

# Navigating Your Multiple Myeloma Journey

This guide was designed to help you understand what to expect, what to ask, and how to be an active partner in your care. Use what helps. Bring it to your appointments. Share it with the people who help take care of you.

**Important safety note.** Do not stop or change a medicine on your own. Always check with your care team first. For a fever of 100.4°F (38°C) or higher, trouble breathing, chest pain, sudden confusion, or heavy bleeding, call 911 or go to the emergency room. For other concerns, call your care team's main line.

## When you are newly diagnosed or in the smoldering stage

Most people have never heard of multiple myeloma before they are diagnosed. The first weeks bring a lot of new information. Your care team is your partner in making sense of it.

### Ask your care team:

- ▲ What type of multiple myeloma do I have, and what is my stage?
- ▲ Is treatment starting now, or are we monitoring first?
- ▲ If we are monitoring, what are we watching for, and how often will we check in?
- ▲ Who should I call between visits, and how do I reach them?

**Vaccinations.** Myeloma can affect your immune system, so vaccines are an important part of your care. Your care team will recommend which vaccines you need and when, based on your treatment plan.

**In the smoldering stage,** multiple myeloma is present but may not yet be active enough to need treatment. Your care team will monitor specific markers to know when treatment should start. Some patients with high-risk smoldering myeloma (eg, patients with smoldering myeloma that has markers associated with an increased

risk of disease progression) may be candidates for treatment or participation in a clinical trial.

**Ask your care team** how they are watching your disease, whether your risk is considered higher, and whether treatment or a trial might be right for you.

## Starting Treatment for Multiple Myeloma

*"Hearing from real people about how they felt when treatment started makes me feel more prepared and, curiously, more relaxed."* — A member of the Smart Patients MM community about to begin induction

Most patients newly diagnosed with multiple myeloma start with a combination of 3 or 4 medicines. A common combination today includes a CD38 monoclonal antibody (Sarclisa [isatuximab] or Darzalex [daratumumab]), a proteasome inhibitor (eg, Velcade [bortezomib]), an immunomodulatory drug (Revlimid [lenalidomide]), and dexamethasone. Your care team will choose the right combination for you based on your health, your goals, and whether a stem cell transplant may be part of your plan.

### Questions to ask before you start:

- ▲ Why is this combination right for me?
- ▲ Is a hematopoietic stem cell transplant part of the plan? When would we decide?
- ▲ How will we know if the treatment is working?
- ▲ Will I be able to continue working and exercising while I'm being treated? Will the quality of my time with my family change?

### Side effects and dexamethasone:

Dexamethasone, often called "dex," is a steroid used in most multiple myeloma treatment plans. It works well but can affect sleep and mood. Your care team has many ways to help manage side effects, including adjusting doses and timing. The most important thing is to tell your team what you are experiencing so they can help.

**When to call your care team:** Uncomfortable side effects, questions about how to take a medicine, or anything that feels off.

**When to call 911 or go to the ER:** Fever of 100.4°F or higher, trouble breathing, chest pain, sudden confusion, heavy bleeding, or severe new pain.



## When You Are in Active Treatment

Your care team will monitor your response to treatment and work with you on side effects along the way.



**Bone health.** Multiple myeloma can weaken bones, so many patients receive a bone-strengthening medicine like Zometa (zoledronic acid) or Xgeva (denosumab). Your care team may recommend a dental checkup before starting, since these medicines can affect the jaw if major dental work is needed during treatment.



**Brain fog and fatigue.** Some multiple myeloma medicines, especially Revlimid (lenalidomide) and Pomalyst (pomalidomide), can cause mild cognitive changes. Fatigue is common throughout treatment. Tell your care team what you are noticing. Dose adjustments and supportive care can help.



**Infection prevention.** Many multiple myeloma treatments lower your ability to fight infection. Wash your hands often, stay current on vaccines, and call your care team right away if you develop a fever.

### At your check-in visits, ask:

- ▲ How am I responding to treatment? What numbers are you watching (M-spike, free light chains, MRD)?
- ▲ Are there changes coming in my plan?
- ▲ What side effects can we work on together?
- ▲ Can you connect me with resources like support groups, a financial counselor, or a dietitian?

