

Mastocytosis - Treatment Options [1]

This section has been reviewed and approved by the [Cancer.Net Editorial Board](#) [2], 05/2014

ON THIS PAGE: You will learn about the different ways doctors use to treat people with mastocytosis. To see other pages, use the menu on the side of your screen.

This section outlines treatments that are the standard of care (the best proven treatments available) for this specific type of disease. When making treatment plan decisions, patients are also encouraged to consider clinical trials as an option. A clinical trial is a research study to test a new approach to treatment to evaluate whether it is safe, effective, and possibly better than the standard treatment. Clinical trials may test such approaches as a new drug, a new combination of standard treatments, or new doses of current therapies. Your doctor can help you review all treatment options. For more information, visit the [Clinical Trials](#) [3] and [Latest Research](#) [4] sections.

Treatment overview

The treatment of mastocytosis depends on the symptoms of the disease, its extent, and the person's overall health. In many cases, different types of doctors often work together to create a patient's overall treatment plan that combines different types of treatments. This is called a [multidisciplinary team](#) [5].

Descriptions of the most common treatment options for mastocytosis are listed below. There is no cure for mastocytosis, although several treatments can be used to relieve symptoms and remove a mastocytoma (tumor). One important treatment for mastocytosis is to avoid anything that may cause the mast cells to release histamine, such as extreme temperatures, alcohol, emotional stress, insect bites, and certain medications.

Take time to learn about all of your treatment options and be sure to ask questions about things that are unclear. Also, talk about the goals of each treatment with your doctor and what you can expect while receiving the treatment. Learn more about [making treatment decisions](#) [6].

Managing symptoms

An important part of care for mastocytosis is relieving a person's symptoms. The most common treatments to help relieve the symptoms of mastocytosis are listed below.

Medications. Antihistamines can help relieve symptoms, such as itching, flushing, and other skin reactions. Other medications can help relieve diarrhea and stomach pain. Steroids may be used to reduce the size of skin lesions. Nonsteroidal anti-inflammatory drugs (NSAIDs) should be used with caution, as these medicines may trigger the release of histamine and can cause severe reactions. Often, people being treated for mastocytosis will carry a syringe of epinephrine, a hormone made by the adrenal glands, in case of a severe allergic reaction.

Ultraviolet light. Sometimes, exposing the skin rashes to a source of ultraviolet (UV) light can help relieve symptoms.

Surgery

Surgery may be performed to remove lesions. Many surgeries on the skin can be performed quickly and easily. Learn more about [surgery](#) [7].

Chemotherapy

Chemotherapy is sometimes used if mastocytosis becomes cancerous. Chemotherapy is the use of drugs to destroy cancer cells, usually by stopping the cancer cells' ability to grow and divide. Chemotherapy is given by a medical oncologist, a doctor who specializes in treating cancer with medication, or a hematologist, a doctor who specializes in treating blood disorders.

Systemic chemotherapy is delivered through the bloodstream to reach cancer cells throughout the body. Common ways to give chemotherapy include an intravenous (IV) tube placed into a vein using a needle or in a pill or capsule that is swallowed (orally). A chemotherapy regimen (schedule) usually consists of a specific number of cycles given over a set period of time. A patient may receive one drug at a time or combinations of different drugs at the same time.

The side effects of chemotherapy depend on the individual and the dose used, but they can include fatigue, risk of infection, nausea and vomiting, hair loss, loss of appetite, and diarrhea. These side effects usually go away once treatment is finished.

Learn more about [chemotherapy](#) [8] and [preparing for treatment](#) [9]. The medications used to treat cancer are continually being evaluated. Talking with your doctor is often the best way to learn about the medications prescribed for you, their purpose, and their potential side effects or interactions with other medications. Learn more about your prescriptions by using [searchable drug databases](#) [10].

Targeted therapy

Targeted therapy is a treatment that targets the disease's specific genes, proteins, or the tissue environment unique to mastocytosis that contribute to its growth and survival. This type of treatment blocks the growth of mast cells while limiting damage to healthy cells.

Recent studies show that not all diseases have the same targets. To find the most effective treatment, your doctor may run tests to identify the genes, proteins, and other factors involved in your mastocytosis. As a result, doctors can better match each patient with the most effective treatment whenever possible. In addition, many research studies are taking place now to find out

more about specific molecular targets and new treatments directed at them.

Tyrosine kinase inhibitors are a type of targeted therapy. For mastocytosis, the target is the unique protein called the c-kit tyrosine kinase receptor (see the [Risk Factors](#) [11] section). Treatment with tyrosine kinase inhibitors, including dasatinib (Sprycel), imatinib (Gleevec), midostaurin (PKC412), and nilotinib (Tasigna), is sometimes considered for patients with a mutation in the c-kit tyrosine kinase receptor. See the [Latest Research](#) [4] section for more information. Patients with more advanced systemic mastocytosis should be tested for this genetic mutation.

Talk with your doctor about possible side effects for a specific targeted therapy and how they can be managed. Learn more about [targeted treatments](#) [12].

Stem cell transplantation/bone marrow transplantation

A stem cell transplant is a medical procedure in which unhealthy bone marrow is replaced by highly specialized cells, called hematopoietic stem cells, that develop into healthy bone marrow. Hematopoietic stem cells are blood-forming cells found both in the bloodstream and in the bone marrow. Today, this procedure is more commonly called a stem cell transplant, rather than bone marrow transplant, because it is the stem cells in the blood that are typically being transplanted, not the actual bone marrow tissue.

Stem cell transplantation is not used frequently in people with mastocytosis because treatment results are inconsistent and there are significant risks with this treatment approach. Learn more about [bone marrow and stem cell transplantation](#) [13].

Getting care for side effects

Mastocytosis and its treatment often cause side effects. In addition to treatment to manage the condition, an important part of treatment is relieving these side effects. This approach is called palliative or supportive care, and it includes supporting the patient with his or her physical, emotional, and social needs.

Palliative care can help a person at any stage of illness. People often receive treatment for the disease and treatment to ease side effects at the same time. In fact, patients who receive both often have less severe symptoms, better quality of life, and report they are more satisfied with treatment.

Palliative treatments vary widely and often include medication, nutritional changes, relaxation techniques, and other therapies. Talk with your doctor about the goals of each treatment in your treatment plan.

Before treatment begins, talk with your health care team about the possible side effects of your specific treatment plan and supportive care options. And during and after treatment, be sure to tell your doctor or another health care team member if you are experiencing a problem so it is addressed as quickly as possible. Learn more about [palliative care](#) [14].

Remission and the chance of recurrence of mastocytosis-related cancer

A remission is when cancer cannot be detected in the body and there are no symptoms. This may also be called "no evidence of disease" or NED. Recurrent mastocytosis-related cancer is cancer that comes back after treatment.

A remission can be temporary or permanent. This uncertainty leads to many survivors feeling worried or anxious that the cancer will come back. While many remissions are permanent, it's important to talk with your doctor about the possibility of the cancer returning. Understanding the risk of recurrence and the treatment options may help you feel more prepared if the cancer does return. Learn more about [coping with the fear of recurrence](#) [15].

Often the treatment plan for a recurrent mastocytosis-related cancer will include the therapies described above, such as surgery and chemotherapy, but they may be used in a different combination or given at a different pace. Your doctor may also suggest clinical trials that are studying new ways to treat this type of recurrent cancer. Supportive care will also be important to help relieve symptoms and side effects.

People with recurrent cancer often experience emotions such as disbelief or fear. Patients are encouraged to talk with their health care team about these feelings and ask about support services to help them cope. Learn more about [dealing with cancer recurrence](#) [16].

If treatment fails

Recovery from mastocytosis-related cancer is not always possible. If treatment is not successful, the disease may be called advanced or terminal mastocytosis.

This diagnosis is stressful, and this is difficult to discuss for many people. However, it is important to have open and honest conversations with your doctor and health care team to express your feelings, preferences, and concerns. The health care team is there to help, and many team members have special skills, experience, and knowledge to support patients and their families. Making sure a person is physically comfortable and free from pain is extremely important.

Patients who have advanced cancer and who are expected to live less than six months may want to consider a type of palliative care called hospice care. Hospice care is designed to provide the best possible quality of life for people who are near the end of life. You and your family are encouraged to think about where you would be most comfortable: at home, in the hospital, or in a hospice environment. Nursing care and special equipment can make staying at home a workable alternative for many families. Learn more about [advanced cancer care planning](#) [17].

After the death of a loved one, many people need support to help them cope with the loss. Learn more about [grief and loss](#) [18].

The next section helps explain clinical trials, which are research studies. Use the menu on the side of your screen to select About Clinical Trials, or you can select another section, to continue reading this guide.

Links:

- [1] <http://www.cancer.net/cancer-types/mastocytosis/treatment-options>
- [2] <http://www.cancer.net/about-us>
- [3] <http://www.cancer.net/node/19231>
- [4] <http://www.cancer.net/node/19234>
- [5] <http://www.cancer.net/node/25356>
- [6] <http://www.cancer.net/node/24582>
- [7] <http://www.cancer.net/node/24720>
- [8] <http://www.cancer.net/node/24723>
- [9] <http://www.cancer.net/node/24473>
- [10] <http://www.cancer.net/node/25369>
- [11] <http://www.cancer.net/node/19226>
- [12] <http://www.cancer.net/node/24729>
- [13] <http://www.cancer.net/node/24717>
- [14] <http://www.cancer.net/node/25282>
- [15] <http://www.cancer.net/node/25241>
- [16] <http://www.cancer.net/node/25042>
- [17] <http://www.cancer.net/node/25113>
- [18] <http://www.cancer.net/node/25111>