

MyelomaAcademy™



NURSING BEST PRACTICE GUIDE

Palliative Care

This document is one of the Myeloma Academy Nursing Best Practice Guides for the Management of Myeloma series. The purpose of this Guide is to enhance knowledge and inform nursing practice on the provision of palliative care for myeloma patients.

After reading this, you should be able to:

- ★ Understand what palliative care entails
- ★ Understand how palliative care can help patients throughout the course of their myeloma
- ★ Understand the nurse's role in the palliative care assessment, intervention and management in myeloma

The information contained within this Guide should be used in conjunction with local policies, protocols and best practice guidelines in oncology.

Background

Myeloma is a complex cancer that is associated with a myriad of symptoms and complications that build up over time. A diagnosis of myeloma and its subsequent treatment can have a devastating impact on patients' quality of life, as well as on the lives of families and carers. The physical and psychological burden of myeloma can be

very debilitating, therefore patients and their families may require palliative input and care throughout the course of their myeloma.

Palliative care describes the active holistic approach to improve the quality of life of patients and their families at every stage from diagnosis onwards. Although myeloma is generally considered incurable, a high, and

KEY FACTS

- ★ General principles of palliative care should be part of a patient's care from diagnosis to end of life
- ★ Supportive care in myeloma is complex and utilising specialist palliative care is essential for some patients
- ★ Palliative care can make a significant difference in improving quality of life for myeloma patients using a holistic approach and integrating psychosocial aspects of patient care
- ★ Patients with symptoms that are difficult to control under routine care can benefit greatly from specialist palliative care input at all stages of their disease

increasing proportion of patients will achieve a good remission following initial treatment but will have complications and symptoms that come and go over time.

Palliative care principles are part of the supportive care of myeloma patients throughout their disease and should not be confused with end of life care. Palliative care can be misunderstood by patients, carers and even by health and social care professionals, as being synonymous with terminal or end of life care^[1]. End of life care is an important part of palliative care, but is just one part.

Typically, palliative care focuses on the concerns of patients and their families and:

- ★ Helps patients manage physical symptoms such as pain, nausea and fatigue
- ★ Considers the psychological and spiritual concerns of patients and families and respects their social and cultural needs
- ★ Uses a team approach to address the needs of patients and their families
- ★ Provides a support system to help patients live as actively as possible until death
- ★ Provides support, advice and care in preparing for and at end of life
- ★ Provides a support system to help families cope during the patient's illness, including bereavement

Depending on patients' and families' needs, palliative care can be differentiated into general palliative care and specialist palliative care.

General palliative care

Is an integral part of routine care delivered by a wide range of health and social professionals working within hospital practice, primary health care and other community places of care involving GPs, hospital doctors and nurses, district nurses and social care staff. Generally, palliative care principles should be part of a patient's care from diagnosis and, in the form of bereavement support, should continue beyond death.

Specialist palliative care

Is provided by specifically trained multidisciplinary teams in hospital, community and hospice settings and delivered in various care settings^[2]. Specialist palliative care can help patients with complex needs and difficult to treat symptoms including bone pain, fatigue, hypercalcaemia and peripheral neuropathy. Other more acute symptoms that may benefit from specialist palliative care include mucositis, nausea and vomiting, constipation and diarrhoea. Physical symptoms are often accompanied by psychological distress, particularly if a patient's treatment options are becoming more limited.

Although, by definition, palliative care is not aimed at treatment of myeloma itself, or extending survival, there is some evidence that earlier palliative care may help extend life in advanced cancer^[3]. Furthermore, by reducing inappropriate treatment, early palliative care may have cost benefits^[4].

The following describes the general approach to palliative care for myeloma patients and provides best practice guidance for nursing interventions and nursing management. It does not cover palliative care towards the end of life, which is found in the **Myeloma Academy Nursing Best Practice Guide: End of Life Care**.

GENERAL RECOMMENDATIONS:

- ★ Assessment and discussion of patients' physical, psychological, social and spiritual needs should be carried out on a regular basis
- ★ Patients should be referred as early as possible for specialist palliative care input to manage symptoms not responsive to standard supportive approaches
- ★ Effective communication between the hospital, community and primary care teams is necessary for effective palliative care to be delivered

NURSING RECOMMENDATIONS:

- ★ The role of palliative care in the management of myeloma should be explained to myeloma patients and their families early on in their care
- ★ Patients' symptoms, and the effectiveness of symptom control measures, should be regularly assessed and monitored
- ★ It is important to find out from the patient and their family how symptoms are impacting their quality of life, and physical and psychological wellbeing
- ★ Patients and families should be provided with information about local palliative care services that are available to them

Medical Approach

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Palliative care plays an integral part in the overall supportive care for myeloma patients. This section provides details of the general medical approach to palliative care in myeloma.

Assessment

Holistic assessment

Holistic needs assessment lies at the core of effective delivery of palliative care and should be an ongoing process throughout the course of the patient's myeloma but particularly at key points around the time post diagnosis, during/after treatment and where disease status or treatment changes.

Active listening and effective communication is key to gaining an understanding of patients' needs. Structured assessments should be carried out that include:

- ★ Physical needs
- ★ Social and occupational needs
- ★ Psychological wellbeing
- ★ Spiritual wellbeing

Various assessment tools are available such as 'The Sheffield Profile for Assessment and Referral to Care (SPARC)' questionnaire and the 'Distress Thermometer' to help inform discussions with patients about their concerns and to formulate action plans.

Assessment of what family and social support patients have and how they are managing at home will help determine their support needs. Activities of daily living may be affected but can be improved by good symptom management or helped with appropriate referral and support. Some palliative care teams have a social worker, physiotherapist and occupational therapist who can provide direct support.

Mood changes affect almost all patients with myeloma at varying times in their disease course, particularly at times of

relapse and if treatment options are limited. Psychological wellbeing can also be significantly affected by the presence of chronic pain, fatigue or other debilitating symptoms, with subsequent effects on a patient's quality of life. If there is persistent distress (more than two weeks), further support is recommended. **See the Myeloma Academy Nursing Best Practice Guide on Psychological Support.**

Assessment should also include patients' spiritual needs which may or may not be related to religion. Spirituality may be defined as a person's sense of peace, purpose and connections with others and beliefs about the meaning of life. Sensitive discussion and assessment should be made in terms of the past (regrets, guilt, shame), present (anger, grief for future, loss of own life, lost sense of purpose) and the future (hopes/fears of dying and death). Questions should be open-ended to draw out meaningful answers from patients.

Specific symptom assessment

In addition to holistic needs assessments, ongoing assessment of specific symptoms using appropriate tools and grading is essential in providing effective symptom management. It is important that symptoms are assessed regularly to determine whether treatment strategies are effective or not and if specialist palliative care is needed. For example, patients who repeatedly score pain over 5/10 should be referred^[5]. The National Cancer Institute (NCI) common toxicity criteria^[6] can be used to grade symptoms, for example, peripheral neuropathy, nausea, constipation or diarrhoea.

Referral

For many patients specialist palliative care will be needed at some stage in their disease pathway. General indicators for referral include one or more of the following:

- ★ The patient has progressive advanced disease, a limited prognosis, and the focus of care is on quality of life
- ★ If patients have complex symptoms (both on or off active myeloma treatment)

- ★ The patient has unresolved complex needs that require more in-depth assessment and review that would benefit from specialist expertise. This might include complicated symptoms, difficult family situations, or ethical issues regarding treatment decisions
- ★ Where patients are undergoing key transition points during the course of their myeloma to assess the need for further specialist services in the community i.e. day hospice, community palliative care nurses
- ★ If healthcare professionals require specialist advice and support in management of patients' symptoms

There are no nationally agreed criteria for access to specialist palliative care services^[2] and teams and areas will vary in the services they are able to provide. Specialist palliative care teams usually have individual referral criteria to ensure they prioritise patients within their catchment area who most require their specialist input.

Ensuring the patient consents for referral to specialist palliative care is essential and the reason for referral should be explained to ensure patients and their families understand. For example a patient may be referred to community specialist palliative care for pain and symptom management and will be managed by a team based in a local hospice. If this is not explained clearly it can cause considerable upset for patients and their families, who may wrongly perceive that the patient is at the end of life.

Following referral to specialist palliative care good communication and close liaison between the treating haematology team and palliative care is essential to ensure continuity of care and optimum symptom management.

