

# HOW TO PLAY AN ACTIVE ROLE IN YOUR MYELOMA TREATMENT AND CARE DECISIONS

Program Resource Guide

<h3>ENGAGE IN YOUR CARE</h3> <ul style="list-style-type: none"> <li>▪ Educate yourself about your myeloma.</li> <li>▪ Partner with your healthcare team on care and treatment decisions.</li> <li>▪ Include a friend or family member in your appointments.</li> <li>▪ Consider a second opinion and/or a consult with a myeloma specialist.</li> </ul>	<h3>MYELOMA RESOURCES</h3> <ul style="list-style-type: none"> <li>▪ The Leukemia &amp; Lymphoma Society (LLS) <a href="http://LLS.org">LLS.org</a></li> <li>▪ Cancer Support Community <a href="http://cancersupportcommunity.org">cancersupportcommunity.org</a></li> <li>▪ Myeloma Crowd <a href="http://myelomacrowd.org">myelomacrowd.org</a></li> </ul>
<h3>SHARED DECISION-MAKING</h3> <p>Process of communication by which <b>patients and clinicians collaborate</b> to make healthcare decisions. The process encourages patients to <b>take a more active role</b> in their care and treatment.</p> <h3>ELEMENTS OF SHARED DECISION-MAKING</h3> <ul style="list-style-type: none"> <li>▪ Earning trust by developing a patient-doctor relationship</li> <li>▪ Empowering yourself by learning about your myeloma</li> <li>▪ Discussing what you learn with your doctor</li> <li>▪ Partnering with your doctor on your care and treatment decisions</li> </ul>	 <p><a href="mailto:question@powerfulpatients.org">question@powerfulpatients.org</a></p>   <p>@power4patients      PowerfulPatients.org</p>
<h3>YOUR MYELOMA TEAM</h3> <ul style="list-style-type: none"> <li>▪ Hematologist / oncologist</li> <li>▪ Advanced practice providers (APP), such as nurse practitioners or physician assistants</li> <li>▪ Nursing team of specialists</li> <li>▪ Nursing team for medication administration</li> <li>▪ Pharmacist</li> <li>▪ Social worker</li> </ul>	<h3>LEARN ABOUT CLINICAL TRIALS</h3> <ul style="list-style-type: none"> <li>▪ Consult with a myeloma specialist</li> <li>▪ Visit The Leukemia &amp; Lymphoma Society (LLS) <a href="http://LLS.org">LLS.org</a></li> <li>▪ Visit <a href="http://Clinicaltrials.gov">Clinicaltrials.gov</a></li> </ul> <h3>VISIT THESE RELATED PROGRAMS</h3> <ul style="list-style-type: none"> <li>▪ Myeloma Treatment Decisions: What Should Be Considered?</li> <li>▪ Myeloma Treatment: When Should a Clinical Trial Be Considered?</li> <li>▪ What You Need to Know Before Choosing a Cancer Treatment</li> <li>▪ Office Visit Planners for Myeloma Patients and Care Partners</li> </ul>

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## QUESTIONS TO ASK ABOUT YOUR MYELOMA TREATMENT PLAN

- What is the medication being used?
- What side effects might I expect?
- How should I take the medication?
- How do I obtain a refill?
- What type of myeloma do I have?
- Are there specific treatment options for my subtype of myeloma?

### Monoclonal Gammopathy of Undetermined Significance (MGUS)

Indicates an abnormal protein (M-protein) in the blood.

While there are no signs or symptoms, occasionally MGUS may progress to a serious condition or blood cancer, such as multiple myeloma.

### Smoldering Myeloma

A very slow-growing type of myeloma where abnormal plasma cells make too much of a single type of monoclonal antibody, and it builds up in the blood or is passed in the urine.

Patients with smoldering myeloma usually have no symptoms but should be monitored closely for signs of progression to multiple myeloma.

## GLOSSARY OF TERMS

**Anemia:** A condition that develops when the body lacks sufficient red blood cells. Symptoms of anemia may include fatigue, weakness, and shortness of breath, among others.

**M-Protein (M-Spike):** Abnormal protein secreted by plasma cells that usually indicate disease when found in the blood or urine. This M-protein is commonly associated with multiple myeloma.

**Minimal Residual Disease (MRD):** Measurement of the number of myeloma cells found in the bone marrow of patients in remission after a clinical response to treatment. MRD is relevant as the residual myeloma cells may indicate progression or relapse.

**Peripheral Neuropathy:** A condition that can affect many different types of nerves and is usually a gradual onset of numbness, pain, burning or tingling in the feet or hands, but can spread upward to the arms and legs.

**Stem Cell Transplant:** A procedure, also called a bone marrow transplant, in which healthy blood stem cells are used to replace damaged or diseased bone marrow. This procedure can be used to treat certain types of blood cancers, including myeloma.

### THE ROLE OF THE CAREGIVER

- Practical responsibilities, including organizing the activities of the day, scheduling appointments, providing transportation, etc.
- Being a trusted support person to share knowledge and aid in decision-making.
- Being a loving family member or friend.

### MORE TOOLS FOR EMPOWERMENT

- Digitally Empowered™
- PEN-Powered Activity Guide
- Empowered Blog
- Empowered! Podcast 