

# Survivorship Care Guidelines for Patients Living With Multiple Myeloma: Consensus Statements of the International Myeloma Foundation Nurse Leadership Board

Elizabeth Bilotti, MSN, APRN, BC, Beth M. Faiman, MSN, APRN-BC, AOCN®,  
Tiffany A. Richards, MS, ANP-BC, Joseph D. Tariman, PhD, APRN, BC,  
Teresa S. Miceli, RN, BSN, OCN®, Sandra I. Rome, RN, MN, AOCN®,  
and the International Myeloma Foundation Nurse Leadership Board

Novel therapies approved over the past decade for the management of multiple myeloma have contributed to improved overall survival in patients with newly diagnosed and relapsed disease. Nurses play a key role in educating, advocating for, and supporting patients throughout the continuum of care. Identifying potential and actual comorbid conditions associated directly with multiple myeloma and its treatment is important, as is confirming those that are patient specific so that prompt intervention can take place; therefore, the International Myeloma Foundation Nurse Leadership Board identified the most significant needs of patients diagnosed with multiple myeloma as bone health, health maintenance, mobility and safety, sexual dysfunction, and renal health. The Nurse Leadership Board then developed a survivorship care plan to assist healthcare providers and patients with multiple myeloma, their partners, and their caregivers to identify these needs.

**M**ultiple myeloma is a malignancy of the plasma cells that are derived from the B-cell lineage. Plasma cells play an integral part in humoral immunity by producing antigen-specific antibodies. Multiple myeloma is characterized by the overproduction of a monoclonal protein that can lead to numerous forms of end-organ damage. Clinical manifestations of multiple myeloma commonly include anemia, renal insufficiency, hypercalcemia, and bone loss and/or destruction (Munshi & Anderson, 2008). Multiple myeloma is the second most common hematologic malignancy in the United States, with an estimated 20,520 new cases diagnosed and 10,610 deaths occurring each

## At a Glance

- ◆ Patients with multiple myeloma are surviving longer and, therefore, may experience continuing effects of their disease and treatment.
- ◆ The International Myeloma Foundation Nurse Leadership Board has identified bone health, health maintenance, mobility and safety, sexual dysfunction, and renal health as areas of care to address for patients with multiple myeloma.
- ◆ The quality of life of survivors can be enhanced through knowledge and evidence-based assessments and interventions.

Elizabeth Bilotti, MSN, APRN, BC, is a nurse practitioner in the Multiple Myeloma Division of the John Theurer Cancer Center at Hackensack University Medical Center in New Jersey; Beth M. Faiman, MSN, APRN-BC, AOCN®, is a nurse practitioner in the Hematology and Medical Oncology Department at the Cleveland Clinic in Ohio; Tiffany A. Richards, MS, ANP-BC, is a nurse practitioner in the Department of Lymphoma/Myeloma at the University of Texas MD Anderson Cancer Center in Houston; Joseph D. Tariman, PhD, APRN, BC, is an advanced practice nurse in the myeloma program at Northwestern University in Chicago, IL; Teresa S. Miceli, RN, BSN, OCN®, is the bone marrow transplant RN coordinator at the Mayo Clinic in Rochester, MN; and Sandra I. Rome, RN, MN, AOCN®, is a clinical nurse specialist in the blood and marrow transplant program at Cedars-Sinai Medical Center in Los Angeles, CA. The authors take full responsibility for the content of this article. Publication of this supplement was made possible through an unrestricted educational grant to the International Myeloma Foundation from Celgene Corp. and Millennium: The Takeda Oncology Company. Bilotti is a consultant, advisory board member, and member of the speakers bureau for Millennium: The Takeda Oncology Company and Celgene Corp.; Faiman is a consultant and a member of the speakers bureau for Celgene Corp. and Millennium: The Takeda Oncology Company; Richards is a consultant and advisory board member for Millennium: The Takeda Oncology Company; and Tariman is a consultant with Millennium: The Takeda Oncology Company. The content of this article has been reviewed by independent peer reviewers to ensure that it is balanced, objective, and free from commercial bias. No financial relationships relevant to the content of this article have been disclosed by the independent peer reviewers or editorial staff. (First submission February 2011. Revision submitted March 2011. Accepted for publication March 26, 2011.)

Digital Object Identifier: 10.1188/11.S1.CJON.5-8

year (American Cancer Society, 2011). In addition, the median age at the time of diagnosis is estimated to be 70 years (Altekruse et al., 2009).

With the advent of novel therapies approved over the past decade for the management of multiple myeloma, an improvement has been noted in overall survival in both the newly diagnosed and relapsed patient populations (Kumar et al., 2010). The development and subsequent approval of the novel agents bortezomib, thalidomide, and lenalidomide have added dramatically to the arsenal of therapeutics clinicians have at their disposal for the management of multiple myeloma. Nurses play a key role in educating, advocating for, and supporting patients throughout the continuum of care. To allow for continued therapeutic benefit with minimal impact on quality of life, identifying potential and actual comorbid conditions, both disease- and patient-specific, is important and allows for prompt intervention.

