

Understanding Mantle Cell Lymphoma



Whether you or a loved one has received a mantle cell lymphoma (MCL) diagnosis, this guide will help you learn about MCL, a rare type of blood cancer. You will find information about what MCL is, what might cause it, and what symptoms to look out for. You'll also learn about the different types of MCL, treatment options, possible side effects, and ways to take care of your mental health. There is support for life after treatment, caregivers, and resources to help along the way. Use this guide to better understand your MCL diagnosis and feel more confident in making decisions about your care.



To learn more about mantle cell lymphoma, visit www.CancerSupportCommunity.org/Mantle-Cell-Lymphoma.

WHAT IS MANTLE CELL LYMPHOMA?

MCL is a rare, often aggressive form of non-Hodgkin lymphoma (NHL).

MCL is a sub-type of NHL known as a B-cell lymphoma. B-cells are white blood cells found in your lymphatic system. The lymphatic system helps your body fight infections and remove waste. MCL usually affects the lymph nodes, but can also be found in blood, bone marrow, and other tissues throughout the body. MCL occurs when there is an abnormal change in the cells on the outer layer of the lymph nodes. This outer layer is called the "mantle zone."

MCL can be treated over time to shrink the cancer and help contain it. For MCL, it is normal to have alternating periods of disease recurrence (MCL comes back) or remission (MCL is controlled or not detected). MCL requires lifelong symptom management and attention. Until a cure is found, MCL is managed like a chronic illness.

In cases where MCL either comes back or does not improve with treatment, some people may get treatments that can result in potential cure or long-term remission, such as a stem cell transplant or CAR-T cell therapy.

MCL RISK FACTORS

The cause of MCL is not fully understood. Most of the time, MCL occurs when there is a change in your genes that affects how B-cells work. This genetic change occurs over time, and scientists don't know what causes it. Lifestyle factors may play a role. The genetic variation that causes MCL cannot be passed on to your children.

You may have cancer risk factors that you can change, like smoking or environmental exposure. There are some risk factors you cannot change, such as your age and sex.

There are several factors that may increase your risk of developing MCL:



Sex at birth – MCL occurs more often in people who are born male.



Age – Although MCL can be diagnosed at any age, people are often diagnosed when they are 60 or older.



Race – White people are more likely to develop MCL than people of other races.



Environmental exposures – Long-term exposure to certain chemicals, pesticides, or radiation may be linked to some MCL diagnoses.

Just because someone has one or a few risk factors does not mean that they will get MCL. Your care team is available to answer your questions and help you understand your risk.



MCL SIGNS & SYMPTOMS

MCL may not cause symptoms at first, or symptoms may look like other common illnesses. The signs and symptoms of MCL may also be similar to those of other common blood cancers. People with MCL may experience a wide range of symptoms. MCL symptoms will vary from person to person.

Common MCL signs and symptoms include:

- **Bruising**
- **Swollen lymph nodes**
- **Fatigue/weakness**
- **Headaches**
- **Night sweats**
- **Fever**
- **Unexplained weight loss/appetite changes**



MCL TYPES

There are 2 main subtypes of MCL. The subtype affects the symptoms you may have, how the disease should be treated, and how well treatment might work. The subtypes are:

1 Classical MCL – This is the most common form of MCL. It is also known as nodal MCL. This type of cancer is typically fast-growing and can be aggressive. Classical MCL starts in your lymph nodes and can impact other organs. Aggressive forms of classical MCL may spread to your GI (gastrointestinal) system, bones, liver, and spleen.

2 Leukemic non-nodal MCL – This type of MCL spreads through your blood, spleen, and bones. Leukemic, non-nodal MCL typically grows more slowly and does not involve your lymph nodes or GI system.

There are other rare forms of MCL that may occur.

Talk with your care team to learn more about your specific type.



