

What symptoms should I watch for?

Symptoms are highly unpredictable and vary greatly from patient to patient. Some patients experience only a few symptoms while others may experience all of them persistently or intermittently.

Initially, only a few signs and symptoms may be present. Often the signs and symptoms may escalate in type, severity, frequency and persistence.

Here are the most common symptoms to watch for:

- ◆ spots or rash on the skin
- ◆ itching, flushing, hives
- ◆ shortness of breath, trouble breathing
- ◆ chest pain and/or racing heart
- ◆ swelling and inflammation
- ◆ gastrointestinal upset including nausea, vomiting, diarrhea, abdominal pain or bloating
- ◆ malabsorption
- ◆ episodes of fainting or dizziness, sudden drops in blood pressure
- ◆ bone, muscle or joint pain
- ◆ fatigue
- ◆ cognitive impairment, anxiety
- ◆ headache
- ◆ sinus problems including ears, nose and throat
- ◆ rapid weight gain or loss
- ◆ sensitivity to sunlight
- ◆ enlarged spleen, liver, lymph nodes

Visit www.mastocytosis.ca for more information.

Mastocytosis

Mastocytosis is a rare disorder caused by an over production of mast cells (a type of white blood cell) accumulating in connective tissue and organs. Often, these mast cells are misshapen, contributing to the instability of the mast cell. When mast cells degranulate in response to a stimuli, they release histamine, heparin and other chemicals to combat the attack. Due to the over-abundance of mast cells, and therefore an over-abundance of chemicals, this degranulation has the potential to cause anaphylaxis.

To add complexity to the disease, these mast cells will often degranulate excessively and inappropriately. Instead of responding to normal stimuli like pathogens, they respond to other triggers such as stress, emotions, foods, chemicals, drugs, smells, etc.

Mastocytosis presents in cutaneous (skin) and systemic (internal) forms.

Mast Cell Activation Syndrome (MCAS)

In MCAS, the number and shape of the mast cell may appear normal. However, MCAS causes mast cells to degranulate excessively and release histamine, heparin and other chemicals into the system, often causing anaphylaxis.

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 disease.



Mast Cell Disease: Mastocytosis & Mast Cell Activation Syndrome (MCAS)

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What triggers should I avoid?

It is extremely important for patients to respect their illness, learn their individual symptoms and identify their triggers.

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)
- ◆ changes in temperature or extreme temperatures, both hot and cold
- ◆ food and drink (specific triggers are individual)
- ◆ exercise
- ◆ friction, pressure or vibration on the skin
- ◆ strong scents including perfumes, chemicals, spices, smoke,
- ◆ emotional and physical stress, including fatigue
- ◆ hormonal fluctuations (i.e. menstrual period)

Visit www.mastocytosis.ca for more information.

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

Early diagnosis is vitally important. If you suspect you have mast cell disease, please visit your doctor. You can reach out to MSC via our website for a list of physicians near you who are familiar with mast cell disease.

It may be helpful to record your triggers and symptoms in a diary to assist your physician with diagnosis.

There are a series of tests available to help with diagnosis including blood tests, skin and bone marrow biopsies. More information on testing and diagnosis are available on our website.

I've been diagnosed with mast cell disease. What should I do?

Mast cell disease is rare, often causing the medical community to be unfamiliar with signs, symptoms and diagnosis. Patients may go untreated for long periods of time before receiving a firm diagnosis.

You should take an active role in your health care by staying informed about these diseases.

See how we can help you - MSC is a national support organization focused on awareness, education, support and guidance for patients, caregivers and health care professionals. Please reach out to see how we can help!

Connect with other patients - It is comforting to know you are not in this alone. There are many on-line forums and support groups that provide peer-to-peer support for mast cell disease. For example, check out the Canadian Masties group on Facebook!

Coming Soon: MSC will soon be publishing regular blog posts to provide up-to-date information, patient stories and other helpful thoughts to keep you informed and connected to other patients.

Get involved - MSC is working hard to provide education and support for patients with mast cell disease.

Volunteers: Recently, we set up a series of volunteer committees in the areas of Fundraising, Communication, Medical Intelligence, Awareness and Education and Patient Support. These committees will help further achieve our goals and provide stronger support for patients and physicians. If you are interested in lending your time to a great cause, we could use your help.

Donate: Please give today and help us raise awareness of mast cell disease! Increased focus on mast cell disease can facilitate more efficient diagnostic processes, better access to treatment and continued support for those affected. Your tax deductible donation will go a long way to helping us continue our progress.

Please reach out to us to learn more about mast cell disease and how we can help you!

website: www.mastocytosis.ca

email: info@mastocytosis.ca