## Overall Issue Statement

Patients diagnosed with multiple myeloma are living longer with the advent of new therapies. Although the disease is incurable, the depth of response, overall survival, and progression-free survival have improved dramatically when the results of autologous stem cell transplantation and regimens containing novel agents are compared with those of conventional chemotherapy (Rajkumar, 2008). According to the National Cancer Institute ([NCI], 2010a), survivorship covers the physical, psychosocial, and economic issues of cancer from diagnosis until

**Nurses play a key role in educating, advocating for, and supporting patients throughout the continuum of care.**

the end of life. Within the context of a multiple myeloma diagnosis, survivorship has become a reality with the overall survival at five years reaching 41% for those diag-

nosed in 2002, compared with only 28% for those diagnosed in 1975 (NCI, 2010b). With improvement in treatment modalities, the intent of therapy has shifted from a goal of palliation to a goal of finding a cure (Rajkumar, 2008).

Regardless of the treatment approach that is taken, assessment of access to healthcare, treatment-related toxicities, disease-specific comorbidities, and quality of life need to be addressed throughout the continuum of care. Based on the clinical experience of the International Myeloma Foundation (IMF) Nurse Leadership Board (NLB) members, a host of issues specific to patients with multiple myeloma were identified and addressed. The goal of this endeavor was to lessen the impact that unmanaged comorbid conditions have on the quantity and quality of life for those living with multiple myeloma through education, prevention, prompt detection, and intervention.

## Needs Assessment

The members of the NLB are clinically active, providing care for individuals and families directly affected by a diagnosis of

multiple myeloma. Through clinical experience, the NLB was aware that a specific and complex set of needs exists in this patient population. The NLB previously published the first comprehensive guidelines for managing novel therapy-associated side effects (e.g., myelosuppression, thromboembolic events, peripheral neuropathy, gastrointestinal disturbances) and steroid-associated side effects because novel agents are frequently prescribed in combination with steroids (Bertolotti et al., 2008). In 2008, the NLB began to discuss the need for an evidence-based approach to managing the survivorship concerns of this patient population. Based on a survey of NLB members and face-to-face discussion, the most significant patient-specific needs of those living with a diagnosis of multiple myeloma were determined to be bone health, health maintenance, mobility and safety, sexual dysfunction, and renal health. All of the conditions can either affect or be affected by the diagnosis and treatment of multiple myeloma. The NLB felt that optimizing the identification and stressing the importance of prompt intervention could lead to further improvement in the quality of life and overall survival of patients diagnosed with this disease.

## Survivorship Care Plan Development

Once the areas of interest had been identified, the NLB formed groups to create specific survivorship care plans. The NLB began by researching (via literature review and group discussions) how multiple myeloma affects individual comorbidities and how the presence of comorbidities affects the natural course of the disease and the disease-specific interventions. A literature review was conducted to determine what the current evidence-based assessment and interventions were and applied to patients with multiple myeloma. The final step in the process was making recommendations for a population-based approach to assessment, intervention, and education. This was intended for both those living with the diagnosis of multiple myeloma and those caring for loved ones (i.e., caregivers) to prevent complications associated with bone health, health maintenance, mobility and safety, sexual dysfunction, and renal health. The rationale for the survivorship care plans was presented in poster form at the 12th International Myeloma Workshop, held in Washington, DC, in 2009. Topics for each of the survivorship guidelines were outlined in a poster presentation at the 13th International Myeloma Workshop in Paris in May 2011.

### Bone Health

About 90% of patients diagnosed with multiple myeloma will develop osteolytic bone lesions at some time during the course of their disease. The clinical implications of osteolytic bone lesions include fractures, pain, spinal cord compression, hypercalcemia, and renal dysfunction. Alterations in skeletal integrity are a common consequence of multiple myeloma, and the impact on patients can range from diminished quality of life to negatively affecting overall survival. Therefore, the management of bone disease in patients with multiple myeloma is an integral part of the treatment plan.

The NLB recognizes that clinicians have the ability to identify patients at risk for disruption in skeletal integrity as a result of

the physiologic alterations in bone metabolism associated with multiple myeloma. Along with recognition of those at risk, an opportunity exists to recommend preventive and therapeutic interventions such as diagnostic monitoring, dietary counseling, medication administration, surgical procedures, and exercise promotion to minimize the risk of developing skeletal-related events. The goals of the bone health survivorship care plan are to illustrate the impact of adequate screening and intervention for bone disease and to provide practice recommendations to reduce and manage bone complications in patients with multiple myeloma.

