Mast Cell Activation Syndrome (MCAS)

MAST CELL ACTION

Understanding MCAS & How It Presents in Assessments

What is MCAS?

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

These chemicals can affect many different organs and systems and cause 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.

Symptoms can vary a lot from person to person and are often mistaken for other conditions. They also fluctuate significantly, even day-to-day or hour-to-hour, which makes MCAS a hidden and unpredictable disability.

Symptoms

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
- Behavioural issues, rages

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, exercise, stress and changes in temperature. 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.

Common triggers include:

- **Temperature changes**
- **Medications**
- **Stress/anxiety**
- **Exercise/ exertion**
- **Fragrances**
- **Specific foods/drinks**
- **Other 'typical' allergens**

Impact on Daily Living

Daily life with MCAS can be profoundly disrupted. People may struggle with mobility because dizziness, pain or weakness limit their ability to walk, stand or sit upright for long periods. Eating and preparing food can be challenging due to multiple food intolerances or reactions to smells and cooking fumes.

Personal care tasks such as bathing, dressing or washing hair may trigger symptoms. Cognitive symptoms, including brain fog can affect communication, concentration and the ability to manage typically straightforward tasks such as planning, remembering information or completing forms.

Fatigue and pain can be overwhelming, leaving people unable to complete everyday tasks and often requiring long periods of rest after even small amounts of activity.

Flares can be unpredictable, and even mild exertion can lead to multi-day crashes. Some people experience significant instability, fainting episodes or sudden drops in blood pressure. Others must avoid many public spaces or social situations because of chemical or fragrance exposure.

This often leads to isolation and difficulties maintaining employment, education, childcare responsibilities or independent living.

People may appear outwardly well during short periods of relative stability, yet experience significant deterioration immediately after or later in the day.

MCAS is difficult to assess because symptoms are fluctuating, often invisible and vary widely between individuals. Medical evidence is frequently fragmented, as symptoms span many specialties and tests may not capture the full picture.

Many people also live with comorbid conditions such as POTS, Ehlers-Danlos Syndrome, or ME/CFS, which interact with MCAS and complicate presentation.

Assessment environments themselves - due to fragrances, cleaning products, or temperature - can trigger reactions, making people appear more anxious or unwell than usual. Brain fog, fatigue or distress during flares can affect communication, meaning individuals may struggle to explain their needs clearly without support.

Support often needed

People with MCAS often need support to manage their symptoms safely, including help recognising when symptoms are escalating and taking appropriate steps to prevent a flare.

Many rely on assistance to maintain a low-trigger environment at home, as tasks such as cleaning, changing bedding or doing laundry can expose them to fragrances or chemicals that provoke reactions.

Practical help with daily living is frequently required, including preparing safe meals, supporting eating and drinking, and assisting with dressing or undressing when fatigue, dizziness or pain limit independence.

Some people need support with personal care, managing medications and/or attending appointments, particularly when symptoms make communication or travel difficult.

In more severe cases, individuals may require emergency support if a sudden escalation of symptoms leads to breathing difficulties, fainting or other acute reactions.

It is important to recognise that even when a person can attempt these activities on a good day, they may not be able to complete them safely, reliably or consistently, and often experience significant deterioration afterwards.

Best Practice for Assessors and Support Needed

Assessors can support people with MCAS by ensuring the environment is as low-trigger for them as possible. This may include avoiding fragrances, aerosols or strong cleaning products before the appointment, and allowing for good ventilation or alternative settings when necessary.

It may be safer for people with MCAS to have an online assessment.

Stress is a common MCAS trigger, so assessments themselves can lead to sudden symptom escalation for some.

Asking about variability, triggers and recovery time is essential, as the ability to complete a task once does not mean it can be done safely, reliably or repeatedly. Understanding how long it takes for someone to recover after everyday activities provides a more accurate picture of their functional capacity.

Lived-experience evidence is an important part of assessment for MCAS. Many people keep diaries of symptoms, triggers or crashes. These can be more representative of daily life than isolated clinical appointments.

People may also require extra time to communicate, breaks during the assessment, or the option to have a carer present.

Some individuals need to change position frequently, lie down, or pause if symptoms escalate. If symptoms are severe, they may need to resume the assessment on a future date. A flexible and patient approach helps ensure an accurate and safe assessment.

For many people with MCAS, the key challenges relate to predictability, safety and sustainability of daily tasks. Someone may manage an activity on a good day but be unable to repeat it consistently or without triggering a flare that causes deterioration.

Reasonable adjustments such as remote or paper-based assessments, the option to delay if unwell, or ensuring assessors receive consistent training on fluctuating and hidden conditions can make a significant difference.

Recognising the legitimacy of symptoms, valuing lived experience and avoiding assumptions based on appearance are essential for a fair assessment.

For further guidance and resources see the Mast Cell Action website (www.mastcellaction.org).