

# Talking about Mantle Cell Lymphoma



## A Guide for Discussions with Your Care Team



Being diagnosed with mantle cell lymphoma (MCL) can be overwhelming. You likely have many questions about what comes next. This resource is intended to help you feel informed and empowered as you navigate your MCL diagnosis. It will discuss an overview of MCL, treatment options, and how to find support and resources. Use this guide to help you take control of your care, set treatment goals, and have more confident discussions with your healthcare team after a diagnosis.



To learn more about mantle cell lymphoma, visit [www.CancerSupportCommunity.org/Mantle-Cell-Lymphoma](http://www.CancerSupportCommunity.org/Mantle-Cell-Lymphoma).



## WHAT IS MANTLE CELL LYMPHOMA?

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

MCL is a sub-type of NHL known as a B-cell lymphoma. There are several dozen different types of B-cell lymphomas. B-cells are white blood cells found in your lymphatic system. 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 found in the cells on the outer layer of the lymph nodes. This outer layer is called the “mantle zone.”

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. These may include bruising and frequent headaches. You might also feel tired or weak, have a fever, or notice changes in your weight or appetite. Some people experience night sweats or find lumps/swollen lymph nodes under their skin. If you notice any of these symptoms, talk to your healthcare provider. MCL symptoms will vary from person to person.

Some things can make it more likely for a person to get MCL. People who were born male have a higher chance of getting MCL than those born female. Most people are diagnosed when they are 60 or older, although MCL can be diagnosed at any age. MCL is also seen more often in White persons compared to persons of other races.

MCL can be treated over time to shrink the cancer and help contain it. For MCL, it's common for the cancer to come back after treatment (recurrence) and then go away again for a while (remission). MCL requires ongoing care and attention for symptoms. 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.



## QUESTIONS TO ASK ABOUT YOUR DIAGNOSIS

What is the stage of my cancer?
Where is the cancer located?
Has the cancer spread? Is the cancer considered “advanced”?
Since MCL is rare, how familiar are you with treating this type of lymphoma? Would you recommend seeing a specialist who focuses on MCL?
Can you explain what makes MCL different from other types of lymphoma?
What does it mean to manage MCL as a chronic condition?

## 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. Treatment options may include:

**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.

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**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](http://www.CancerSupportCommunity.org/Clinical-Trials).

**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.

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Talk to your care team about 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.

## QUESTIONS TO ASK ABOUT YOUR TREATMENT OPTIONS

What are my treatment options for MCL?
How soon do I need to start treatment?
What will my treatment cost, and what does my insurance cover?
What side effects should I expect from my treatment?
What is the plan if the cancer comes back or stops responding to treatment?



## SETTING YOUR PERSONAL GOALS FOR TREATMENT

Here are some questions for you to consider and discuss with your care team, as you think about your personal and treatment goals. These conversations can help make sure you and your care team are making treatment decisions together. You may also find it helpful to discuss your goals with your family and loved ones first. You may also find comfort speaking with people outside your close circle, like other MCL patients who understand your experience.



### USE THIS LIST OF QUESTIONS TO HELP GUIDE THESE DISCUSSIONS:

<b>Physical, Emotional, &amp; Well-Being</b>	<ul style="list-style-type: none"> <li>• What do I want to be able to do physically during or after treatment?</li> <li>• What does feeling “emotionally well” look like for me? What personal or emotional goals do I want to focus on?</li> </ul>
<b>Relationships &amp; Social Support</b>	<ul style="list-style-type: none"> <li>• Are there upcoming family milestones or events I want to be present for?</li> <li>• How can I maintain meaningful relationships during treatment?</li> <li>• Are there resources or guides to help me talk about cancer with loved ones?</li> <li>• Is getting or staying involved in my community, advocacy, or support groups important?</li> </ul>
<b>Day to Day Responsibilities</b>	<ul style="list-style-type: none"> <li>• Do I want or need to continue working or attending school? What kind of support or changes will help me with this transition?</li> <li>• What changes could help me balance treatment with my everyday responsibilities?</li> <li>• What kind of help do I need at home or with daily tasks?</li> <li>• Who can I talk to about practical issues like work, transportation, or financial assistance?</li> <li>• Who do I want to make medical decisions for me if I am unable? What documents (e.g., advanced medical directives) can I use to record these choices?</li> </ul>
<b>Personal and Spiritual Growth</b>	<ul style="list-style-type: none"> <li>• What spiritual and wellness practices are important to me? Are there spiritual practices or beliefs that bring me comfort?</li> <li>• What helps me feel connected to something bigger than myself?</li> </ul>