**In this issue:** “Maintaining Bone Health in Patients With Multiple Myeloma: Survivorship Care Plan of the International Myeloma Foundation Nurse Leadership Board” (pp. 9–23).

## Health Maintenance

Multiple myeloma and the adverse events associated with treatment can contribute to a decline in well-being by affecting multiple organ systems. Inherent comorbid conditions in this patient population, with an average age at the time of diagnosis of 70 years, can negatively affect the ability of providers to prescribe and administer adequate antimyeloma therapy.

The NLB is aware that adequate screening and education may help prevent the onset and decrease the severity of comorbid conditions. Many commonly observed illnesses in this patient population include heart disease, endocrine disorders, sensory deficits, and bone loss (National Institute on Aging, 2009). Both multiple myeloma and its treatment can contribute to worsening of these underlying conditions, making it a challenge to manage this patient population. The goals of the health maintenance survivorship care plan are to

- Illustrate the impact of routine health maintenance screening and management of comorbid conditions in patients with multiple myeloma.
- Describe contributing modifiable and nonmodifiable risk factors for each comorbid condition.
- Provide current evidence-based screening recommendations to identify risk factors, whether from therapy, multiple myeloma, or part of the patient’s inherent risk unrelated to the diagnosis of multiple myeloma.

**In this issue:** “Routine Health Maintenance in Patients Living With Multiple Myeloma: Survivorship Care Plan of the International Myeloma Foundation Nurse Leadership Board” (pp. 25–40).

## Mobility and Safety

Although the actual incidence of falls in older adults is unknown, an estimated 33% of older adults will experience a fall. Common clinical consequences of multiple myeloma and its therapy include fatigue, weakness, neurologic compromise, metabolic disturbances, bone loss, pain, and decreased mobility. Because the majority of all patients diagnosed with multiple myeloma are older adults (age 65 and older), the risk of falling already exists and is enhanced by these additional risks. The adverse sequelae and increased morbidity associated with falls in older adults has an additional negative effect on the long-term prognosis for patients diagnosed with multiple myeloma.

The NLB has used clinical assessment tools as part of a multidisciplinary approach to patient management aimed at assessing

patient functional status. Understanding patients’ fall risk and current levels of functioning are integral to recommending appropriate interventions for prevention of immobility and the restoration of function. The goals of the functional mobility and safety survivorship care plan are to introduce the current screening tools available for assessment of risk and functional status, describe the contributing risk of both the multiple myeloma diagnosis and its treatment, and provide practice recommendations to reduce and manage immobility as well as improve safety in patients with multiple myeloma.

**In this issue:** “Mobility and Safety in the Multiple Myeloma Survivor: Survivorship Care Plan of the International Myeloma Foundation Nurse Leadership Board” (pp. 41–52).

## Sexual Dysfunction

Sexual dysfunction affects approximately 31%–43% of men and women in the United States (Ganz & Greendale, 2007). Contrary to popular belief, sexual dysfunction is not a part of the normal aging process and often occurs as a result of disease or treatment side effects.

Sexual dysfunction in patients living with multiple myeloma may result as a consequence of treatment, nerve root compression, or other comorbidities such as hyper-

tension, diabetes, or coronary artery disease. In addition, patients may develop body image disturbance or have pain as a result of their disease, which also affects their sexuality.

Patients and their partners may experience sexual dysfunction across the sexual response cycle, including desire, arousal, orgasm, or resolution. However, physiologic or psychological changes to sexuality are considered sexual dysfunction only when they have a negative effect on relationships. The sexuality survivorship care plan focuses on defining sexual dysfunction, discussing risk factors for the development of sexual dysfunction, providing tools for sexual assessment, and describing interventions for patients and their partners who may be experiencing a disruption of the sexual response cycle.

**In this issue:** “Sexual Dysfunction in Multiple Myeloma: Survivorship Care Plan of the International Myeloma Foundation Nurse Leadership Board” (pp. 53–65).

## Renal Health

Kidney dysfunction is one of the common clinical features of symptomatic multiple myeloma, which often is present for the duration of a patient’s lifespan. Decreased creatinine clearance is a common consequence of kidney dysfunction and, ultimately, affects clearance of antimyeloma therapies and other medications. In addition, chronic insult to the kidneys from other illnesses, treatment, or multiple myeloma itself negatively affects renal function and puts patients at higher risk for additional complications, such as bone loss, myelosuppression, infection, and anemia.

The NLB observed that clinicians have the ability to identify patients at risk for kidney damage as a result of multiple myeloma

Optimizing the identification and stressing the importance of prompt intervention can lead to further improvement in quality of life and overall survival.

and to institute preventive and therapeutic interventions to prevent progression to end-stage renal disease. The goals of the renal survivorship care plan are to illustrate the effect of adequate screening for kidney diseases in patients with multiple myeloma, describe contributing risk and environmental factors that may affect renal function both positively and negatively, and provide practice recommendations to reduce and manage renal complications in patients with multiple myeloma.

