

MCAS & hEDS: When Your Immune System Overreacts

Understanding the Connection Between Mast Cells and Connective Tissue Disorders

If you live with **hypermobile Ehlers-Danlos Syndrome (hEDS)** and often feel like your body is overreacting to the world around you — from foods, scents, or stress to seemingly nothing at all — you're not alone. Many people with hEDS experience **Mast Cell Activation Syndrome (MCAS)**, a condition where **immune cells called mast cells become hypersensitive** and release chemicals that cause widespread symptoms.

While MCAS is still a developing field of study, it may be one of the **missing links** behind many unexplained hEDS symptoms. Here's what we know so far.

What is MCAS?

Mast cells are immune cells that live in your skin, gut, lungs, brain, and connective tissue. They help fight infection, heal wounds, and signal the immune system. But in MCAS, **these cells release their chemical contents (like histamine, prostaglandins, and cytokines) too often or too easily**, leading to inflammation and irritation in multiple systems.

Why Does This Happen in hEDS?

People with hEDS often have fragile or dysfunctional **extracellular matrix (ECM)** tissue. Since mast cells live in the ECM, any dysfunction in this environment can:

- Make mast cells more reactive
- Impair their ability to settle back down after activation
- Increase their sensitivity to pressure, friction, hormones, and allergens

Research also suggests that **hormonal cycles, stress hormones, chronic infections, and gut dysbiosis** can worsen mast cell behaviour in hEDS.

What Might It Feel Like?

MCAS symptoms vary from person to person, but common patterns include:

- Flushing, itching, hives, or rashes
- Gastrointestinal issues (nausea, diarrhoea, bloating)
- Air hunger, chest tightness, or wheezing
- Headaches, brain fog, or temperature swings
- Food or drug sensitivities
- Feeling "wired but tired," anxious, or overstimulated



These symptoms may come in waves or flare with:

- Heat or cold
- Friction or pressure on the skin
- Menstrual cycles
- Emotional stress or illness
- Chemical or food triggers

How Do I Know If It's MCAS?

MCAS is a diagnosis of exclusion and can be hard to confirm. Many people go years without proper recognition. There is no single test, but diagnosis usually involves:

- Symptom pattern tracking
- Trying mast cell stabilisers or antihistamines
- Ruling out allergy and other immune conditions
- Lab tests (like tryptase, chromogranin A, or prostaglandin metabolites) during flares

A knowledgeable immunologist, GP, or integrative specialist can help investigate further.

What Helps?

Symptom Management

- **H1 blockers:** Cetirizine, loratadine
- **H2 blockers:** Famotidine, ranitidine
- **Mast cell stabilisers:** Cromolyn, ketotifen (if available)
- **Natural support:** Quercetin, vitamin C, DAO enzymes
- **Anti-inflammatory care:** Gentle diet, low histamine cooking, stress regulation

Lifestyle Tips

- Keep a **trigger diary**
- Rest during flares
- Use **loose, soft clothing**
- Avoid skin friction, extremes of temperature
- Talk with your doctor before making changes to your care



How ConnectED Can Help

The **ConnectED App** allows you to:

- Track flare patterns, triggers, and exposures
- Log responses to medications or environmental changes
- Build a report to take to your clinician

What Science is Telling Us

Although MCAS is still emerging, recent research suggests:

- Mast cells interact directly with **nerve and fascia cells** in the ECM
- They are sensitive to **mechanical pressure, hormones, and inflammation**
- MCAS may be more common in people with **connective tissue disorders and neurodivergent traits**

This is early-stage science, and more research is needed. But patient experience has led the way.

This page is for education only and is not a substitute for medical care. Please speak with your healthcare provider for individual advice.

About the Author

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Tracy is an intensive care nurse and systems thinker with lived experience of hypermobile Ehlers-Danlos syndrome (hEDS), dysautonomia, and mast cell activation. She is the founder of **ConnectED Health**, an initiative combining clinical research, patient insight, and AI technology to improve diagnosis and care for complex, multisystemic conditions. Tracy works collaboratively with researchers and clinicians to bridge the gap between emerging science and real-world patient care.