

Mast Cell Activation Syndrome (MCAS) for employers

What is Mast Cell Activation Syndrome?

Mast Cell Activation Syndrome (MCAS) is a condition which can develop in children or adults. Mast cells are part of the immune system and play a crucial role in defending the body against infections and other harmful substances. In people affected by MCAS, chemicals called mediators are released by their mast cells too frequently or abundantly, and/or in response to triggers that are not typically considered to be harmful, for example; foods or chemicals in the environment. This can lead to a wide range of symptoms that affect multiple parts of the body.

In MCAS, mast cells can be triggered by a wide range of stimuli, such as stress, food, medications, environmental factors, and even changes in temperature or humidity. This can cause a variety of symptoms, such as flushing, hives, swelling, abdominal pain, diarrhoea, headaches, and difficulty breathing. Symptoms can be mild or severe and vary from person to person.

You can find out more and download our free resources at mastcellaction.org



How does MCAS impact people at work?

People affected by MCAS may experience difficulties in performing their work duties due to the unpredictable nature of their symptoms. For example, an employee may experience a flare-up of symptoms during a meeting or presentation, leading to decreased productivity or the need for time off work.

It is important for HR to understand MCAS and work with employees to make reasonable accommodations to ensure they can effectively perform their job duties. This may include flexible work arrangements, modified work schedules, or workplace adjustments to reduce exposure to triggers. Additionally, HR should be aware of any potential discrimination or harassment against employees with MCAS and ensure they are provided with appropriate support and resources.

As an HR department, it is important to understand how to support an employee with Mast Cell Activation Syndrome (MCAS). MCAS is a condition that can be considered a disability under the Equality Act 2010, and employers have a legal duty to make reasonable adjustments to accommodate employees with disabilities. Reasonable adjustments could include changes to the work environment, working arrangements, finding different ways to do something, and providing equipment, services, or support.



Identifying an individual's needs

Identifying an employee's needs is the first step in supporting them. This can help when considering adjustments during a job application, as well as when requesting adjustments for employees in the workplace. Adjustments that could be helpful for MCAS include reducing exposure to triggers like strong scents or chemicals, flexible working to accommodate medical appointments or times when the employee may be experiencing symptoms, a slower working pace, and additional support from colleagues or management.

You could provide the table below to help employees to organise their thoughts and prepare for a conversation with HR about reasonable adjustments that can be made to support them in the workplace.

Employees may wish to complete this for each symptom/issue to enable you to gain a more complete understanding of their individual needs.

Symptom/issue e.g. Headache, nausea, rashes, vertigo, difficulty breathing, asthma attack, etc.	
Known triggers e.g. Fragrances / scents	
How it can affect aspects of the role	
What reasonable adjustments could be considered?	

Reasonable adjustments

Reasonable adjustments can help to reduce the individual's exposure to triggers, provide support for the symptoms they experience and help them to be able to perform their work duties more successfully. Even simple measures can make a significant difference for someone living with MCAS.

Every individual with MCAS experiences different triggers and symptoms, so support will be unique for each person. However, reasonable adjustments that may be helpful for people with MCAS could include:

Fragrance

Requesting that scent-free cleaning products are used in the areas they work in, asking colleagues to kindly avoid spraying fragrance, removing any scented candles, reed diffusers, or air fresheners in the space, removing scented hand wash and air fresheners from the work toilet, the option to work in a safer space within the office, and provision of an air purifier with an Ultra Hepa filter in the communal working space.

Lighting

Lower lighting environments without fluorescent lights and with warmer uplighters, if light sensitivity is an issue.

Flexible working

Flexible working to accommodate medical appointments or times when the employee may be experiencing flares of symptoms, leaving early or starting late, time off for appointments that doesn't need to be made up elsewhere, compressed hours, working from home during the summer months to avoid going outside, hybrid or remote working, phased return to work after an absence, and reduction in contractual hours.

Pacing

A slower working pace, flexibility around targets and deadlines, adapting the role to reduce mental or physical task demand, distributing the workload differently across a team, providing virtual training rather than in-person, avoidance of heavy lifting or strenuous activity like high-intensity exercise that can increase histamine, work instructions being given in writing rather than just verbally, giving someone more time to complete a test during a job interview and providing a written copy of interview questions during a job interview.

Reasonable adjustments

Equipment, services, or support

Assistive technology, such as voice-to-text software to reduce the use of a keyboard for those with joint pain in hands and wrists, screen reading software for those with visual impairments such as blurred vision, reminder systems to reduce the impact of any difficulty with memory, note-taking systems to support processing large amounts of information provided in meetings, blue, amber, and red light blocking glasses, noise-cancelling headphones to help with noise sensitivity, provision of an emergency buzzer for further support from colleagues, access to medical facilities, such as a private space to administer medication or rest if needed, a shelf or cupboard with all emergency medications along with a plan for administering medications and who will be responsible if the employee is unable to do so, a room free from all known triggers with an UltraHepa Air Purifier for the employee to use, a comfortable space to lie down, support from colleagues or management; such as providing assistance during a reaction, sharing the workloads, and being flexible at the last minute if a reaction does occur or allowing the employee to work from home.



Reasonable adjustments

Communication

MCAS is a medical condition that affects individuals in different ways. To support an employee with MCAS, it is essential to communicate their needs to the HR department or their line manager as soon as possible. The employee may use different ways to communicate their needs, such as using our templates or requesting a meeting with the HR department or line manager to discuss their needs. Providing a letter from their healthcare provider outlining their diagnosis, symptoms, and recommended accommodations can help support their request.

Employers have a duty to provide reasonable adjustments to support employees with health conditions promptly. It is important to keep a record of what was discussed and when, follow up each conversation with an email, and ask those involved to confirm they agree with the points covered.

If, as an employer, you refuse an employee's request, you must explain why you feel it is unreasonable and work with the employee to understand what other adjustments could support them. You may consider suggesting alternative adjustments that the employee has not considered before.

The employee should document their progress and any issues that arise. They may need to share some of their adjustments with their colleagues, and it is important to raise this in a team meeting, in 1:1 catch-ups, via email, or through their manager where appropriate. If there are any changes to their health before the next review, there should be a plan in place of how these should be raised with their line manager and how this will be managed, especially if any additional adaptations are needed.

Ben spoke to his employer about MCAS and his need for reasonable adjustments at work. His symptoms were headaches, fatigue and nausea. His line manager helped him to implement a fragrance-free policy in the office, Ben is now thriving in his role and has recently been promoted!

Top tip for supporting someone with MCAS

Be understanding and empathetic: Understand that people with MCAS may have good days and bad days, and their symptoms may vary. Be empathetic to their situation, and provide support as needed.

Provide a safe environment: Ensure that the work space and work environment is safe for people living with MCAS. This can include avoiding the use of scented products or cleaning agents that can trigger symptoms.

Be aware of triggers: Be aware of the triggers that can cause symptoms in an individual with MCAS, such as certain foods, chemicals, or environmental factors. If you notice that they are experiencing symptoms, check if they have been exposed to any of their triggers.

Be flexible: Be flexible with work including and provide extra breaks if needed. This can help reduce stress and allow the individual to manage their symptoms better.

Recognise uniqueness: Understand that each person with MCAS experiences a unique set of symptoms and triggers and there is no 'one size fits all' approach.





Further support

If you have found the information in this pack to be useful and would like to access further information, support and resources, please visit:

mastcellaction.org

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Make your legacy a lifeline for people with MCAS, leave a gift in your will to Mast Cell Action.



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