

MCAS & Me:

A Quick Guide to Mast Cell Activation Syndrome for Loved Ones

What is MCAS?

Mast Cell Activation Syndrome (MCAS) is a condition which can develop in children or adults. Mast cells are a type of blood cell found in all parts of the body. They are a key part of the immune system and help defend against things like infections or allergens.

In a healthy state, mast cells release chemicals (like histamine) when they detect something harmful, such as an allergen. This helps the body to react and protect itself. In MCAS, mast cells become overactive. They release too many chemicals even when there's no real danger.

Symptoms

MCAS causes a wide range of symptoms that affect multiple parts of the body. These might include itching, hives, stomach pain, headaches, or trouble breathing. The symptoms can vary a lot from person to person and are sometimes mistaken for other conditions.

During an MCAS reaction, your loved one may experience mental health symptoms, such as anxiety, anger, depression or a sense of 'impending doom'. This is because the chemicals released by mast cells can affect the brain and nervous system.

Nasal-ocular

- Nose congestion
- Eye watering and itching

Respiratory

- Sore throat
- Hoarseness
- Wheezing
- Shortness of breath
- Throat swelling

Cardiovascular

- Chest pain
- Low blood pressure
- Fast heart rate
- Fainting or light-headedness

Genital and urinary

- Genital pain or swelling
- Pain when urinating
- Vaginal pain, discharge or itching
- Bladder urgency or loss of control

Dermographic

- Flushing/redness
- Hives or wheals
- Itching with or without a rash
- Swelling

Neurological

- Headache
- Brain fog (memory and concentration difficulties)
- Numbness, pain or tingling skin
- Anxiety
- Mood changes, irritability

Musculoskeletal

- Joint & muscle pain
- Osteoporosis (brittle bones)
- Loss of bone mass

Gastrointestinal

- Bloating
- Stomach cramps or pain
- Reflux
- Feeling or being sick
- Diarrhoea
- Constipation
- Dumping syndrome
- Food allergies or intolerance

General

- Extreme tiredness
- Anaphylaxis, which can be life threatening



What are Mast Cell Triggers?

Triggers and symptoms of MCAS vary greatly between individuals, and change over time. Triggers can include fragrances, chemicals, exercise, infections, mould, stress and changes in temperature.

Common triggers include:



Temperature changes



Exercise/ exertion



Stress/anxiety



Specific foods/drinks



Medications



Fragrances



Other 'typical' allergens

Most people affected by MCAS struggle to identify all of their triggers and each person has a unique set of triggers that cause their mast cells to overreact.

Symptoms may worsen after infections, surgeries, or significant stress.

Management and Treatment

The aim of treatment is to manage symptoms through lifestyle, medication and supplements.

Prescription medications may be prescribed such as anti-histamines, mast cell stabilisers, leukotriene inhibitors and others.

If your loved one experiences anaphylaxis as part of their reactions, an epi-pen may be required.

Natural supplements and dietary changes can help and people often explore these with a Nutritional Therapist or a Dietician experienced in MCAS.

It is important to identify and eliminate any underlying infections which may be driving mast cell activity.

Living with MCAS

Living with MCAS involves more than managing the physical symptoms; it also impacts upon emotional and social wellbeing.

Emotionally, your loved-one may feel overwhelmed, trying to manage a complex condition without much guidance. They may feel anxious about avoiding triggers and isolated, especially when symptoms are invisible or dismissed. They may grieve a loss of their former identity.

Socially, they may feel burdened by strict routines such as special diets and medication schedules. They may need more help and support from others which can feel like a loss of independence and prompt feelings of guilt and frustration.

However, it is important to recognise that people with MCAS and their loved ones can lead happy and fulfilled lives. Symptoms can fluctuate and improve with time and careful management.



How to support your loved one



Provide Emotional Support



Allow your loved one to express their feelings and frustrations. Listen without judgement and validate their experiences. Try to be a stable and grounding presence for them.



Encourage your loved one to connect with others who have MCAS. Online communities and peer support services can be a valuable source of comfort and information.



Ensure a safe environment



Eliminate triggers: Use safe products, keep the home well-ventilated, avoid mould, and avoid using strong fragrances or cleaning chemicals or toiletries.



Support with diet: Plan healthy meals that avoid potential triggers and help your loved one to identify and avoid foods they need to eliminate in their diet.



Help your loved one manage stress through activities which bring joy and relaxation. This might include light exercise, hobbies, mindfulness meditation and spending time with family and friends.



MCAS can cause fatigue, where people have less energy to 'spend'. This is often referred to as the 'Spoon Theory'. Your loved-one may need help with household chores, shopping, collecting prescriptions, or personal care when they are on flare days. Over-exertion can lead to a crash afterwards, and they should pace.



Provide Support at Medical Appointments



Keep a Symptom Diary: Help your loved one to track symptoms, triggers and reactions. This will allow healthcare providers to tailor their treatment plans more effectively.



Ask healthcare providers about treatment options, potential side effects, and any concerns you may have.



Learn about MCAS and take time to understand your loved one's specific triggers and symptoms.



Support your loved-one to advocate for themselves, and speak for them if they need you to.



Be Prepared for Emergencies



Ensure that emergency medications, such as antihistamines or epinephrine injectors, are always easily accessible. Ensure you and your loved one know how to use them and when to seek medical help.



Keep a list of emergency contacts, including healthcare providers, on hand. Make sure you know the quickest route to the nearest medical facility.

Scan this QR code to find out more about the Spoon Theory

