

# Caregivers of Multiple Myeloma Survivors

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Patients living with multiple myeloma (MM) face complex decisions throughout their journey relative to their diagnosis, options for treatment, and how their disease and treatment choices may affect them physically, emotionally, financially, and spiritually. Patients considering a hematopoietic stem cell transplantation face specific self-management challenges. The availability of a reliable caregiver is a prerequisite to transplantation eligibility. Currently, the majority of clinical management is episodic and provided in the outpatient setting. Therefore, the bulk of care for patients living with MM is provided by the patient together with his or her caregivers. Caregivers face similar challenges to those faced by the patient living with MM. They are required to take in complex information, perform often complicated or technical procedures such as line care or injections, assist the patient with activities of daily living, and attend the myriad of appointments required. Understanding the dynamics of the patient-caregiver relationship, the strengths and weaknesses unique to that relationship, common elements of caregiver stress or strain, and available tools and strategies to promote a sense of control and enhance self-management skills may improve the health-related quality of life for both the patient with MM and his or her caregiver.

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Living with multiple myeloma (MM), either as a patient or as a caregiver, implies a need to adapt to the requirements of the diagnosis, how it affects the individual patient, and what changes are necessary to support the patient, including treatment and supportive care.

The patients and caregivers spend the majority of their time at home and receive the bulk of their health care in the outpatient setting. Therefore, assimilating complex information, often very rapidly, and developing skills for self-management of many complex processes is expected. The complexity of self-management skills and behaviors of patients and caregivers varies based on the individual disease attributes, the treatment plan, the general health of the patient, and social and financial situations unique to each patient. The chronic disease trajectory of MM is characterized by variability in survival and time to progression or relapse. Each relapse brings new challenges, and each episode of care creates patient and caregiver vulnerability. Patients considering a hematopoietic stem cell transplantation (HSCT) face specific self-management challenges. The availability of a reliable caregiver is a prerequisite to transplantation eligibility.

The diagnosis of MM, as with most cancer diagnoses, is a life-changing event. For the caregiver, whether formal or informal, this includes the uncertainty associated with a complex diagnosis, the fear of losing a loved one, and the often immediate need to provide skilled care, emotional support, and assistance with day-to-day necessities. Caregivers are most often relatives of the patient, but also may be friends, acquaintances, or volunteers. The number of caregivers and how they interact with the patient will vary, and all caregivers will experience some level of stress and feelings of uncertainty. In addition to struggling to find a unique role in supporting the patient, the caregiver also is dealing with his or her own feelings about the patient's diagnosis with an incurable disease, the often sudden change in day-to-day activities, and the uncertainty about the ability to provide care for the patient. Having unexpected changes in the plan of care based on changes in the patient status is not uncommon, which adds to the stress for both the patient and the caregiver. Understanding the role of the caregiver in patients living with MM (including those undergoing HSCT), the dynamics of the patient-caregiver relationship, and the key

elements of caregiver stress are necessary to effectively support both patients with MM and caregivers. The majority of patients with MM are older adults, requiring a working knowledge of the unique needs of the older adult for effective management. For younger patients, considering the change in family dynamics is necessary, as are the common challenges of managing a family with children while managing the care requirements for the patient. Optimal patient outcomes require the development of tools and strategies to support caregivers of MM survivors.

## Preparing the Patient and Caregiver for Self-Management

The overall goal for the treatment of MM remains an early and sustained complete response (CR) with an acceptable level of toxicity and quality of life (QOL) (Palumbo & Cavallo, 2012). Achieving a CR has been identified as a key factor in improved progression-free survival and overall survival (OS); however, achieving a CR does not imply eradication of the malignant clone. The improvement in OS over time is attributed primarily to novel agents, with patients exposed to these agents achieving statistically significant longer survival compared to those who have not (Palumbo & Anderson, 2011). HSCT remains an important treatment option for MM in patients eligible for transplantation. This approach to therapy requires planning and collaboration among multiple healthcare providers, the patients, and their caregivers to allow adequate preparation for treatment, follow-up, and effective management of the expected treatment-emergent adverse events (TEAEs). Proactive and aggressive TEAE management is critical to allowing continuation of each treatment long enough to obtain and maintain an optimal response. Early identification and prompt intervention of common TEAEs will limit the severity of treatment and reduce the probability of patients discontinuing treatment prematurely.

With the majority of care provided in the outpatient setting, patients and their caregivers are expected to take a primary role in the self-management of their disease, including early identification and reporting of TEAEs. Some of the key elements of the caregiver role are provided in Figure 1. Many informal caregivers may feel inadequately prepared to assume responsibility for these tasks because of a lack of knowledge, the presence of health problems themselves, or preexisting dynamics between the patient and the caregiver (van Ryn et al., 2011). This may increase caregiver stress and contribute to a sense of loss of control.

