietary triggers it is often wise to work with a naturopathic physician who can guide efforts to identify triggers and to modify diet.

Who Can Help?

One of the challenges faced by patients with hypermobility disorders and associated conditions can be finding medical providers who are knowledgeable about the conditions. While physical therapy can be helpful in many ways, and while physical therapists can screen for warning signs of conditions, making a formal diagnosis of a medical condition that is not a movement disorder is beyond the scope of a physical therapist. So, a medical provider is needed. Additionally, in the case of MCAS, the primary treatments are with medications and supplements, and physical therapists do not prescribe these.

The first place to start when there is suspicion of MCAS is an open and honest discussion with your primary care provider. If you do not have a provider, or they are not knowledgeable about how to diagnose and treat the problem, many patients have found referrals to medical, osteopathic or naturopathic providers through the [Oregon Area Ehlers Danlos Support Group](#). This is a private support group on [Facebook](#).

Notes: