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Mastocytosis - Follow-Up Care [1]

This section has been reviewed and approved by the [Cancer.Net Editorial Board \[2\]](#), 06/2016

ON THIS PAGE: You will read about your medical care after treatment is completed, and why this follow-up care is important. To see other pages, use the menu.

Care for people diagnosed with mastocytosis doesn't end when active treatment has finished. Your health care team will continue to manage any side effects, monitor your overall health, and check to make sure a mastocytosis-related cancer has not returned. This is called follow-up care.

Your follow-up visits will include blood tests and possibly scans or other imaging studies. Normally, follow-up visits are most frequent in the first 3 years after treatment, but patients are encouraged to have lifelong follow-up care. Learn more about the [importance of follow-up care \[3\]](#).

Managing long-term and late side effects

Most people expect to experience side effects when receiving treatment. However, it is often surprising that some side effects may linger beyond the treatment period. These are called long-term side effects. In addition, other side effects called late effects may develop months or even years afterwards. Long-term and late effects can include both physical and emotional changes.

People who received ultraviolet (UV) rays for cutaneous mastocytosis should be aware of an increased risk of [skin cancer \[4\]](#) in the future. Follow-up physical examinations and skin evaluations are important in the early diagnosis and prevention of this condition.

In addition, chemotherapy may cause several long-term side effects:

- People who have received certain drugs may develop lung damage.
- Heart damage in the form of a weakened heart muscle may occur in people who have received a higher dose of doxorubicin (Adriamycin) or radiation therapy to the chest.
- Infertility (inability to have children) or early menopause can occur in people who have received high-dose cyclophosphamide (Cytoxan, Neosar) or other chemotherapy. Learn more about fertility concerns and preservation for [men](#) [5] and [women](#) [6].
- Secondary cancers like leukemia are more common in people who received chemotherapy. Secondary cancers are cancers that develop as a result of the treatment for another type of cancer.

Talk with your doctor about your risk of developing such side effects based on the type of mastocytosis, your individual treatment plan, and your overall health. If you had a treatment known to cause specific late effects, you may also have certain physical examinations, scans, or blood tests to help find and manage them.

Watching for recurrence

If you were treated for a mastocytosis-related cancer, 1 goal of follow-up care is to check for a recurrence. Cancer recurs because small areas of cancer cells may remain undetected in the body. Over time, these cells may increase in number until they show up on test results or cause signs or symptoms. During follow-up care, a doctor familiar with your medical history can give you personalized information about your risk of recurrence. Your doctor will also ask specific questions about your health. Some people may have blood tests or imaging tests done as part of regular follow-up care, but testing recommendations depend on several factors, including the type and stage of cancer originally diagnosed and the types of treatment given.

Keeping personal health records

You and your doctor should work together to develop a personalized follow-up care plan. Be sure to ask about any concerns you have about your future physical or emotional health. ASCO offers [forms to help create a treatment summary to keep track of the treatment you received and develop a follow-up care plan](#) [7] once treatment is completed.

This is also a good time to decide who will lead your follow-up care. Some people continue to see a specialist, while others transition back to the general care of their family doctor or another health care professional. This decision depends on several factors, including the type of mastocytosis, side effects, health insurance rules, and your personal preferences.

If a doctor who was not directly involved in your cancer care will lead your follow-up care, be sure to share your cancer treatment summary and follow-up care plan forms with him or her, as well as all future health care providers. Details about your treatment are very valuable to the health care professionals who will care for you throughout your lifetime.

Making healthy lifestyle choices

People recovering from mastocytosis are encouraged to follow established guidelines for good health, such as not smoking, limiting alcohol, eating well, maintaining a healthy weight, managing stress, and having recommended cancer-screening tests. Talk with your doctor to develop a plan that is best for your needs. Moderate physical activity can help rebuild your strength and energy level. Your doctor can help you create an appropriate exercise plan based upon your needs, physical abilities, and fitness level. Learn more about [making healthy lifestyle choices](#) [8].

The next section offers [Questions to Ask the Doctor](#) [9] to help start conversations with your health care team. Or, use the menu to choose another section to continue reading this guide.

Links

[1] <http://www.cancer.net/cancer-types/mastocytosis/follow-care>

[2] <http://www.cancer.net/about-us>

[3] <http://www.cancer.net/node/29386>

[4] <http://www.cancer.net/node/31378>

[5] <http://www.cancer.net/node/25268>

[6] <http://www.cancer.net/node/29096>

[7] <http://www.cancer.net/node/25394>

[8] <http://www.cancer.net/node/24554>

[9] <http://www.cancer.net/node/19235>