Patient and family education with consistent information, frequent reinforcement of key concepts, and active participation of the patient and family is critical to optimizing outcomes (Kurtin & Demakos, 2010). Communicating clearly to the patients, and their caregivers, as well as to any collaborating providers, will reduce the anxiety associated with expected TEAEs and encourage consistency in the approach to management. Patients and caregivers should be encouraged to keep a binder that includes important contact information, a patient medical history, medications, supportive care resources, and a log of their treatment plan, blood counts, transfusion history, TEAEs, and how they were treated. This will provide an invaluable tool for not only the patient and caregiver, but also the healthcare team.

### Direct Care

- Monitoring and reporting or recording treatment side effects
- Administering medications
- Deciding whether to call a healthcare provider
- Deciding whether medicine is needed
- Performing technical procedures: dressing changes, line care
- Communicating with healthcare providers

### Care Coordination and Life Management

- Transportation
- Accompanying the patient to appointments
- Communication to other family members, friends; being a gate keeper and advocate
- Household maintenance, financial management, shopping, cooking
- Availability for emergencies
- Completing medical forms, keeping track of bills, applications for assistance
- Engaging the healthcare system

### Emotional Support

- Balancing medical expectations while maintaining hope
- Listening
- Providing reassurance

FIGURE 1. Key Elements of the Caregiver Role

Individualizing patient and caregiver education also will encourage effective self-management behaviors. The average American reads at an eighth-grade level; however, most patient education materials are written well above that level (Fagerlin, Zikmund-Fisher, & Ubel, 2011). Visits to healthcare professionals often last 15–20 minutes, making it difficult to communicate complex ideas in a way that the patient and family will be able to understand, synthesize, and apply to informed care decisions. Healthcare professionals expect patients, family members, or other designated caregivers to assume a primary role in managing the illnesses (including managing TEAEs), reporting signs and symptoms, communicating among providers, and continuing to take an active role in decision making (Kurtin, 2012). However, patients with multiple health problems may have difficulty understanding the complexity of balancing their cancer treatment with the continued management of existing illnesses.

The most common toxicity associated with all active therapies for MM, including a transplantation, is myelosuppression (Kurtin & Bilotti, 2013). Infections, neutropenic fevers, and bleeding are the most common reasons patients seek emergency treatment following transplantation and are a major cause of morbidity and mortality. Although the definition of engraftment suggests adequate bone marrow function for outpatient management, many centers are conducting the majority of care for patients undergoing autologous HSCT (AHSCT) in the outpatient setting. Setting expectations for expected cytopenias and the anticipated time to recovery, providing concrete criteria for monitoring and reporting the signs and symptoms that require immediate attention, and developing standards for interventions will provide reassurance to the patient, promote early identification and treatment of infections, and limit

hospitalizations. Each preparative regimen, ongoing treatment, and supportive care plan will carry specific recommendations for frequency of clinic visits, laboratory monitoring, ancillary testing, and supportive care. An individualized plan for monitoring and managing TEAEs should be prepared, discussed, and updated throughout the transplantation process to assist the patient and his or her caregiver in self-management.

## Impact of Patient Quality of Life on the Caregiver

Caregiving intensity will vary throughout the MM disease continuum based on a number of treatment-, disease-, and patient-related factors. Similarly, health-related QOL (HRQOL) for the patient also will vary. Understanding factors that impact HRQOL for the patient with MM is necessary for understanding the variability in caregiver stress and QOL throughout the disease and treatment trajectory, and will provide guidance in developing tools and strategies for support of the caregiver.

Patients who receive an AHST can generally expect to return to or surpass pretransplantation physical and emotional role function and QOL. Patients with anxiety, depression, and symptom distress prior to transplantation are more likely to experience these same symptoms in the post-transplantation period, and women are more likely to experience post-transplantation depression overall (Wells, Booth-Jones, & Jacobsen, 2009). In addition, women generally return to work later than men and are less likely to return to work overall than men (Kirchoff, Leisenring, & Syrjala, 2010). Older adult patients are more likely to adapt socially following transplantation (Sherman, Simonton, Latif, Plante, & Anaissie, 2009). Understanding these elements of patient HRQOL is essential to anticipating and evaluating potential caregiver strain and caregiver QOL.

Langer, Yi, Storer, and Syrjala (2010) conducted a prospective longitudinal study evaluating marital adjustment, satisfaction, and dissolution among 121 patients undergoing HSCT and 117 spouses at six time points starting with the pretransplantation evaluation period through five years of follow-up. Fifty-nine of the 121 initially married patients with a participating spouse survived to five years with only 7% (n = 4, two male, two female patients) of the marriages ending in dissolution. Interestingly, female spouses reported a higher rate of relationship maladjustment at all time points in the study. The authors suggest that these findings specific to female spouses of male patients may reflect societal norms in which females are expected to be caregivers, the tendency for female caregivers to provide the care without enlisting the help of family and friends, and the fact that women in general are more likely to be affected by the physical and psychological distress of their male partner/patient (Langer et al., 2010). The ability of the caregiver to adapt to the multitude of stressors inherent in the process of HSCT for patients with MM has been shown to affect family relationships important to the post-transplantation adjustment of the patient (Fife, Monahan, Abonour, Wood, & Stump, 2009).

