

Steps To Managing Your Mast Cell Activation Syndrome

“So, you think you have MCAS. Now what?”

If you are still learning about the signs and symptoms of MCAS, <https://www.mastzellaktivierung.info/en/symptoms.html> and www.tmsforacure.org have excellent info. This handout is about management once you think you may have MCAS. There is no silver bullet, no single magical intervention that will fix everything. Each of the strategies listed here might only help 10%, but together several of them may provide 50% or more benefit, which is good.

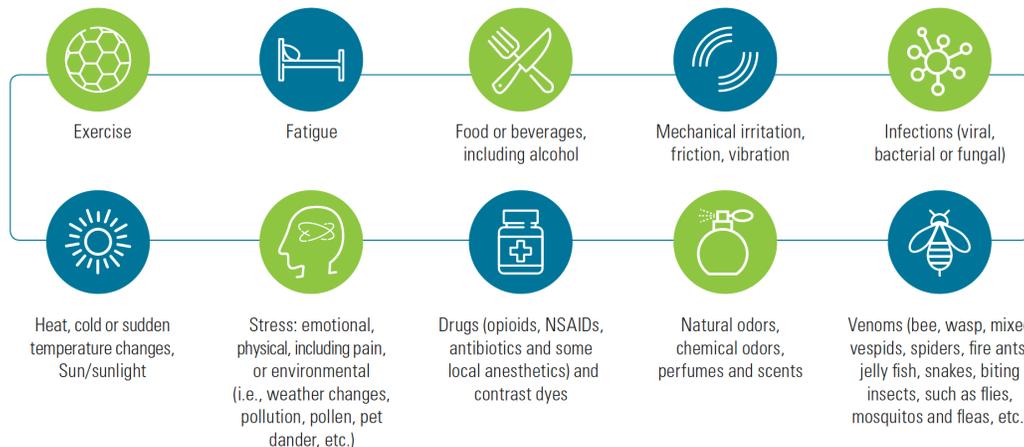
Because symptoms of MCAS are normally quite variable, you might need to try a strategy for 3-4 weeks to see if it helps. The impact of changes is easiest to see if you only change one thing at a time. Yes, this is frustratingly time-consuming. Consider keeping a symptom diary.

There are 3 basic approaches to managing MCAS:

1. Identify your triggers and avoid them. Easier said than done, but essential. Medications won't work well if you are constantly exposed to triggers. Trigger sensitivity can vary over time, and often build on one another, so you might react to something one day and not another. You may react to a trigger immediately, or any time within 24-48 hours.
2. Take supplements or nutraceuticals (therapeutic foods) that alter the mast cells, histamine, or response to histamine.
3. Take medications that alter the mast cells, histamine, or response to histamine. Reliable overview at: <https://tmsforacure.org/treatments/medications-treat-mast-cell-diseases/>

This handout focuses on identifying and avoiding triggers, and will briefly discuss supplements. Talk to your doctor about appropriate medications (www.tmsforacure.org has good info about medications for managing MCAS, which you can discuss with your doctor). A booklet from Mast Cell Action on trigger management: https://www.mastcellaction.org/assets/_/2023/06/26/6fb5eefc-26e1-40a8-a724-0ea2d7310952/mcas-self-management-toolkit.pdf?v=1

Types of MCAS Triggers. (graphic from www.tmsforacure.org, “The Mastocytosis Chronicles” 2020-21 edition)



- **Stress, fear, anger and excitement.** Stress and other strong emotions cause the nervous system to release histamine, which makes sensory nerves (including those that process pain) even more sensitive. (www.mastzellaktivierung.info) Stress management strategies can calm both the nervous and immune systems, decreasing both pain and MCAS symptoms. Active relaxation using strategies such as mindfulness meditation, slow breathing, yoga breathing, etc. can decrease inflammation. Distraction, such as reading or playing video games does not have the same effect. If you are not already using an active relaxation strategy at least 10 minutes/day every day, consider starting. Admittedly, this takes time and effort, but you are almost guaranteed some benefit.
- **Food.** Many people with MCAS react to a wide range of foods. Common sensitivities include histamine, gluten and lactose, but each person is different, and your sensitivities may change over time.
 - https://www.mastzellaktivierung.info/downloads/foodlist/21_FoodList_EN_alphabetic_withCateg.pdf probably has the most comprehensive list of foods that are well/not well tolerated, with comments about things like how freshness and other characteristics affect tolerance (e.g., green bananas are better than ripe bananas). The web site even has a cookbook for people with MCAS. The list can be downloaded at https://www.mastzellaktivierung.info/downloads/foodlist/21_FoodList_EN_alphabetic_withCateg.pdf

