

Coping with “Watch and Wait” for Multiple Myeloma



“Watching” and “waiting” to see if cancer will progress makes most people feel anxious and unsure about the future. These feelings may get stronger at certain times. These may include if you have symptoms, are waiting for test results or

a doctor’s visit, or reach a milestone, like 5, 10, or 15 years after your diagnosis. It is normal to feel like you want to do something now. It can help to know what to look for, understand your test results, and learn strategies to cope with “watch and wait.”

Watch and Wait

Blood conditions like monoclonal gammopathy of undetermined significance (MGUS) or asymptomatic/smoldering myeloma are slow-growing and don't need immediate treatment. They require attention. The risk to progress to cancer is very low, but there is no way to tell whose MGUS will lead to multiple myeloma. For smoldering myeloma, the risk is higher, but with early attention, treatment can help manage the disease.

“**Active Surveillance**” or “**watch and wait**” means you keep a regular schedule (every 6 months to once per year) for blood tests and sometimes other tests to look for signs of multiple myeloma.

If test results show that your M protein (an abnormal protein) level is getting higher and/or you have symptoms of multiple myeloma, then you would begin treatment.



What are Signs of Multiple Myeloma (MM)?

- Elevated levels of M protein and/or other myeloma markers in the blood
- Bone pain, damage, and fractures
- Anemia-related fatigue, weakness, or difficulty breathing
- Kidney (renal) failure
- Infection and illness
- Loss of appetite and weight loss
- Headaches, confusion, and blurred vision

How to Cope with “Watch and Wait”

- ✓ **Learn to stay empowered.** Ask questions so you feel informed and prepared for next steps. You can't control some aspects of cancer, but you can learn about your diagnosis, what symptoms to look for, how to improve your health now, and how to make informed decisions for your care.
- ✓ **Keep a calendar.** Keep a calendar with dates for your next tests. After the date is scheduled, try to forget about it. It's normal to feel anxious before tests. Be gentle with yourself when you feel stressed.
- ✓ **Know about symptoms, keep notes, and talk with your team.** Keep a diary with how you feel, your test results, and what you learn along the way. Ask about symptoms that concern you. Talk with your health care team and share your notes or questions.

- ✓ **Be thoughtful about your diet.** Research shows that eating more plants (fruits, vegetables, beans, seeds, whole grains) and less meat, processed foods, and sugar helps us maintain a healthy body weight and gives our bodies critical nutrition to fight illness and disease. Try to eat thoughtfully. To learn more about healthy eating, visit www.CancerSupportCommunity.org/Diet-Nutrition.
- ✓ **Aim to exercise more.** Exercise is essential for strength, a healthy body weight, and feeling better. It will help protect frail bones and improve your overall health. Try to exercise every day for at least 30 minutes. Even walking is great.
- ✓ **Try relaxation strategies.** It's normal to have fears, but it helps to let them go. Yoga, breathing relaxation exercises, and doing activities you enjoy can help you relax. There are meditation, mindfulness, and hypnosis apps that work well too.
- ✓ **Seek help or support when you need it.** Social workers, counselors, or clergy members can help you work through concerns. They can help you find services for financial aid, transportation, home care, and emotional support.
- ✓ **Know your options and learn about new treatments.** At any time you may be eligible for a new treatment in a clinical trial. Ask your doctor if a clinical trial could help you. Stay aware of new treatments and strategies for MM care.
- ✓ **Focus on what gives you pleasure.** Focus on what makes you feel good, not your worries. Make time for what you enjoy. Pamper yourself in small ways—you deserve it!

WHAT TESTS ARE DONE TO CONFIRM, TRACK, AND FOLLOW UP ON MULTIPLE MYELOMA?

BLOOD & URINE TESTS to look for:

- Blood counts: Complete blood count (CBC) to monitor anemia; Comprehensive panel to monitor electrolytes (calcium and creatinine) for kidney function
- How much M protein is in your blood: serum protein electrophoresis (SPEP)
- Light chain M protein (kappa or lambda): 24-hour urine electrophoresis or serum free light chain (SFLC) testing
- Bone loss: blood calcium and Vitamin D level tests
- Staging: beta 2-microglobulin (β2M) test, lactate dehydrogenase (LDH), and serum albumin

KIDNEY TESTS to look for:

- Kidney damage and the Bence Jones protein (from M protein): 24-hour urine test
- How well the kidneys function: blood test for creatinine, blood urea nitrogen (BUN), and 24-hour urine for creatinine clearance

SCANS to look for:

- Broken bones and lytic lesions: a skeletal survey, x-rays, MRI, CT, or PET scan

BONE MARROW BIOPSY to look for:

- Myeloma cells in bone marrow: a bone marrow biopsy. A pathologist will look at blood, tissue, and bone marrow samples under the microscope to identify cells. Used at the time of diagnosis and occasionally at relapse.

BIOMARKER TESTS DONE ON BONE MARROW SAMPLES to look for:

- Mutations in the DNA of myeloma cells: Fluorescence in situ hybridization (FISH), karyotyping, and DNA sequencing

Multiple Myeloma Information & Support

American Society of Clinical Oncology • 888-282-2552 • www.asco.org

CancerCare • 800-813-4673 • www.cancercares.org

National Institute of Health's Clinical Trial Search • ClinicalTrials.gov

International Myeloma Foundation • 800-452-2873 • www.myeloma.org

The Leukemia & Lymphoma Society • 800-955-4572 • www.LLS.org/myeloma

For clinical trials: www.LLS.org/clinicaltrials

Multiple Myeloma Research Foundations • 866-603-6628 • www.themmr.org

For clinical trials: www.themmr.org/treatment-options/clinical-trials

NCCN Guidelines for Patients: Multiple Myeloma • www.nccn.org/patientresources/patient-resources/

Myeloma Central • www.myelomacentral.com/

Patient Advocate Foundation • 800-532-5274 • www.patientadvocate.org

National Cancer Institute • 800-422-6237 • www.cancer.gov

Cancer Support Community Resources

The Cancer Support Community's (CSC) resources and programs are available free of charge. To access any of these resources below call 888-793-9355 or visit www.CancerSupportCommunity.org.

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–Fri, 9 am–9 pm 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. www.CancerSupportCommunity.org/FranklySpeakingAboutCancer.

Services at Local CSCs and Gilda's Clubs — With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. www.CancerSupportCommunity.org/FindLocation.

MyLifeLine — CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Connect with other Multiple Myeloma patients by joining the Managing Multiple Myeloma online discussion board. Sign up 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.

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

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This book is available to download and print yourself at www.CancerSupportCommunity.org/Multiple-Myeloma. For print copies of this booklet or other information about coping with cancer, visit Orders.CancerSupportCommunity.org.

The Cancer Support Community provides this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

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