Although at least 20 different assessment tools exist for screening adult caregivers of patients undergoing HSCT, the impact of caregiver strain or burnout on patient outcomes is not well researched in the MM and HSCT literature (Wulff-Burchfield,

Jagasia, & Savani, 2013). Concepts gleaned from studies in other high-risk populations, including the mentally ill and frail older adults, suggest caregiver stress or burnout may negatively affect mortality, frequency of hospitalizations, and adherence to treatment routines (Wulff-Burchfield et al., 2013). Assessment of caregiver stress should be incorporated throughout the treatment continuum. Common signs of caregiver stress include anxiety, depression, emotional distress, loss of appetite, weight loss, fatigue, sleep disturbance, and loss of physical strength (Bevans & Sternberg, 2012; Wulff-Burchfield et al., 2013) (see Figure 2).

Fife et al. (2009) examined factors influencing the adaptation of caregivers of patients undergoing HSCT (N = 192) prior to hospitalization for transplantation (T1), during the hospitalization following the stem cell infusion, about one week prior to planned discharge (T2), and one month after discharge (T3). The patients included varied diagnoses, including MM, with 151 patients undergoing AHST (79%) and 41 patients (21%) undergoing allogenic HSCT. The majority of caregivers participating in this study were female (72%), married to the patient (91%), working full time (58%), and Caucasian (93%). Emotional distress increased significantly from T1 to T3, and coping strategies declined in that same time period. Interestingly, the sense of personal control, spirituality, and the caregiver-patient relationship remained stable from T1 to T3. A greater sense of personal control (p < 0.001), spirituality (p < 0.001), and active coping (p < 0.001) were strongly correlated with adaptation and lower levels of distress. Increased patient symptoms (p < 0.0001), financial strain (p = 0.0033), caregiver life changes (p < 0.0236), and avoidance as a coping strategy (p = 0.0079) were correlated with increased levels of distress. Avoidance was associated with negative adaptation.

<b>Physical Health Problems</b>	Pain, loss of physical strength, sleep disorders, fatigue and exhaustion, changes in appetite, sexual dysfunction, decreased libido, and exacerbation of preexisting health problems
<b>Social Problems</b>	Changes in usual routines and lifestyle; social isolation; reduced contact with outside family, friends, colleagues; and changes in work status, such as increased days off, distraction, loss of employment
<b>Emotional Problems</b>	Anxiety, fear, uncertainty, despair, disbelief, depression, sorrow and a sense of loss, loneliness, feelings of inadequacy, powerlessness, and feeling a lack of control
<b>Financial Problems</b>	Loss of wages, difficulty in paying bills; lack of sick leave; managing health claims and bills; premature use of retirement funds, often with penalty; and inability to contribute to 401(k) with loss of employer-matched contributions

**FIGURE 2. Selected Problems Faced by Caregivers**

Note. Based on information from Armoogum et al., 2013; Ferrell et al., 2013; Fife et al., 2009; Molassiotis et al., 2011; Stenberg et al., 2010; van Ryan et al., 2011; Wulff-Burchfield et al., 2013.



## Implications for Practice

- ▶ Educate caregivers about the stresses and expectations they will face during the patient's journey with multiple myeloma.
- ▶ Provide assistance to caregivers of patients with multiple myeloma by suggesting hospital and community resources to help them cope with added responsibility.
- ▶ Assess caregivers for impaired quality of life caused by the physical and emotional demands of assisting the patient through pre- and post-treatment phases of care.

These data emphasize the need to adequately assess the coping strategies, patient-caregiver dynamics and communication patterns, and elements of spirituality (sense of meaning and peace as well as faith) for both the patient and caregiver prior to, during, and following HSCT. Strategies to adequately prepare the patient and caregiver for self-management strategies will promote a sense of personal control.

Screening the patient and caregivers, both together and separately, for pretransplantation stressors and existing coping behaviors, with periodic reassessment may reduce caregiver strain by assisting with a tailored support plan. Setting realistic

**Caregiver Stress–10 Symptoms** identifies key stress-related symptoms often experienced by caregivers.

<http://myeloma.org/SGLTools/support/Caregiver-Stress---10-Symptoms.pdf>

**Caring for the Caregiver** is a booklet created by the National Cancer Institute that offers both recommendations and resources for caregivers of patients with cancer.

[www.cancer.gov/cancertopics/coping/caring-for-the-caregiver](http://www.cancer.gov/cancertopics/coping/caring-for-the-caregiver)

**Coping Tips for Caregivers A–Z** offers 26 tips from the International Myeloma Foundation.

[http://myeloma.org/images/link\\_thumb\\_nail/copingtipscaregivers.jpg](http://myeloma.org/images/link_thumb_nail/copingtipscaregivers.jpg)

**Coping With the Cost of Cancer** is a comprehensive guide by the Cancer Support Community that offers strategies, tips, and resources for managing the financial aspects of cancer care.

<http://myeloma.org/SGLTools/support/Coping-with-the-Cost-of-Care.pdf>

**Facing Forward: When Someone You Love Has Completed Cancer Treatment** is a booklet created by the National Cancer Institute that shares common reactions and feelings that many caregivers experience once treatment is over. It also shares practical tips to help caregivers navigate through this time.

[www.cancer.gov/cancertopics/coping/someone-you-love-completed-cancer-treatment](http://www.cancer.gov/cancertopics/coping/someone-you-love-completed-cancer-treatment)

**Now You Are a Caregiver** is a part of the Caregiver Resource Directory. It includes important forms, such as a daily pain journal, a medication schedule, and a fatigue journal.

[www.netofcare.org/content/pdf/1-nowyouarecaregiver.pdf](http://www.netofcare.org/content/pdf/1-nowyouarecaregiver.pdf)

**Taking Care of Yourself** is an article highlighting side effects that some caregivers may experience, and strategies for their management and prevention.

[www.curetoday.com/index.cfm/fuseaction/article.show/id/2/article\\_id/185](http://www.curetoday.com/index.cfm/fuseaction/article.show/id/2/article_id/185)

FIGURE 3. Caregiver Resources

expectations for the patient and caregiver prior to signing the consent for HSCT, in terms of potential physical, emotional, social, and spiritual challenges, with expected duration of these changes, based on the individual patient attributes and type of transplantation, may help in identifying the needed support. Understanding the common patient and caregiver perceptions and associated daily activities will allow development of patient- and caregiver-specific supportive care strategies. All caregivers should be encouraged to outline their available resources including family, friends, volunteers, organizations, and Internet resources. Female caregivers of male patients, in particular, should be encouraged to seek tangible help from family and friends and take breaks from caregiving.

Communication strategies between caregivers and patients vary widely. Discordance between caregiver and patient knowledge-seeking behaviors may add burden to the caregiver, particularly in instances where bad news may be shared (Molasiotis, Wilson, Blair, Howe, & Cavet, 2011). The caregiver must prepare for the possibility of an unfavorable outcome, in some cases even death of the patient, but may be conflicted with a need to bolster hope while continuing to help the patient manage the day-to-day tasks of living with MM. Strategies to promote effective patient and caregiver self-management include several key elements: consistent and clear communication that allows the patient to make informed decisions, reinforcement of key messages at each visit, adjustment of visit frequency to the specific phase of survivorship and healthcare needs, integration of community programs and resources, and development of mutually determined goals (Kurtin, 2012; McCorkle et al., 2011). Key qualities of clear communication include adequate description of the disease and prognosis; open, honest, and timely communication; and increased patient participation in decision making with clinician assessment of individual preferences for information (Colosia et al., 2011; Rodin et al., 2009). Communication of risks versus benefits is perhaps one of the most complicated processes necessary for informed decision making and consent for treatment, including HSCT. Healthcare professional descriptions often are complex and not well understood by the patient and family (Fagerlin et al., 2011).

Healthcare professionals can provide additional support by allowing patients adequate time to review presented material, if clinically possible; providing written materials in addition to verbal explanations; identifying community-based, national, or international resources for patient support; and incorporating members of the multidisciplinary team in the discussion with patients (Barry, 2011; McCorkle et al., 2011). Selected resources for patients with MM and caregivers are included in Figure 3. Optimally, the multidisciplinary team members will be well informed about the individual patient situation to avoid conflicting or confusing messages. Incorporation of adult learning principles, adaptation for language barriers, and consideration of the spiritual and cultural needs of the patient and caregiver are ideal.

## Caregiver Self-Care

The level of distress experienced by caregivers of patients undergoing HSCT has been shown to exceed that of the patient themselves, and caregivers are less likely to be screened for,

### Disease-Related Information

- Causes, disease process
- Severity and prognosis

### Treatment-Related Information

- Treatment options and expected outcomes
- Expected side effects, monitoring, and treatment strategies
- Complementary and alternative therapies
- Options for a second opinion
- Insurance coverage and out-of-pocket expenses
- Nutrition and activity guidelines for the patient
- When and who to call for help
- Criteria and procedure for emergent care
- Operating policies for each setting of care: visitation, children, supplies, expected duration of appointment or length of hospital stays
- Record keeping

HSCT—hematopoietic stem cell transplantation; OT—occupational therapist; PT—physical therapist

### Support Services

- Support groups: disease-specific, HSCT-focused, and general
- Local, regional, national, and international organizations
- Drug assistance programs
- Spiritual, religious, and cultural support
- Communication skills—providers, family, friends
- In-home assistance: skilled care, PT or OT, custodial care, household work
- Food or grocery delivery services

### Caregiver Self-Care

- Maintaining a healthy lifestyle: nutrition, exercise, sleep
- Relaxation or meditation
- Intimacy or sexual health
- Spirituality
- Treatment for depression and anxiety
- How to ask for and organize help

## FIGURE 4. Caregiver Support and Informational Needs

seek, and receive support services (Fife et al., 2009; Langer et al., 2010). Factors associated with caregiver distress include avoidance behaviors, financial strain, and life changes for the caregiver. Financial strain is inevitable for patients undergoing an HSCT. Loss of employment and, in many cases, a fear of losing insurance is of major concern. This may present added stress in trying to balance the needs of the patient, the need to maintain employment, manage a household, and care for other members of the family. If the patient is the primary wage earner, the spouse or partner may need to seek additional employment. Patients who are single and have limited or no access to relatives as caregivers present a particular challenge.

Out-of-pocket expenses during treatment may be substantial and add to financial strain. A pilot study conducted by Majhail et al. (2013) evaluating out-of-pocket expenses for patients and caregivers ( $n = 22$ ) in the first three months following HSCT estimated median expenses of \$2,440 (range = \$199–\$13,769), with those requiring temporary relocation to housing near the transplantation center incurring higher expenses than those who do not require relocation (median = \$5,247 versus \$716). The majority of patients in this pilot study had private insurance through a managed care plan (56%), with Medicaid (20%) and Medicare (18%) being less common (Majhail et al., 2013). Meehan et al. (2006) estimated median out-of-pocket costs for housing for the caregiver during the patient's inpatient stay to be \$560. In addition to housing, copayments for visits and medications, transportation, and food represented the most common sources of out-of-pocket expenses in these studies. Prior authorization for HSCT is a part of the initial screening of patient eligibility. Similar rigor should be applied in discussion of individual financial resources, including anticipated out-of-pocket expenses based on the region and available assistance programs.

Sherwood et al. (2008) evaluated 80 caregivers of patients with primary brain tumors. An increased need for assistance with independent ADLs in patients was correlated with lost time from work in this population of caregivers. Measures of ADLs or independent ADLs have been incorporated into measures of vulnerability (performance status, comorbidities,

and frailty) and are central to risk-adapted treatment selection for patients being considered for a stem cell transplantation or other more intensive therapies for MM (Palumbo et al., 2011).

Caregiver life change is a complex concept with wide variability. Caregiver burden is a result of the responsibilities of caregiving (direct care, indirect care, other care responsibilities) and the changes in normal routines and lifestyle as a result of these responsibilities (Stenberg, Ruland, & Miaskowski, 2010). All caregivers experience some level of caregiver burden and secondary effects on physical, social, and emotional well-being. For those caregivers who continue to work, the added burden of caregiving may affect work life and the ability to maintain employment. Several studies have identified a number of physical, social, emotional, and spiritual elements of caregiver burden or distress. Familiarity with these attributes will assist in assessing caregiver distress, developing individualized support strategies, and promoting caregiver self-care (see Figure 4).

Some of the unmet needs identified by caregivers in these studies include managing concerns for cancer recurrence, finding out about financial support and government benefits, strategies to maintain the caregiver's own physical and emotional health, balancing the needs of the patient with the caregivers own needs, sexuality and sexual health, and dealing with other caregivers and non-caregivers (Armoogum, Richardson, & Armes, 2013; Ferrell, Hanson, & Grant, 2013).

## Conclusion

Caregivers are essential for the optimal outcomes of patients with MM throughout the disease process, in particular during HSCT. Active participation of caregivers, whether formal or informal, is expected to be, yet not always, readily available or feasible for all patients. Familiarity with local, regional, national, and international resources together with development of local network of support will facilitate development of an interdisciplinary and individualized supportive care plan. The vulnerability of the patients and their caregivers in the transplantation process requires careful assessment of potential attributes or

dynamics that place them at risk. Similar to the widely accepted approach to risk-adapted treatment selection based on disease and individual clinical attributes, an equally rigorous risk-adapted approach must be applied to assessment and planning for both the patient and the caregiver. Understanding the dynamics of the patient-caregiver relationship, the strengths and weakness unique to that relationship, common elements of caregiver stress or strain, and available tools and strategies to promote a sense of control and enhanced self-management skills may improve the HRQOL for both the patient and the caregiver.

