

What are the symptoms to watch for?

Symptoms are highly unpredictable and vary greatly from patient to patient.

However, the most common symptoms to watch for include:

- ◆ spots or rash on the skin
- ◆ itching, flushing, hives
- ◆ anaphylaxis, wheezing (caused by a specific trigger)
- ◆ idiopathic or atypical anaphylaxis (not caused by a specific trigger)
- ◆ chest pain and/or racing heart
- ◆ gastrointestinal upset including nausea, vomiting, diarrhea, abdominal pain or bloating
- ◆ malabsorption
- ◆ episodes of fainting or dizziness, sudden drops in blood pressure
- ◆ bone pain
- ◆ fatigue
- ◆ cognitive impairment, anxiety
- ◆ rapid weight gain or loss
- ◆ sensitivity to sunlight



What are Mastocytosis and Mast Cell Activation Syndrome (MCAS)?

Mastocytosis is a rare myeloproliferative neoplastic (MPN) disorder caused by misshapen, overactive or an abundance of mast cells in various organs, tissues and/or systems in the body. Mastocytosis affects skin (cutaneous form), internal organs (systemic form), and/or bone marrow (aggressive form).

Mast Cell Activation Syndrome (MCAS)

MCAS is similar to Mastocytosis except the number or shape of the mast cells may appear normal. However, MCAS causes mast cells to degranulate excessively and release histamine, heparin and other chemicals into the system.

This degranulation creates many unpleasant and sometimes life-threatening symptoms (like anaphylaxis) in patients with both Mastocytosis and MCAS.

Mastocytosis and MCAS are not contagious and patients of all ages, genders and demographics are affected. There is no cure for Mastocytosis or MCAS. Patients require a careful balance of trigger avoidance and medication to manage the symptoms.

Visit our online sites below for more information.

Join our support forum - it's free!

email: info@mastocytosis.ca
website: www.mastocytosis.ca
support: cmsadmin.proboards.com
photos: www.flickr.com/photos/mastocanada



An information pamphlet for Patients, Caregivers & Medical Professionals, about the potentially life threatening RARE disorders

Mastocytosis & Mast Cell Activation Syndrome

Read inside to help you get started on taking an active role in managing your illness.

Mastocytosis Society Canada is here to help

Mastocytosis and Mast Cell Activation Syndrome

What triggers should I avoid?

Symptoms occur when mast cells have been triggered to degranulate.

Common triggers that cause degranulation include:

- ◆ *insect stings including mosquito, wasp, hornet and bee*
- ◆ *pain medications such as non-steroidal anti-inflammatory drugs (NSAIDs) and narcotics (codeine, morphine)*
- ◆ *extreme temperatures, both hot and cold*
- ◆ *food and drink that are high in histamines or are known to trigger histamine release (i.e. shellfish, alcohol, fermented foods)*
- ◆ *exercise*
- ◆ *friction, pressure or vibration on the skin*
- ◆ *strong scents including perfumes and chemicals*
- ◆ *emotional and physical stress*

I think I might have this. What should I do?

Early diagnosis is vitally important to prevent the least amount of damage to your body and/or avoid sudden death. If you demonstrate some or all of the above mentioned symptoms and triggers, please visit your doctor as soon as possible. It would be a good idea to record your triggers and reactions in a diary as mast cell disorders present differently for each patient. This would be good information to take to your doctor. There are a series of tests that are available to help with diagnosis; the most common are a series of blood tests, skin and bone marrow biopsies. More information on testing and diagnosis are available on our website.

I've been diagnosed with Mastocytosis or MCAS. What should I do?

Unfortunately, the medical community at large is in the learning process of understanding the full implication of mast cell disorders. Often times, patients go untreated for long periods of time because their physicians are unfamiliar with testing, diagnosis and treatment of these disorders. You need to take an active role in your health by staying informed about this disorder.

You need to learn more about the disorder!

Mastocytosis Society Canada (MSC) is a national, non-profit organization that is focused on education, assistance with patient referrals, counseling and mutual support, as well as research. MSC is in the process of establishing an Interprofessional & Medical Advisory Committee (IMAC) that will be led by Dr. Gary Sibbald. This is a panel of medical and other experts with knowledge and experience working with mast cell disorders. This committee will be established to assist patients, physicians and caregivers through the more technical side of education and diagnosis.

You need to connect with other patients! We have an active online patient support forum that currently has nearly 300 registered Canadian participants. This forum is a wealth of information on research, medication shortages, patient surveys and general discussions about symptoms, triggers and medications. The forum is an excellent opportunity to connect with other patients who are in a similar situation to you. Here you will find education, understanding and empathy. To join our forum, send an email to support@mastocytosis.ca and you will very quickly be connected to other patients, caregivers and supporters.

You need to get involved! MSC is working hard to advocate for patients with mast cell disorders. We need volunteers and member support. Annual membership fees are \$25 and go toward supporting our initiatives to educate, assist with referrals, provide counselling and mutual support, and advance research in Canada. For membership information, please visit our website at www.mastocytosis.ca or email us at info@mastocytosis.ca. We could sure use your help!

Please visit our website to learn more about this disorder. We also encourage you to join our forum for information about medical advances, surgery and emergency protocols, detailed dietary information, lists of medication, patient stories, ongoing projects and current initiatives.

email: info@mastocytosis.ca
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support: cmsadmin.proboards.com
photos: www.flickr.com/photos/mastocanada

*We welcome new volunteers & members.
Join us.*