DIAGNOSING MCL

To diagnose MCL, your doctor will order several tests, including biopsies, blood tests, and imaging tests. These tests will confirm the exact type and stage of MCL. This will help you and your doctor decide the best treatment options for you.



Blood tests

- Complete blood count (CBC)
- Comprehensive metabolic panel (CMP)
- Lactate dehydrogenase (LDH) test
- Uric acid level test

Imaging tests

- Colonoscopy
- Computed tomography (CT) scan, with or without contrast
- Upper endoscopy
- Positron emission tomography (PET) scan

The type of imaging test you may need will depend on the location of your cancer. These tests help your doctor determine how far your cancer has spread. Ask your doctor which imaging test is the best next step for you.



Biopsies

A lymph node biopsy is when your doctor takes a sample of your lymph node to be examined. Your doctor may take a biopsy of one or several of your lymph nodes during this procedure.

A bone marrow biopsy involves a needle inserted into your hipbone to get a sample of liquid or tissue from the bone marrow. Bone marrow is where blood cells are made.

- The removal of liquid is an aspiration.
- The removal of tissue is a biopsy.

Your sample is sent to the lab to be tested by the pathologist. A pathologist is a doctor who looks at tissue or blood under a microscope to find any signs of disease. Your care team will use your biopsy to confirm your MCL diagnosis. A biopsy can also help determine the spread of your cancer. Speak with your care team to understand which biopsy type they recommend for you.



STAGES OF MCL

Your doctor will use a staging system to diagnose and treat your MCL. A cancer's "stage" is a measure of how far it has spread. Your doctor will use your MCL type and stage to work with you to create your treatment plan.

There are four MCL stages:

Stage 1 Cancer is found in only one lymph node or organ.

Stage 2 Cancer is found in two or more lymph nodes on the same side of your diaphragm (a large breathing muscle below the lungs).

Stage 3 Cancer is found in two or more lymph nodes on each side of your diaphragm. Or it is found in your spleen and above your diaphragm.

Stage 4 Cancer is found in areas outside of your lymph nodes. MCL typically spreads to the lungs, bone marrow, GI tract, or liver.

Knowing the stage of your cancer is important during treatment planning. Understanding your cancer's stage can help you and your care team select the best treatment option.



TREATMENT OPTIONS

There are a number of treatments that work to manage MCL. Until a cure is found, MCL is managed like a chronic illness. Most people will need treatment on and off throughout their life. Your doctor will look at your age, overall health, and MCL type to work with you to make a treatment plan.



Watch and Wait With MCL

Slow growing MCL may be monitored using a “watch and wait” approach. This involves watching for any signs that your disease may be progressing without any use of treatment. It may also be referred to as “active surveillance.” Some people can live for years without treatment. For this approach, you are still regularly seen by your care team and complete tests for any signs of progression. Let your care team know of any new or changing symptoms. If your cancer progresses, your care team may recommend starting treatment.

Chemotherapy involves the use of drugs to destroy cancer cells. It is a systemic (whole body) treatment. It may be given by IV (through a vein) or in pill form (by mouth).

Immunotherapy works with the body’s immune system to find, attack, and kill cancer cells. These drugs help the immune system to better recognize and attack cancer cells.

- **CAR T-cell (chimeric antigen receptor T-cell) therapy** is a new type of immunotherapy. This modern treatment approach uses a lab-made protein along with your own immune cells to find and attack cancer. CAR T-cell therapy is currently for people whose cancer didn’t respond to previous treatment or came back after treatment.

Radiation therapy is the use of high-energy rays to kill or damage cancer cells. Your care team may recommend radiation for early stage MCL.

Targeted therapy uses drugs to target specific changes in cancer cells that help them grow, divide, and spread. Targeted therapy drugs are designed to be more precise. They fight cancer cells while causing less harm to other cells in the body.

- A common treatment approach for MCL is a combination of chemotherapy and targeted therapy. While effective for rapidly growing cancers, this approach may be too aggressive for some people. Speak with your doctor to find out if this is the right treatment approach for you.