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## References

- Armoogum, J., Richardson, A., & Armes, J. (2013). A survey of the supportive care needs of informal caregivers of adult bone marrow transplant patients. *Supportive Care in Cancer, 21*, 977-986. doi:10.1007/s00520-012-1615-4
- Barry, M.J. (2011). Helping patients make better personal health decisions: The promise of patient-centered outcomes research. *JAMA, 306*, 1258-1259. doi:10.1001/jama.2011.1363
- Bevans, M.F., & Sternberg, E.F. (2012). Caregiving burden, stress, and health effects among family caregivers of adult cancer patients. *JAMA, 307*, 398-403. doi:10.1001/jama.2012.29
- Colosia, A.D., Peltz, G., Pohl, G., Liu, E., Copely-Merriman, K., Khan, S., & Kay, J.A. (2011). A review and characterization of the various perceptions of quality cancer care. *Cancer, 117*, 884-896. doi:10.1002/cncr.25644
- Fagerlin, A., Zikmund-Fisher, B.J., & Ubel, P.A. (2011). Helping patients decide: Ten steps to better risk communication. *Journal of the National Cancer Institute, 103*, 1436-1443. doi:10.1093/jnci/djr318
- Ferrell, B., Hanson, J., & Grant, M. (2013). An overview and evaluation of the oncology family caregiver project: Improving quality of life and quality of care of oncology family caregivers. *Psycho-Oncology, 22*, 1645-1652. doi:10.1002/pon.3198
- Fife, B.L., Monahan, P.O., Abonour, R., Wood, L.L., & Stump, T.E. (2009). Adaptation of family caregivers during the acute phase of adult BMT. *Bone Marrow Transplantation, 43*, 959-966. doi:10.1038/bmt.2008.405
- Kirchoff, A.C., Leisenring, W., & Syrjala, K.L. (2010). Prospective predictors of return to work in the five years after hematopoietic cell transplantation. *Journal of Cancer Survivorship, 4*, 33-44. doi:10.1007/s11764-009-0105-2
- Kurtin, S. (2012). Primary care of the cancer survivor: A collaborative continuum-based model for care. In J. Payne (Ed.), *Current trends in oncology nursing* (pp. 191-210). Pittsburgh, PA: Oncology Nursing Society.
- Kurtin, S., & Bilotti, E. (2013). Novel agents for the treatment of multiple myeloma: Proteasome inhibitors and immunomodulatory agents. *Journal of Advanced Practice Oncology, 4*, 307-321.
- Kurtin, S.E., & Demakos, E.P. (2010). An update on the treatment of myelodysplastic syndromes [Online exclusive]. *Clinical Journal of Oncology Nursing, 14*, E29-E44. doi:10.1188/10.CJON.E29-E44
- Langer, S.L., Yi, J.C., Storer, B.E., & Syrjala, K.L. (2010). Marital adjustment, satisfaction, and dissolution among hematopoietic stem cell transplant patients and spouses: A prospective, five-year longitudinal investigation. *Psycho-Oncology, 19*, 190-200. doi:10.1002/pon.1542
- Mahjail, N.S., Rizzo, J.D., Hahn, T., Lee, S.J., McCarthy, P.L., Ammi, M., . . . Pederson, K. (2013). Pilot study of patient and caregiver out-of-pocket costs of allogeneic hematopoietic cell transplantation. *Bone Marrow Transplantation, 48*, 865-871. doi:10.1038/bmt.2012.248
- McCorkle, R., Ercolano, E., Lazenby, M., Schulman-Green, D., Schilling, L.S., Lorig, K., & Wagner, E.H. (2011). Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA: A Cancer Journal for Clinicians, 61*, 50-62. doi:10.3322/caac.20093
- Meehan, K.R., Fitzmaurice, T., Root, L., Kimitis, E., Patchett, L., & Hill, J. (2006). The financial requirements and time commitments of caregivers for autologous stem cell transplant recipients. *Journal of Supportive Oncology, 4*, 187-190.
- Molassiotis, A., Wilson, B., Blair, S., Howe, T., & Cavet, J. (2011). Living with multiple myeloma: Experiences of patients and their informal caregivers. *Supportive Care in Cancer, 19*, 101-111. doi:10.1007/s00520-009-0793-1
- Palumbo, A., & Anderson, K. (2011). Multiple myeloma. *New England Journal of Medicine, 364*, 1046-1060.
- Palumbo, A., Brinchen, S., Ludwig, H., Dimopoulos, M.A., Blade, J., Mateos, M.V., . . . Sonneveld, P. (2011). Personalized therapy in multiple myeloma according to patient age and vulnerability: A report of the European Myeloma Network (EMN). *Blood, 118*, 4519-4529. doi:10.1056/NEJMra1011442
- Palumbo, A., & Cavallo, F. (2012). Have drug combinations supplanted stem cell transplantation in myeloma? *Blood, 120*, 4692-4698. doi:10.1182/blood-2012-05-423202
- Rodin, G., Mackay, J.A., Zimmerman, C., Mayer, C., Howell, D., Katz, M., . . . Brouwers, M. (2009). Clinician-patient communication: A systematic review. *Supportive Care in Cancer, 17*, 627-644. doi:10.1007/s00520-009-0601-y
- Sherman, A.C., Simonton, S., Latif, U., Plante, T.G., & Anaissie, E.J. (2009). Changes in quality-of-life and psychosocial adjustment among multiple myeloma patients treated with high-dose melphalan and autologous stem cell transplantation. *Biology of Blood Marrow Transplantation, 15*, 12-20. doi: 10.1016/j.bbmt.2008.09.023
- Sherwood, P.R., Donovan, H.S., Given, C.W., Lu, X., Given, B.A., Hricik, A., & Bradley, S. (2008). Predictors of employment and lost hours from work in cancer caregivers. *Psycho-Oncology, 17*, 598-605. doi:10.1002/pon.1287
- Stenberg, U., Ruland, C.M., & Miaskowski, C. (2010). Review of the literature on the effects of caring for a patient with cancer. *Psycho-Oncology, 19*, 1013-1025. doi:10.1002/pon.1670
- van Ryn, M., Sanders, S., Kahn, K., van Houtven, C., Griffin, J.M., Martin, M., . . . Rowland, J. (2011). Objective burden, resources, and other stressors among informal cancer caregivers: A hidden quality issue? *Psycho-Oncology, 20*, 44-52. doi:10.1002/pon.1703
- Wells, K.J., Booth-Jones, M., & Jacobsen, P.B. (2009). Do coping and social support predict depression and anxiety in patients undergoing hematopoietic stem cell transplantation? *Journal of Psychosocial Oncology, 27*, 297-315.
- Wulff-Burchfield, E.M., Jagasia, M., & Savani, B.N. (2013). Long-term follow-up of informal caregivers after allo-SCT: A systematic review. *Bone Marrow Transplantation, 48*, 469-473. doi:10.1038/bmt.2012.123



