

THE PRO-ACTIVE MYELOMA PATIENT TOOLKIT

Program Resource Guide



TIPS FOR PATIENTS FACING A NEW MYELOMA DIAGNOSIS

- Seek a second opinion from a specialist in myeloma.
- Understand your staging, lab values, and risk factors.
- Know who is on your healthcare team and understand who will be in charge of your treatment plan.
- Gain a clear understanding of your treatment options, then work with your healthcare team to make a decision based on your myeloma.
- Consider joining a support group, either locally or online. Find a support group:
 - International Myeloma Foundation: <https://www.myeloma.org/support-groups>
 - The Leukemia & Lymphoma Society: <https://www.lls.org/support/support-groups>

OPTIMIZING OFFICE VISITS

- Prepare a list of questions and take notes. Download and print the Pro-Active Myeloma Patient Toolkit Office Visit Planner: <https://powerfulpatients.org/office-visit-planner-myeloma/>
- Bring a friend or family member and discuss your visit on the way home.
- Take part in treatment decisions. Questions to ask include:
 - What if my treatment does not work?
 - What are potential complications of treatment?
 - What are alternative treatment options?

RESOURCES FOR MYELOMA EDUCATION

The International Myeloma Foundation myeloma.org	Myeloma Crowd myelomacrowd.org
The Leukemia & Lymphoma Society lls.org	Patient Empowerment Network powerfulpatients.org
The Multiple Myeloma Research Foundation themmrf.org	Patient Power patientpower.info

GLOSSARY OF TERMS

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.

MGUS (monoclonal gammopathy of undetermined significance): 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.

MRD (minimal residual disease): 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: The condition can affect many different types of nerves but 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. The condition is often caused by multiple myeloma or its treatment.

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.