



How does Systemic Mastocytosis Affect the Body?

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What Is Systemic Mastocytosis?

Systemic Mastocytosis is a rare group of conditions where the body makes too many mast cells. Mast cells are a type of immune cell that help protect us from infections by releasing chemicals like histamine to generate an immune response. However, when there are too many mast cells, they can release these chemicals in large amounts. This usually results in symptoms like those found in allergic reactions. Some of these may be potentially life-threatening and known as anaphylactic reactions. Symptoms of anaphylaxis include swelling, hives, difficulty breathing, and feeling of passing out.

Hives – welts on the skin that are raised and itch.

Symptoms of Systemic Mastocytosis

Systemic Mastocytosis can produce a wide variety of symptoms affecting various organs in the body.

- **Skin:** The most common findings are multiple reddish-brown coin-sized spots found on the arms and legs but also chest, back and scalp. They can form a hive-like reaction when rubbed or become itchy during a reaction. This is called urticaria pigmentosa or “maculopapular cutaneous mastocytosis”. Other skin symptoms typically occur during a reaction and include:
 - Flushing – patches of redness where the skin is warm to the touch- typically on the face and chest
 - Itching – itching of the skin which may be all over the body or only in specific places.
 - Vomiting (Vomiting is when the contents of the stomach passes up the esophagus back into the mouth. The Esophagus is the muscular tube which connects the mouth to the stomach.)
 - Diarrhea (Diarrhea refers to passing frequent and/or loose or watery stools. Acute diarrhea goes away in a few days and becomes chronic when it lasts longer than 4 weeks.)
 - Patients with more severe forms of mastocytosis may have enlarged livers with abnormal liver function tests and issues absorbing nutrients through the intestines.
- **Digestive Tract (GI System):** Symptoms during a reaction in the GI tract may include common symptoms found in many other GI conditions. These include:
 - Pain or cramping in the abdomen
 - Nausea (Nausea refers to when you have the feeling you will vomit. It often occurs with stomach discomfort.)

The Abdomen is the area between the chest and the hips that contains the stomach, small intestine, large intestine (colon), liver, gall bladder, pancreas, and spleen. It is also sometimes referred to as the belly area.

- **Other symptoms:** Patients may typically have more chronic (daily) symptoms and issues affecting various parts of the body that may or may not be part of a reaction. These can make daily living activities difficult and include
 - Fatigue – a feeling low energy and/ overly tired
 - Weak bones and risk for bone fractures
 - Chronic pain often affecting bones and possibly the joints
 - Palpitations or feelings of a fast heartbeat
 - Chest tightness and throat closing sensations with reactions
 - Allergic type reactions and intolerances to many medications and foods.
 - Severe reactions to certain things such as bee stings causing anaphylaxis.

The most common triggers for the reactions experienced in those with Systemic Mastocytosis include medications (particularly antibiotics, anesthetics, morphine, non-steroidal anti-inflammatory pain medications), alcohol, insect stings, stress, menses or changes in temperature.

Presentations Not Suggestive of Mastocytosis (and occur by themselves without other symptoms or signs of Systemic Mastocytosis):

- Swelling in parts of the body
- Multiple chemical or environmental sensitivities
- Multiple food intolerances not explained by true food allergies on testing
- Symptoms like depression, anxiety, or non-specific weakness/numbness
- Chronic nonspecific symptoms such as chronic fatigue, and general bone/muscle pain

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