## Dear Doctor, Could your patient's unexplained gastrointestinal symptoms be caused by Mast Cell Activation Syndrome?

Ruth Slater and Helen Bowes Mast Cell Action, UK

## Objectives

To understand the range of gastrointestinal (GI) symptoms experienced by Mast Cell Activation Syndrome (MCAS) patients, and the tests and investigations for gastric conditions undertaken before MCAS is diagnosed.

To demonstrate the importance of GI-associated MCAS management strategies and highlight the role of gastroenterologists in the MCAS care pathway.

### Background

MCAS is a condition in which mast cells are inappropriately activated by everyday triggers such as food, chemicals, stress, infection and medicines.<sup>1</sup> This leads to a wide range of inflammatory and allergic-type symptoms.

Due to the high presence of mast cells in the GI tract and their regulatory role (Figure 1), GI symptoms are some of the most frequent and chronic manifestations of MCAS.<sup>2</sup>

Thus, individuals with symptoms of MCAS are often referred to a gastroenterologist to undergo investigations and tests for a wide range of gastric conditions, prior to a confirmed or suspected diagnosis of MCAS.

## Methods

An online survey was distributed to patients across the UK with confirmed or suspected MCAS.

The survey asked patients about their GI symptoms, GI-associated tests and investigations undertaken prior to their confirmed or suspected MCAS diagnosis, and medical/dietary strategies used to manage their condition.

### Results

A total of 142 patients (112 adults; 30 children) responded to the survey; caregivers completed the survey on behalf of patients <18 years of age (Figure 2).

A gastroenterologist was leading the care of 32 adults (29%) and 13 children (43%) at the time of survey completion.

### Most Common GI Symptoms

The most common GI symptoms experienced by adult MCAS patients included bloating, pain, diarrhoea and nausea. In children, frequently reported GI symptoms included pain, GERD and constipation (Figure 3).





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### Tests and Investigations

Many patients underwent investigations and tests for gastric conditions (Figure 4A). Frequent GI-associated tests included endoscopies, colonoscopies and stool tests (Figure 5).

Commonly diagnosed gastric conditions included IBS, GERD and coeliac disease. These rates were substantially reduced compared to the number of tests and investigations (Figure 4B); this was particularly evident for coeliac disease.

A range of diagnostic tests were used for suspected MCAS (Figure 6).

### Management Strategies

The most frequently reported medical management strategies involved sodium cromoglicate, ranitidine, and proton-pump inhibitors (Figure 7).

Dietary management strategies were reported by the majority of participants (Figure 8). This commonly included low histamine diets and exclusion diets, though in some cases tube feeding was required.

### Conclusions

A broad range of GI symptoms are frequently experienced by patients with MCAS.

Patients often undergo investigations and tests for gastric conditions prior to an MCAS diagnosis, with varying degrees of success.

To achieve an accurate diagnosis of MCAS and suitable medical/dietary support, patients suffering potential GI symptoms of MCAS require improved access to appropriate tests and clinical review; gastroenterologists have an important role in this pathway.

### **Abbreviations**

EDS: Ehlers-Danlos syndromes; FODMAP: fermentable oligo-, di-, mono-saccharides and polyols; GERD: gastroesophageal reflux disease; GI: gastrointestinal; HSD: hypermobility spectrum disorders; IBD: inflammatory bowel disease; IBS: irritable bowel syndrome; IgE: immunoglobulin E; MCAS: Mast Cell Activation Syndrome; NMH: urinary N-methylhistamine; PGs: Prostaglandins; POTs: postural tachycardia syndrome; RAST: radioallergosorbent test; SIBO: small intestinal bacterial overgrowth.

### References

**1.** Valent P, et al. Int Arch Allergy Immunol. 2012;157(3):215-225; **2.** Afrin LB, et al. Annals of Medicine. 2016;48(3):190–201; **3.** Albert-Bayo M, *et al.* Cells. 2019;8(2):135.

### Acknowledgements

We would like to thank the participants in this survey for taking the time to share their experiences. Editorial and Design Support provided by Costello Medical.

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