

What the Results Mean

No single mast cell mediator test is definitive; a positive result is not to say that a person certainly has MCAS, as high levels could be attributed to other causes and, similarly, a negative result is not sufficient to rule out an MCAS diagnosis. However, when considered alongside other diagnostic evidence, these mediator tests can provide reasonable confidence in a diagnosis.

Other diagnostic evidence can include:

- Clinical symptoms of MCAS across multiple body systems.
- A positive response to treatments for MCAS.
- Ruling out of other diagnoses.

Multiple tests are often conducted; ideally, two abnormal biochemical values are required to diagnose MCAS.



MAST CELL
ACTION

Mast Cell Action is a UK-based charity supporting people affected by Mast Cell Disease. We are founded and run by people who have MCAS or care for someone with MCAS, so we know exactly how it feels!

The Mast Cell Action website offers support, information and resources, as well as sharing details of events within the MCAS community, such as our weekly virtual Zoom sessions.

You can also reach out for support by email or joining our Facebook community support groups.



mastcellaction.org



info@mastcellaction.org

With thanks to Nina Rogers, Dr Bethan Myers and Dr José Costa for their expertise and contribution to this leaflet.



Testing for MCAS

Diagnosing MCAS requires a systematic, stepwise approach, which means that it can take a considerable amount of time for individuals to receive a formal diagnosis of MCAS.

Key steps in diagnosing MCAS include recognising symptoms, investigating response to treatment, undertaking mediator tests and ruling out other diagnoses.

This leaflet provides information on the 24hr urine tests which can support a diagnosis.



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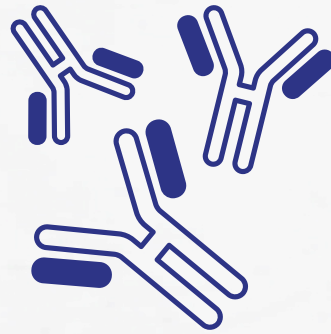
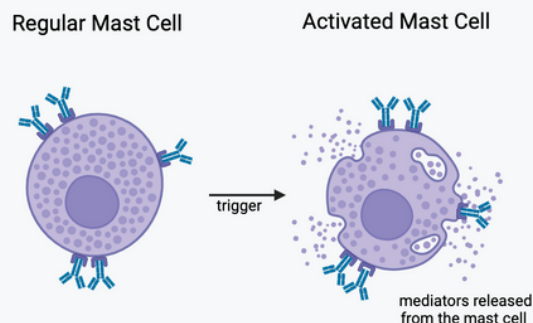
What is MCAS?

Mast Cell Activation Syndrome (MCAS) is a condition which can develop in children or adults. People with MCAS experience a collection of symptoms which affect different body systems. Among others, symptoms can include hives, flushing, nausea/sickness, pruritus, reflux, joint and muscle pain, fatigue and diarrhoea.

High levels of mast cell mediators may be released during MCAS reactions.

MCAS symptoms are unique to each individual, can come and go and may often change over time within the same person. This can make it difficult to identify specific triggers, and the number of triggers and severity of symptoms may continue to increase or change over time.

Further information about the symptoms of MCAS and self-management of MCAS symptoms can be found on our website at mastcellaction.org/mcas-symptoms.



How Can We Test For MCAS?

Mast cell mediators are chemicals released by mast cells. In people affected by MCAS, mast cell mediators are released too frequently or abundantly, and/or in response to triggers that are not typically considered to be harmful, for example; foods, scents or chemicals in the environment.

24-hour urine collection is a way of testing for MCAS. It involves testing for mast cell mediators. Elevated levels of these can be suggestive of MCAS but having normal levels doesn't rule out MCAS and repeated testing may be needed.

The markers which can be tested using a 24-hour urine collection include:

N-Methyl Histamine

Prostaglandins; DM, D2, F2a

Other tests for MCAS include; blood tests and biopsies (from the gut, bladder, skin or bone marrow)

Test Instructions

- Do not collect the first urine sample of the day. For example, go to the toilet as normal.
- Collect the second urination of the day and all urine samples for the next 24 hours. For example: from 08:00AM to 08:00AM the next day.
- Each fresh urine sample must be collected in a separate container and then refrigerated.
- Once chilled, this can then be decanted into the main collection container
- Please label the container with the following: Name, DOB, Date of sample, Sex, Date and time of collection.
- Collect every drop you pass during the 24 hours, and finish the collection by passing urine at exactly the same time the next morning. You should add this final specimen to the bottle to complete the collection.
- Urine should be collected in a clean, preservative & acid-free container.
- The container for sample collection should be stored in a cool place.
- Samples must be kept chilled throughout the collection, during storage, and during transport (using ice packs and a cool bag).
- Please return the sample and the request form to the Laboratory.
- If you are on any medication please give the Phlebotomist/ Receptionist/ Laboratory full details when you return your sample.

IMPORTANT NOTICE

For 2 days prior to sample collection you must avoid the following:

Aspirin • Indomethacin • Anti-inflammatories