**In this issue:** “Renal Complications in Multiple Myeloma and Related Disorders: Survivorship Care Plan of the International Myeloma Foundation Nurse Leadership Board” (pp. 66–76).

## Future Directions

The NLB is collaborating with the IMF to disseminate the information compiled from the various components of the entire survivorship care plan tailored to address the disease-specific and demographic-specific assessments and interventions. The strategic plan for widespread dissemination to both healthcare providers and patients includes presentations at educational seminars and symposia (regional meetings and support groups), printed manuscripts, and patient and provider quick reference guides summarizing the recommendations.

An additional opportunity to increase the dissemination and improve the use of this information is related to the development of a computer-based interactive program to create patient-specific survivorship care plans. As recommended by the Institute of Medicine’s *From Cancer Patient to Cancer Survivor: Lost in Transition* report (Hewitt, Greenfield, & Stovall, 2006), this could include the traditional components of a care plan, such as diagnostic information, treatment summary, risk assessment, and prospective plans to address medical and psychosocial issues. In addition, recommendations related to the areas of interest identified as specific to the needs of patients with multiple myeloma could be included.

Ultimately, the goal of the NLB is to improve the quality of life of myeloma survivors by enhancing the knowledge of patients, caregivers, and healthcare providers through evidence-based, disease-specific assessments and interventions.

*The authors gratefully acknowledge Brian G.M. Durie, MD, Robert A. Kyle, MD, and Diane P. Moran, RN, MA, EdM, senior vice president of strategic planning at the International Myeloma*

*Foundation, for critical review of the manuscript; and Lynne Lederman, PhD, medical writer for the International Myeloma Foundation, for assistance in preparation of the manuscript.*

**Author Contact:** Elizabeth Bilotti, MSN, APRN, BC, can be reached at [ebilotti@humed.com](mailto:ebilotti@humed.com), with copy to editor at [CJONEditor@ons.org](mailto:CJONEditor@ons.org).

## References

- Altekruse, S.F., Kosary, C.L., Krapcho, M., Neyman, N., Aminou, R., Waldron, W., . . . Edwards, B.K. (2009). Surveillance Epidemiology and End Results. SEER cancer statistics review, 1975–2007. Retrieved from [http://seer.cancer.gov/csr/1975\\_2007](http://seer.cancer.gov/csr/1975_2007)
- American Cancer Society. (2011). *Cancer facts and figures, 2011*. Washington, DC: Author.
- Bertolotti, P., Bilotti, E., Colson, K., Curran, K., Doss, D., Faiman B., & The International Myeloma Foundation Nurse Leadership Board. (2008). Management of side effects of novel therapies for multiple myeloma: Consensus statements of the IMF Nurse Leadership Board. *Clinical Journal of Oncology Nursing, 12*(3, Suppl.), 9–12.
- Ganz, P.A., & Greendale, G.A. (2007). Female sexual desire—Beyond testosterone. *Journal of the National Cancer Institute, 99*, 659–661. doi:10.1093/jnci/djk175
- Hewitt, M., Greenfield, S., & Stovall, E. (2006). *From cancer patient to cancer survivor: Lost in transition*. Washington, DC: National Academies Press.
- Kumar, S.K., Rajkumar, S.V., Dispenzieri, A., Lacy, M.Q., Hayman, S.R., Buadi, F.K., . . . Gertz, M.A. (2010). Improved survival in multiple myeloma and the impact of novel therapies. *Blood, 111*, 2516–2520. doi:10.1182/blood-2007-10-116129
- Munshi, N.C., & Anderson, K.C. (2008). Plasma cell neoplasms. In V.T. DeVita Jr., T. Lawrence, & S.A. Rosenberg (Eds.), *Cancer principles and practice of oncology* (8th ed., pp. 2305–2342). Philadelphia, PA: Lippincott Williams and Wilkins.
- National Cancer Institute. (2010a). Dictionary of cancer terms. Retrieved from <http://www.cancer.gov/dictionary/?expand=5>
- National Cancer Institute. (2010b). Fast facts—Statistics stratified by cancer site: Surveillance Epidemiology and End Results. Retrieved from <http://seer.cancer.gov/faststats/selections.php?#Output>
- National Institute on Aging. (2009). Working Group 3: Effects of comorbidity on cancer. Retrieved from <http://www.nia.nih.gov/ResearchInformation/ConferencesAndMeetings/WorkshopReport/WorkingGroupReports/WorkingGroup3.htm>
- Rajkumar, S.V. (2008). Treatment of myeloma: Cure versus control. *Mayo Clinic Proceedings, 83*, 1142–1145. doi:10.4065/83.10.1142