## MCL TREATMENT SIDE EFFECTS

It helps to learn more about the side effects of MCL treatment before you begin. This way, you will know what to expect. When you know more, you can work with your care team to better manage any symptoms during and after treatment. Report any side effects to your care team as you experience them. This will help them understand how your body responds to treatment and offer options to provide relief.

Below are potential treatment side effects people with MCL may experience. Think about how severe they are and how often they have affected you since your last doctor's visit, if at all. Talk to your care team about how to best manage them.

TREATMENT SIDE EFFECTS	Rarely	Sometimes	Often
Fatigue (feeling very tired) or weakness			
Infections, bruising, or shortness of breath, which may be caused by low blood cell counts			
Pain, numbness, or swelling in hands or feet; joint or muscle pain			
GI issues (nausea, vomiting, diarrhea, constipation)			
Fever or chills			
Changes in taste or appetite, mouth pain/sores, dehydration, decreased appetite			
Skin changes, like rash or itchiness			
Difficulty thinking clearly or remembering (brain fog or "chemo brain"), memory changes			
Mood changes (feeling worried, anxious, overwhelmed, depressed)			
Fear of disease progression or upcoming appointments			
Other side effects not listed here:			

Side effects from cancer treatment vary from person to person. For many people, treatment side effects lessen or go away once treatment is finished. For more information about how to manage treatment side effects, visit [www.CancerSupportCommunity.org/Managing-Side-Effects](http://www.CancerSupportCommunity.org/Managing-Side-Effects)



## MEMBERS OF THE MCL CARE TEAM

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After being diagnosed with MCL, one of your first steps will be to build your care team. You will work with many healthcare professionals over the course of your MCL experience. Each member plays an important role in your care. This team-based approach ensures every part of your health and lifestyle is considered. Every member of your care team should communicate and coordinate to help create a treatment plan that works for you.

**A medical oncologist or hematologist** specializes in the treatment of cancer. They will offer cancer treatment options and referrals to specialists. This includes chemotherapy, immunotherapy, and targeted therapy.

**A pathologist** is a doctor who looks at tissue or blood under a microscope to find any signs of disease.

**A nurse navigator or patient navigator** can help you manage your care. They help schedule appointments, get answers to your questions, recommend educational resources, and support you during your treatment.

**A physical therapist (PT) and occupational therapist (OT)** help you maintain or improve your physical functioning and ability to perform activities of daily living.

**A nurse practitioner, nurse, or physician assistant** may work with the oncologist and help answer questions about your MCL diagnosis. These healthcare professionals are also a great resource to speak with about your mental health. They can connect you with social workers, counselors, psychiatrists, and others.

**A social worker, therapist, or counselor** help you and your caregiver find resources to cope with cancer and its treatment side effects. Social workers can help with practical concerns. Social workers and therapists are trained mental health professionals who can help you address your emotions through individual or group therapy.



**A registered dietitian (RD)** is trained to recommend foods and other ways to make sure your body gets the nutrients it needs. RDs can help you manage symptoms such as appetite changes, nausea, taste changes, and dietary restrictions.

**A financial navigator** helps you and your loved ones understand the cost of different treatments and how your insurance plan may help cover costs. They may also help find financial assistance programs or payment plans to help ease the burden of receiving treatment.

**You** are an important member of your care team. Your voice matters in every decision being made. It is important to speak up about what you want, how you feel, and how side effects are affecting your daily life. It is normal to feel worried about speaking up in a room full of health professionals. But advocating for yourself is important to your health. The right care team for you will listen and bring you into conversation with them about the course of your care.

## GETTING A SECOND OPINION

It is always okay to seek a second opinion any time during your cancer experience. Hearing another doctor's care approach may help you understand your MCL diagnosis and feel more confident in your treatment options. There are many reasons you may search for a second opinion during your care. You may be looking for a new treatment approach, searching for a team with a new communication style, or simply need more information before making a big decision. It is important to find a care team that makes you feel heard and involved in your treatment planning. You should not be afraid of offending your original doctor when you seek a second opinion.