**A helpful question when facing a decision:** “If this were someone you cared about, what would you recommend?” This invites your care team to share the experience and judgment behind the options they are offering.



## When Your Treatment Changes

Treatment options for multiple myeloma have expanded significantly in recent years. If your disease changes or returns, your care team may discuss new options with you. Common ones include:

- ▲ **Antibody–drug conjugate combinations** (Blenrep [belantamab mafodotin]) given with other medicines. Given as injections.
- ▲ **Bispecific antibody therapy** (such as Elrexfio [elranatamab], Lynozyfic [linvoseltamab], Tecvayli [teclistamab], or Talvey [talquetamab]) sometimes given together or with other medicines. Given as injections after a short hospital stay for the first doses.
- ▲ **CAR T-cell therapy** (such as Carvykti [ciltacabtagene autoleucel] or Abecma [idecabtagene vicleucel]) uses your own immune cells, modified in a lab. Includes a hospital stay and a recovery period with a caregiver at home.
- ▲ **Clinical trials** of newer therapies.

**The order matters.** The sequence in which you receive these therapies can affect how well later ones work. Your care team is thinking about both your current treatment and what comes next.

### Questions to ask:

- ▲ Why is this option right for me now?
- ▲ How does this choice affect what we can do next?
- ▲ What does daily life look like on this treatment?
- ▲ Is a clinical trial something we should consider?



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**Side effects worth knowing about.** Bispecific antibodies and CAR T-cell therapies can cause cytokine release syndrome and immune effector cell–associated neurotoxicity syndrome during the first doses, which is why those are given in the hospital, where they can be managed. Talvey (talquetamab) is a bispecific antibody that works against a unique target and so may also cause changes in taste, dry mouth, and skin or nail changes. Blenrep (belantamab mafodotin) can affect the surface of the eye, so regular eye exams are part of treatment. Your care team will explain what to expect with your specific therapy and how they will help you manage what comes up.

**About eligibility.** Not every patient is a candidate for every therapy. Things like heart or kidney function, other medical conditions, or whether you have someone available to stay with you during recovery may shape what is right for you. Your care team will explain what options are open and why.



## For Care Partners

Care partners are an important part of the care team. You may be helping track medicines, watching for symptoms, coordinating appointments, or simply being present. This work matters.

### You can ask the care team:

- ▲ To speak with you directly, not only with the patient
- ▲ For written instructions you can refer to at home
- ▲ Who to call when you see something the patient does not
- ▲ About caregiver support resources at the cancer center

**Watch for and call about:** Fever of 100.4°F or higher, sudden confusion, new trouble breathing or chest pain, falls or new severe pain, or refusing fluids for half a day. When in doubt, call.

**Take care of yourself.** Caregiver burnout is real. Build a small group who understand what you are managing. Take breaks before you need them. Stay current on your own medical care. Many cancer centers and online groups offer caregiver support.



## Resources to Know About

Foundations that may help with copay costs: These funds open and close throughout the year. Sign up for email alerts to know when they open.

- ▲ Healthwell Foundation
- ▲ Patient Advocate Foundation Co-Pay Relief
- ▲ PAN Foundation
- ▲ Blood Cancer United (formerly LLS); also offers a \$500 clinical trial travel grant
- ▲ CancerCare

**Finding a multiple myeloma specialist.** Many patients work with both a local oncologist and a multiple myeloma specialist who they may see less often, sometimes by video visit. The HealthTree Foundation ([healthtree.org](http://healthtree.org)) and the International Myeloma Foundation ([myeloma.org](http://myeloma.org)) both have directories.

**Patient communities.** Smart Patients ([smartpatients.com](http://smartpatients.com)) hosts an active myeloma community where patients and care partners share experiences. The International Myeloma Foundation supports more than 150 patient-led local support groups across the country.

**Clinical trials.** Trials are an option at every stage, including newly diagnosed and smoldering myeloma. SparkCures ([sparkcures.com](http://sparkcures.com)) and [clinicaltrials.gov](http://clinicaltrials.gov) can help you and your care team identify trials that may be right for you.