Stem cell transplants are a type of procedure that infuses healthy blood-forming cells (stem cells) into the body. Stem cells can come from a sample of your blood or from an outside donor (someone else's donated blood). Stem cell transplants may also be referred to as bone marrow transplants.

This treatment approach includes a combination of chemotherapy and stem cell transplantation. First, you will receive high doses of chemotherapy. The goal of chemotherapy is to kill the cancer cells. After chemotherapy, stem cells are infused back into your blood. This treatment option is commonly best for younger people and people healthy enough to handle its serious risks.

Clinical trials are research studies that test new treatments or learn how to use existing treatments better. They find new and better ways to prevent or treat MCL. These trials are closely monitored and approved by the U.S. Food and Drug Administration (FDA). For more information on clinical trials and how to find them, visit www.CancerSupportCommunity.org/Clinical-Trials.

Effective communication with your care team helps them understand how treatment is affecting you, both physically and mentally. Your care team will share the best ways to manage side effects from treatment. For people with rare cancers, like MCL, open communication is especially important. Your care team may need to connect you with specialists for MCL and other rare blood cancers. Communication is key when making informed decisions about your cancer care.

MCL TREATMENT SIDE EFFECTS

Every person's experience with cancer treatment is different. Side effects will vary depending on the type of treatment you receive. There are physical side effects that are common with certain treatment types. It is helpful to know the side effects of different treatment options when making your treatment plan with your care team.

MCL treatment side effects are commonly caused by low blood cell counts. Common side effects of MCL treatment include:

- Fatigue/weakness
- Nausea & vomiting
- Weight & appetite changes
- Risk of anemia, infection, & bleeding
- Hair loss
- Changes in the mouth & esophagus (tube below the throat that carries food and drink to the stomach)
- Constipation & diarrhea
- Fever/chills

Treatment for MCL can affect your body in many ways. Different treatment options may come with different possible side effects. Managing side effects is an important part of your care, and your care team can help. Your doctor may refer you to a palliative and supportive care specialist.



COPING WITH MANTLE CELL LYMPHOMA

MCL is a chronic condition that requires long-term disease management. There are likely to be periods of remission (when the cancer goes away) and periods of relapse (when the cancer comes back). Managing the stress and anxiety of life with MCL can be difficult. It's hard when you feel unsure of what the future holds. This can make coping with your diagnosis especially unique and challenging.

During and after treatment for MCL, it is important to lean on your support system. Your support system may include family, friends, your care team, or support groups. Being open about how you're feeling can help you manage the emotional ups and downs. MCL can bring changes in your health and mental well-being, so staying flexible and learning to adjust is key. Ongoing support from mental health specialists can help you cope with stress, anxiety, and fears of recurrence. Financial concerns are also common, so talk to your care team and financial navigators about resources that can help. Lean on organizations that offer free services, education, and support.

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You are likely to have emotional ups and downs, which may or may not be predictable or associated with your physical diagnosis or progression of the disease. Just knowing that you're in for a roller coaster and that what goes down goes back up is something I've found helpful to keep in mind.”

- *Chris, Patient Advocate*



While managing your physical health during and after MCL treatment is important, so is managing your mental health. It is common to feel alone or like no one understands what you are going through. Finding a community of people with your cancer type may help you feel heard and supported. Reaching out to others for support can make a big difference. You do not need to face these feelings alone. Prioritizing your emotional well-being is an important part of living with and managing MCL over time.

Discover more tips and tools to cope with MCL, visit www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns

SUPPORT THROUGH SURVIVORSHIP

MCL can have lasting effects. It is completely normal to need ongoing emotional and physical support after your active treatment ends. MCL often requires ongoing monitoring and management. It may be difficult to cope with a lifelong diagnosis. If you are feeling lasting stress and anxiety, you are not alone. Having support during every step of your MCL experience is an important part of staying healthy.

