

Mast Cell Activation Syndrome (MCAS): A Patient's Guide

What is MCAS?

MCAS is a condition where your mast cells (a type of immune cell) become overactive, leading to various symptoms that can affect multiple parts of your body.

Common Symptoms

- Skin issues (rashes, itching).
- Respiratory problems (frequent sinusitis, hay fever-like symptoms).
- Gastrointestinal issues (food sensitivities, gut pain, heartburn, nausea, vomiting, diarrhea).
- Other symptoms may include headaches, fatigue, and mild cognitive problems.

Diagnosis

Diagnosing MCAS can be challenging. Your doctor may diagnose an “MCAS-like” condition based on your symptoms and response to treatment, even without formal testing.

Treatment Trial

Your doctor may suggest a treatment trial using a combination of two types of antihistamine medications:

- One H1 Blocker (available over-the-counter):
Choose ONE of the following, to be taken twice daily at twice the standard dose:
 - Fexofenadine: 360mg
 - Cetirizine: 20mg
 - Levocetirizine: 10mg
 - Loratadine: 20mg
 - Desloratadine: 10mg

PLUS

- One H2 Blocker (usually requires a prescription):
Choose ONE of the following, to be taken twice daily:
 - Famotidine: 40mg
 - Nizatidine: 300mg

You'll try one medication from each category at the same time for 1–2 weeks.

What to Expect

- Initial Response: After starting the treatment, observe how your symptoms change over 1–2 weeks.
- If Very Effective:
 - For the over-the-counter H1 Blocker: You may gradually reduce the dose to find the lowest amount that still manages your symptoms effectively.
 - For the prescription H2 Blocker: Consult with your doctor before making any changes.
- If Partially Effective:
 - For the H1 Blocker: You might try switching to a different option from the list to see if one works better for you.
 - For the H2 Blocker: Discuss with your doctor about possibly trying the other option.
- If Minimally Effective: Your doctor might suggest additional medications or different approaches.
- Ongoing Management:
 - Keep track of your symptoms and how they respond to different medications and doses.
 - You may find that you need to adjust your medication (especially the H1 Blocker) based on symptom flare-ups or improvements.
 - Always inform your doctor about any changes you make to your treatment plan.

Remember, everyone's experience with MCAS is different. Be patient and communicate openly with your healthcare team about your symptoms and response to treatment. While you have some flexibility with the over-the-counter medication, always consult your doctor before making significant changes to your treatment plan, especially with prescription medications.