

# What is MCAS?

## Information for Disability Officers & Needs Assessors

Mast Cell Activation Syndrome (MCAS) is a type of immune system disorder where mast cells, a type of white blood cells, are overactive and release an excessive amount of chemicals called mediators into the body, causing a range of symptoms such as:

### Nasal-ocular (nose and eyes)

- Nose congestion
- Eye watering and itching

### Respiratory (lungs & breathing)

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

### Musculoskeletal

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

### Genital and urinary

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

### Dermographic (skin)

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

### General

- Extreme tiredness
- Anaphylaxis, which can be life threatening



### Neurologic (brain and nerves)

- Headache
- Brain fog (memory and concentration difficulties)
- Numbness, pain or tingling skin
- Anxiety
- Behavioural issues, rages

### Cardiovascular

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

### Gastrointestinal (digestive system)

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

These symptoms can be triggered by various factors including stress, exercise, certain foods, medications, and environmental factors.

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MCAS is a fluctuating condition which can be managed through lifestyle changes, medications (including anti-histamines and mast cell stabilisers) and avoidance of triggers.

However, since the range of potential triggers is extremely wide it can be difficult to completely avoid them.

As a result, students' performance is likely to vary over the course of their studies. They may need support regarding coping with absences from classes; applying for extensions and deferrals; and managing their workload. Institutional support such as lecture capture technology and flexible attendance policies can be helpful in enabling students to maintain their studies during a flare. Where a student is aware of specific triggers for their MCAS they may need support in avoiding those or in setting up reasonable adjustments such as fragrance-free spaces.

MCAS is a condition that can be considered a disability under the Equality Act 2010, and universities have a legal duty to make reasonable adjustments to accommodate students with disabilities. Reasonable adjustments can include changes to the environment, assessment arrangements, and providing equipment, services, or support.

### Common MCAS triggers:

<b>Temperature changes</b>		<b>Fragrances</b>		<b>Stress/ anxiety</b>	
<b>Exercise/ exertion</b>		<b>Specific foods/drinks</b>		<b>Other 'typical' allergens</b>	
<b>Medications</b>					

## Impacts of MCAS in HE

Common impacts of MCAS that are particularly relevant to HE include:

- Reactions to a wide range of triggers including chemicals and foodstuffs (these can be, but are not always, anaphylactic reactions). Cleaning products, fragrances/air fresheners etc used on campus may act as a trigger and first aiders may need to be aware of the potential for anaphylaxis;
- Brain fog, fatigue and variable performance during a flare of the condition which can affect attendance and exams/assessments;
- Pain, numbness & tingling which can impact attendance, fatigue levels etc;
- Dietary restrictions and gastrointestinal & urinary symptoms that may impact attendance/result in a need to access to toilets more frequently;
- Fainting & dizziness, so first aiders need to be aware;
- Anxiety.

## DSA & Medical Evidence issues

MCAS is a difficult condition to diagnose because the tests available in the UK are currently unreliable and limited, as well as difficult to access, even privately. Getting an NHS diagnosis can be an uphill struggle and take a long time. Most adult MCAS patients are identified decades after they first experience symptoms. Often MCAS patients acquire other diagnoses along the way, and MCAS is often co-occurring with conditions such as POTS, EDS, IBS, allergies and mental health diagnoses.

As a result, meeting the DSA requirement for medical evidence for MCAS can be challenging. However, if students have other diagnoses, then medical evidence about those may support applications for DSA and access arrangements for exams.



## **Access arrangements & reasonable adjustments to consider:**

### **Exams and assessments**

- Taking an exam in a separate room (so that fragrances etc worn by other candidates don't impact the student)
- Rest breaks (if fatigue is an issue or if frequent toilet visits are needed)
- Environmental conditions (windows open/closed; limiting cleaning in the room prior to the exam)
- Invigilation arrangements (such as requesting that invigilators don't wear fragrances)

### **Support on campus**

- Lectures: lecture capture can be helpful if the student is unable to attend a lecture e.g. due to a flare or a reaction.
- Labs/Studios/Practicals: Practical classes that take place outside of lecture theatres can pose additional challenges when you have MCAS. For example, there are likely to be many different chemicals and cleaning agents used in laboratories, art studios and IT labs. Students may need environmental adjustments.
- Fluctuations in the condition: Attendance may be impacted by flares of MCAS or by fatigue. Liaising with faculty staff and making arrangements for temporary remote study may be needed.
- Lifts & lockers: these may be useful if the student experiences fatigue and/or pain or if they need to carry lots of equipment e.g., in practical subjects.
- First Aid and/Security teams may need to be made aware if the student experiences anaphylaxis.

### **Accommodation & travel to campus**

Location: halls of residence close to campus or on campus can minimise walking distances to lectures. A referral for accessible accommodation may be needed e.g. a studio flat or en suite room to minimise exposure to triggers.

### **Support on placements/field trips/visits**

Some workplaces will pose additional challenges regarding exposure to triggers and fatigue. Support for the student to discuss their needs with the placement employer would be helpful. Any off-campus activities may need additional risk assessments.

## The Boom and Bust Theory

The Boom and Bust Theory is a concept that can help adults living with Mast Cell Activation Syndrome (MCAS) to understand and manage their energy levels. It is based on the idea that when people with chronic illness have periods of high activity or stress, or 'over-do it', they experience a "boom" of activities. However, this boom is often followed by a "bust," where the body becomes exhausted and symptoms may worsen.

To manage the boom and bust cycle, adults with MCAS should aim to balance their activities and energy levels and avoid overexerting themselves during periods of high stress or activity. This can involve planning ahead, prioritising tasks, and pacing themselves throughout the day to avoid becoming overwhelmed.

This is particularly relevant at university where, particularly in the first weeks, the pace of social activities, attending lectures and classes, getting used to living alone and finding out about a new area can be incredibly exciting, but also tiring! It's also important in the run-up to exams or assessments – staying up all night to meet a deadline or revise for tomorrow's exam may have significant impacts on your health. Pacing your workload over a longer period of time and taking time to rest as you go are good tips to follow.

In addition, adults with MCAS can also focus on building their resilience and improving their overall health and well-being. This can involve practising self-care activities such as getting enough sleep, eating a healthy diet, and engaging in stress-reducing activities such as meditation or yoga. Check out what your university offers in these areas – as well as sports societies and the gym many universities have wellbeing programmes where you can learn mindfulness meditation and other relaxation approaches.

**Overall, by understanding and managing the boom and bust cycle, adults with MCAS can improve their quality of life and reduce the impact of symptoms on their daily activities.**

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**For more information and additional resources, please visit [mastcellaction.org](https://mastcellaction.org)**