# Hematopoietic Stem Cell Transplantation for Multiple Myeloma

**Y**ou or someone you know has been diagnosed with multiple myeloma (MM) and has been considered for a hematopoietic stem cell transplantation (HSCT). Hearing the words HSCT or bone marrow transplantation can be frightening. You probably have many questions.

Caregivers, described as anyone who is providing assistance to the patient diagnosed with myeloma, also are living with myeloma. Each caregiver experience is unique, based

on the amount of care you are providing, the complexity of the care, and how independent your loved one is.

Caregivers also can experience anxiety and depression. The demands on you, both physical and emotional, can at times be overwhelming. It is important that you, the caregiver, know that you are not alone. A number of resources and healthcare professionals are available to help you prepare for the HSCT, organize your resources, and stay well during the process.

*Several key concepts will help you manage the role of caregiver for the patient with MM during the HSCT process.*

Although your loved one may have difficult days, allow the myeloma survivor to do as much self-care as possible. This will help them to stay active, maintain stamina, and become independent. There will be days when your loved one needs more help. Ask your healthcare team for guidance in balancing their need for assistance with their capability for independence throughout the HSCT process.

Seek support for caring for the myeloma survivor. Discuss the day-to-day challenges of caregiving with the healthcare team at each visit, recognize that asking for help is OK, and seek out support and assistance from other family members and friends to allow for breaks.

Organize your resources and assign or define specific tasks. For example, "I need someone to take [the patient] to the clinic on Tuesday mornings at 8 am."

Make a list of things you need. Keep it updated as the needs change. Continue to ask for help.

- One item that friends can assist with is creating a blue box. Have friends organize a box of small gift items, sayings, jokes, prayers, or good thoughts that you can take out one by one when you're having a blue day. In addition, explore strategies for communicating with family and friends, assign a gate keeper, and consider online resources: [www.caringbridge.com](http://www.caringbridge.com) or [www.lotsahelpinghands.com](http://www.lotsahelpinghands.com).

Know that all things are not of equal importance. Some things need immediate attention, some things can wait; prioritize. Myeloma is a like roller coaster, with many ups and downs. It's not a sprint, it's a marathon. You need to pace yourself and deal with priorities as they come up. Sometimes "good enough" is "good enough."

- Group tasks by categories (i.e., work, family, household tasks, personal care tasks, errands, and physician visits).

### Do Not Let Your Insurance Lapse

If the patient carries the insurance and is going to be out of work for a long period of time, find out if you have long-term disability or short-term disability. You may also need to look into COBRA. Familiarize yourself with the most current laws, both local and national, that may affect your ability to obtain health insurance.



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- Create a list from your group of tasks and manage by the level of importance.

Join a support group or attend group meetings for caregivers and/or patients with myeloma. Talk with family, friends, clergy, or others about your thoughts or worries instead of keeping them inside.

Ask for help from family and friends to maintain your household.

- If your transplantation center is near your home, you may need help with housework, yard work, home maintenance, and other day-to-day activities needed to run a household.

If you need to relocate temporarily for the HSCT, you will need to explore options for a house sitter and others needed to maintain the home until you return. When you return, it is unlikely you and the myeloma survivor will be able to maintain the home without some help.