- A helpful app: [*Food Intolerances: Histamine, FODMAPs & IBS Guide*](#). It has a strawberry logo.
- Some foods don't contain histamine, but cause histamine to be released in your gut. Also avoid these for a low-histamine diet.
- Note that histamine levels in food can change based on how fresh or ripe the food is, so it can be variable.
- Some people don't have enough of the enzyme that normally breaks down histamine in the gut: diamine oxidase (DAO). For some people, this is a genetic deficiency. Also, some medications inhibit DAO. There is a blood test for DAO, and DAO supplements are available over-the-counter. (Comas-Baste, 2020)
- People with significant GI symptoms may also benefit from a FODMAP diet. See Monash University website: <https://www.monashfodmap.com/about-fodmap-and-ibs/high-and-low-fodmap-foods/>
- **Alcohol.** All alcohol can irritate MCAS, but red wine and beer are often worst. Amazon sells enzymes that may help.
- **Medications:** Some medications aggravate MCAS symptoms. Always talk to your medical provider before discontinuing any prescription medication. Common medications that trigger MCAS include opioids, antibiotics, NSAIDs, and alcohol-containing medications, some local anesthetics, and contrast dyes for imaging tests. People with MCAS can react to the 'inactive' ingredients in medications, so the brand or formulation can make a difference. You can look up inactive ingredients in medications at <https://dailymed.nlm.nih.gov/dailymed/>. In general, dyes (red>yellow>blue) and alcohols tend to cause reactions, but each person is different. Different dose pills may have different inert ingredients: for example, switching from one 50mg dose to two 25 mg might help. Schofield, 2019 gives several helpful case examples.
- **Environmental stresses.** The best solution is to avoid or minimize any you are sensitive to. Air purifiers may also help.
 - **Odors, fragrances, chemicals** such as detergents and soaps.
 - **Environmental allergens** such as pollens, molds, animal dander, etc.
 - **Temperature/weather:** Heat, cold, sudden temperature changes, sunlight, and pressure changes (e.g. storm blowing through). Controlling your environment can help.
 - **Sound:** Loud noises, low or high wavelength noises, electricity.
- **Venoms** (biting insects, jelly fish, etc.). Avoid as much as possible. Carry an epi pen if you have anaphylactic response. If you just have a local response, try topicals such as Benadryl or cortisone ointments, or use ice-packs.
- **Exercise:** Excessive exercise can cause a flare, especially in hot weather. However, lack of exercise is a significant risk factor for chronic pain and may aggravate common comorbidities such as Hypermobility Spectrum Disorder or Postural Orthostatic Tachycardia Syndrome. So, try to exercise moderately rather than avoiding exercise entirely.
- **Fatigue.** Improve your sleep and pace yourself to manage fatigue. If you are not familiar with 'sleep hygiene' principles, check <https://www.sleepfoundation.org> or download free app CBT-I. A good presentation of managing fatigue with EDS is at <https://www.ehlers-danlos.com/wp-content/uploads/Parry-Practical-Pacing-and-Fatigue-Management-5.pdf>
- **Mechanical irritation,** friction, rubbing of clothes, watchbands, etc. If you are sensitive to these, try to minimize them.
- **Hormones:** Mast cells have estrogen receptors and respond to female monthly cycles. Mast cells are stimulated by estrogen and inhibited by progesterone. If this is a significant contributor for you, talk to your MD.
- **Supplements** may help reduce mast cell activity or sensitivity to mast cell mediators. Research shows some benefit from the following: (Uranga, 2020)
 - **Vitamin C** may be a mast cell stabilizer and may help break down histamine
 - Flavonoids: **quercetin**, flavone, luteolin, fisetin, rutin, kaempferol, myricetin, caffeic acid, nobiletin or morin
 - **Vitamin D**, vitamin E, carotenoids
 - Cannabidiol, palmithoethylethanolamide (PEA)
 - Omega-3 fatty acids (e.g. fish oil)
 - Green tea, Curcumin, Cinnamon extract
- Web site with suggestions for natural (non-prescription) care of MCAS: <https://hoffmancentre.com/natural-treatments-for-mcas/>
- People with dietary histamine intolerance may also benefit from diamine oxidase (DAO) supplements. (Comas-Baste, 2020)
- Reliable list of medication options: <https://tmsforacure.org/treatments/medications-treat-mast-cell-diseases/>
- Some people make a home-made cromolyn cream for topical use (cromolyn is likely absorbed systemically, as well): <http://www.mastokids.org/magic-masto-lotion/?fbclid=IwAR0oupiqall-wWMswkzTIQvqbm9xIULB3wF7fhHjXSNi7CscX8P0V1cD1yM>

Unless otherwise noted, information comes from the following sources:

- www.tmsforacure.org. "The Mastocytosis Chronicles" for 2020-21, Guideline for clinicians at <https://tmsforacure.org/physicianresources/>. Also www.maztzellaktivierung.info

Additional References:

- Comas-Basté O, Sánchez-Pérez S, Veciana-Nogués MT, Latorre-Moratalla M, Vidal-Carou MDC. Histamine Intolerance: The Current State of the Art. *Biomolecules*. Aug 14 2020;10(8)
- Uranga JA, Martínez V, Abalo R. Mast Cell Regulation and Irritable Bowel Syndrome: Effects of Food Components with Potential Nutraceutical Use. *Molecules*. Sep 20 2020;25(18)
- An excellent emergency MCAS guide: <https://tmsforacure.org/wp-content/uploads/2016-TMS-ER-Protocol-Pages-2.pdf>
- Schofield JR, Afrin LB. Recognition and Management of Medication Excipient Reactivity in Patients With Mast Cell Activation Syndrome. *Am J Med Sci*. 2019;357(6):507-11.

Good books:

- **Lawrence Afrin, MD:** *Never Bet Against Occam: Mast Cell Activation Disease and the Modern Epidemics of Chronic Illness and Medical Complexity*
- **Amber Walker, PT:** *Mast Cells United: A Holistic Approach to Mast Cell Activation Syndrome*. Also: *The Trifecta Passport*