It is important to stay in touch with your care team, even after treatment ends. During survivorship, it remains important to regularly speak with your care team for continued guidance, support, and any needed monitoring. Ask your care team to connect you with support services or to find other MCL patients and caregivers. Many people also find it meaningful to share what they have learned along the way, becoming a source of support for others on a similar journey.



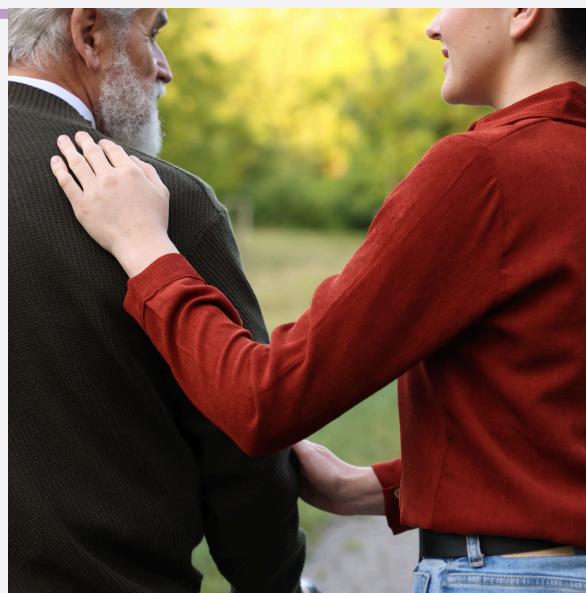
CAREGIVING FOR MANTLE CELL LYMPHOMA

Stepping into a new role as a cancer caregiver can come with many different emotions. It is normal to feel overwhelmed, stressed, or even frustrated as you balance your own life with your loved one's needs.

As an MCL caregiver, you may provide medical, emotional, financial, or logistical support over time. Common caregiver roles include medication and appointment management. You may need to assist your loved one with their daily activities. Caregiving for a loved one comes with many responsibilities. These tasks, in addition to your own, can easily become overwhelming.

Caregivers need support for their own emotional and physical health as well. It is important to prioritize a healthy lifestyle and emotional connection. Reach out to other caregivers to hear about their experience. You may find yourself putting your own needs second during these busy times. Your overall well-being impacts your ability to provide support. Be open and honest about how you are doing with those around you so they can better support you.

For more information, visit www.CancerSupportCommunity.org/Caregivers



RESOURCES

MANTLE CELL LYMPHOMA RESOURCES

Cancer Support Community

888-793- 9355

www.CancerSupportCommunity.org/Mantle-Cell-Lymphoma

Blood Cancer United (formerly Leukemia & Lymphoma Society)

800-955-4572

www.BloodCancerUnited.org/

American Cancer Society – B-cell Lymphoma

www.Cancer.org/Cancer/Types/Non-Hodgkin-Lymphoma/B-Cell-Lymphoma

NCI Clinical Trials Registry

www.ClinicalTrials.gov



Cancer Support Community Resources

Cancer Support Helpline® — Have questions, concerns, or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon-Thurs 11am-8pm ET and Fri 11am-6pm ET.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Frankly Speaking About Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

Services at Local CSCs and Gilda's Clubs — With the help of over 200 locations, in 50 markets, CSC and Gilda's Club centers provide services free of charge to people impacted by cancer. Attend support groups, educational sessions, wellness programs, and more
www.CancerSupportCommunity.org/FindLocation.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at **www.CancerExperienceRegistry.org**.

MyLifeLine® — CSC's secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now at **www.MyLifeLine.org**.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at **www.CancerSupportCommunity.org/Become-Advocate**.

This publication is available to download and print yourself at **www.CancerSupportCommunity.org/Mantle-Cell-Lymphoma**.

For print copies of this publication or other information about coping with cancer, visit **Orders.CancerSupportCommunity.org**.

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