Remember, your care team will be an important part before, during, and after MCL treatment. Finding a care team that values your goals is an important part of feeling empowered and supported throughout the MCL treatment process.



To learn more about getting a second opinion, visit [www.CancerSupportCommunity.org/blog/Should-I-Get-Second-Opinion](http://www.CancerSupportCommunity.org/blog/Should-I-Get-Second-Opinion).



## QUESTIONS TO ASK ABOUT YOUR CARE TEAM

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What's the best way to reach you or the team if I have questions between visits?

Can you tell me who will be part of my care team and what each person's role is in my treatment?

How do you usually involve patients in making decisions about their treatment?

My previous doctor said [insert recommendation]. Does your approach differ?

If I decide to get a second opinion, will that affect my treatment?

Are there experts in MCL or cancer centers you recommend for a second opinion?

Your communication with your care team may change over time. There will be times when you talk often and times when you don't talk as much. Always remember that there are members of your care team available when you need guidance and support.



## COPING WITH MCL

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Living with MCL can be emotionally challenging. MCL is a chronic condition that requires lifelong monitoring and management. Even after active treatment ends, it is normal to feel anxious about the possibility of the cancer coming back. Lifelong symptom monitoring can become tiring and too much to think about. It is hard when you feel unsure of what the future holds. This can make coping with your diagnosis especially unique and challenging.

 Visit [www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns](http://www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns) to find additional information to support you during your cancer diagnosis.

There may be days, or even longer, when you feel physically or emotionally well. And there may be times when you do not feel as well. It can be challenging to try to keep up with frequent changes during MCL.



## QUESTIONS TO ASK ABOUT YOUR SUPPORT OPTIONS

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Are there support groups for people living with MCL?

How can I manage the fear of recurrence?

What symptoms should I watch for, and how do I know when something is important to report?

How often will I see you now that I am finished with active treatment?

Do you have suggestions for connecting with other MCL survivors?



Understand that ***it is normal*** to experience ups and downs when living with a chronic condition like MCL.

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It can feel isolating to be diagnosed with a rare cancer like MCL. It may be difficult to find people who can relate to your cancer experiences. You may feel alone as you transition from active treatment into survivorship and disease management. When you begin seeing your care team less often, it is important to find other ways to connect with those around you. Leaning on support groups, mental health professionals, and your loved ones can help you manage each day. Patient advocacy groups, like **Cancer Support Community**, can help connect you to the support you need.

# RESOURCES

## **MANTLE CELL LYMPHOMA RESOURCES**

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### **Cancer Support Community**

888-793- 9355

[www.CancerSupportCommunity.org/Mantle-Cell-Lymphoma](http://www.CancerSupportCommunity.org/Mantle-Cell-Lymphoma)

### **Blood Cancer United (formerly The Leukemia & Lymphoma Society)**

800-955-4572

[www.BloodCancerUnited.org/Lymphoma](http://www.BloodCancerUnited.org/Lymphoma)

### **American Cancer Society – B-cell Lymphoma**

[www.Cancer.org/Cancer/Types/Non-Hodgkin-Lymphoma/B-Cell-Lymphoma](http://www.Cancer.org/Cancer/Types/Non-Hodgkin-Lymphoma/B-Cell-Lymphoma)

### **NCI Clinical Trials Registry**

[www.ClinicalTrials.gov](http://www.ClinicalTrials.gov)



## Cancer Support Community Resources

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**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](http://www.CancerSupportCommunity.org/FindLocation)**.

**Cancer Experience Registry®** — Help others by sharing your cancer patient or cancer caregiver experience via survey at **[www.CancerExperienceRegistry.org](http://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](http://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](http://www.CancerSupportCommunity.org/Become-Advocate)**.

This publication is available to download and print yourself at **[www.CancerSupportCommunity.org/Mantle-Cell-Lymphoma](http://www.CancerSupportCommunity.org/Mantle-Cell-Lymphoma)**.

For print copies of this publication or other information about coping with cancer, visit **[Orders.CancerSupportCommunity.org](http://Orders.CancerSupportCommunity.org)**.

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