Ask for help in organizing care for your family members or your pets. If you are relocating to another city for the HSCT, ask about the policies for visitation for family members and pets. Find out what resources are available in your home center and in the transplantation center for support of children with a parent who is undergoing a HSCT.

Plan ahead. You may need to consider time off work if possible. As soon as HSCT is discussed as a possible treatment option, discuss the best time to use any time off to meet the demands of the HSCT process ([www.dol.gov/whd/regs/statutes/fmla.htm](http://www.dol.gov/whd/regs/statutes/fmla.htm)).

*(Continued on the next page)*

## Caregiver Guide (Continued)

Considering the impact of your loved one's health on your family's finances can be a major source of anxiety.

- Contact your insurance carrier and find out exactly what your deductibles are. If you have a cap, determine what your maximum out-of-pocket expenses are, what providers are in network, and how out-of-network providers are handled.

Seek out a myeloma specialist or get a second opinion. If there are no myeloma specialists in your area (50-mile radius), petition your insurance provider that an out-of-network myeloma specialist be considered in network.

Ask for an insurance case management worker. This person will be your point of contact for all insurance billing and questions, with no need to re-explain the entire case each time you call. Case managers are available for all life-threatening conditions with all insurance companies.

Every state has a state insurance department. Contact them for unbiased insurance information and local laws. They also provide resources for finding insurance companies, pools, filing, financial requirements, and much more.

There currently is a two-year waiting period to get on Medicare. You may qualify for supplemental Social Security disability during this period. Consider making an appointment with your local Medicare office to help with the paperwork and requirements to avoid possible denials. If you are denied, appeal. Ask if a Medicare representative is available who has handled other patients diagnosed with myeloma (they will know the proper codes and procedures to get a quicker approval). For more information visit [www.medicare.gov](http://www.medicare.gov).

Contact your town hall for available services, including home heating oil, electricity, school lunch programs, church ministries, or food pantries, as needed.

If you were not in charge of handling home finances, you'll need to get up to speed. If you always handled the bills, be prepared to make adjustments depending on your finances.

- Remember that every bill is negotiable, including medical bills. Call all of your creditors and let them know you or your

### Organize Your Contacts

Transplantation center healthcare team and contact information should include the following:

Center: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

Physician: \_\_\_\_\_

Nurse practitioner or physician assistant: \_\_\_\_\_

Transplant coordinator: \_\_\_\_\_

Social worker: \_\_\_\_\_

Nutritionist: \_\_\_\_\_

Physical therapist: \_\_\_\_\_

Pharmacist: \_\_\_\_\_

Other support: \_\_\_\_\_

### Self-Care Tips and Resources

- Taking care of yourself is necessary to continue the caregiver role. <http://bmtinfonet.org/before/caregivers>
- Join a support group that provides support to caregivers. Contact the International Myeloma Foundation to locate a group near you. [www.myeloma.org](http://www.myeloma.org)
- Schedule regular medical and dental evaluations for yourself.
- Participate in activities that help to rejuvenate your energy (i.e., crafts, meditation, massage, and music therapy) and avoid burnout. <http://bit.ly/16jutNz>
- Write in a journal to express your feelings and experiences.
- Participate in health-promotion activities, such as a healthy diet, physical activity, and restful sleep.
- Information can be found at the National Caregiver's Library [www.caregiverslibrary.org/home.aspx](http://www.caregiverslibrary.org/home.aspx)

spouse is out of work and would like to make payment arrangements. Have an amount in mind that you can afford each month and offer that as your payment. As long as you are making payments, your account will not go to collections. Keep your credit intact by continuing monthly payments.

- Also, you may have to reduce or cut out some services. Eating out, TV, and phone extras may need to be cut back. Use coupons when possible.

Visit the International Myeloma Foundation website for additional information regarding possible side effects and strategies for symptom management and wellness ([www.myeloma.org](http://www.myeloma.org)).

Ask for assistance in planning for the HSCT process.

- Pretransplantation evaluation
  - Time required at the transplantation center, housing options, preparation for any testing, how soon will testing results be available, and when will the final decision to proceed to transplantation be made
- Hospitalization
  - Preparative regimen and side effects, infusion of peripheral stem cells and side effects, engraftment, common adverse events and management, discharge criteria, visitation policies, and housing options for families
- Outpatient care
  - How to prepare the home prior to discharge, frequency of visits, expectation of the caregiver, and can the myeloma survivor be alone?
    - What symptoms require immediate or emergency care? What special precautions are needed for the patient? Are there any dietary restrictions? Specific care guidelines and any equipment needed?
    - Taking a temperature, heart rate, respiratory rate, and blood pressure; central venous catheter care; medication management; drug-drug interactions; drug-food interactions; calendar to organize treatment schedule: tests and clinic visits
    - Log for tracking any reactions, side effects, intolerance; make notes of drugs, dates, and describe events; resources for drug assistance; dates medication refills are required.