Understanding patients' wishes

It is important to understand the wishes of patients who are living with a progressive disease such as myeloma and outcomes are uncertain. Advance care directives (ACD) are documents which, after informed

discussion, can give patients an opportunity to establish what forms of care they do, or do not wish to receive. Examples include whether patients wish to receive dialysis if they develop renal failure, or if they wish to receive intravenous antibiotics whether they develop a life-threatening infection. Discussion on ACD is sometimes avoided because it is thought this will induce anxiety and that patients will 'lose hope', but evidence suggests this is not the case^[7]. A do not attempt resuscitation (DNAR) request may be included in an ACD or made out separately.

Symptom management

Managing symptoms and meeting supportive care needs to enhance quality of life is already embodied in the standard day-to-day care of myeloma patients and families and delivered by haematologists, nurses, GPs and district nurses.

Several Myeloma Academy Nursing Best Practice Guides are available on the nursing management of a range of symptoms and complications associated with myeloma and should be referred to for guidance on specific treatment and management issues. Relevant guides include those on:

- ★ Pain
- ★ Fatigue
- ★ Peripheral neuropathy
- ★ Gastrointestinal (GI) toxicities
- ★ Psychological support

As mentioned, if a patient has been referred for specialist palliative care, liaison between the hospital and community teams is particularly important, and the role of the patient's key worker is central. An example would be a patient who requires opiates for pain relief in the community; it is necessary to establish who is responsible for co-ordinating management of their analgesia; this would include monitoring effectiveness, adverse effects and decisions about dose adjustment or escalation of treatment. Communicating changes in treatment is essential from both the hospital and community teams.

Palliative care services

Hospices may have a day hospice service facility as part of the support they can provide. This might be for a fixed number of sessions, or be open-ended, depending on the individual service. Day hospices may be able to offer symptom management, complementary therapies, befriending, physiotherapy, occupational therapy, counselling or social worker access. This service may also help patients feel less isolated and give family members some free time to focus on their own needs.

Some hospices offer short inpatient stays for complex symptom management needs or for respite care. A few hospices have facilities for red cell transfusions.

Nursing interventions and management

Nurses are key members of the multidisciplinary team and play a central role in the palliative care of myeloma patients.

The following provides best practice recommendations for nursing interventions related to palliative care provision in myeloma, and for nursing management involving a holistic approach to care and in providing education and support for myeloma patients and families.

Interventions

- ★ Carry out a comprehensive and regular holistic needs assessment
- ★ Regularly assess symptoms and the impact of other comorbidities or malignancies
- ★ Use appropriate scales/measures to assess and report to the medical team pain, neuropathy or GI toxicity
- ★ Assess the effect of symptom management and report unrelieved or poorly managed symptoms to the medical team
- ★ Request a review if treatment requires modification or changing with documented evidence of patient assessment and treatment to date
- ★ Liaise with the medical team about referral to specialist palliative care team
- ★ Contact specialist palliative care teams for advice when needed
- ★ Liaise with the primary care team to ensure continuity of palliative care when the patient is discharged or treatment changes are made

Management

- ★ Ensure that a patient consents to referral for specialist palliative care, and understands why they are being referred and what this means for them
- ★ Advise the patient and family of the importance of reporting changes in symptoms and provide details of the appropriate healthcare team to contact
- ★ If a patient is being discharged home, clarify who is responsible for which aspects of ongoing palliative care, for example monitoring of pain control and potential dose changes of analgesia
- ★ Find out what palliative care services are available locally for patients
- ★ Consider whether a patient may benefit from attending a day hospice, if available
- ★ Promote good communication between all healthcare professionals involved in management of the patient and ensure community teams are updated about any changes to treatment
- ★ Use principles of good communication to help patients express their wishes and concerns
- ★ Development of refractory myeloma may be an appropriate time to initiate discussion on patients' wishes, including those at end of life



Summary

Myeloma patients frequently have symptoms that require both general and specialist palliative care approaches. Nurses play a crucial role in communicating with patients and monitoring and managing symptoms, and palliative care principles should be part of routine supportive care. Nurses can also initiate timely referrals for specialist palliative care support to promote optimum symptom management.

Nurses also have a role in providing education and support to patients and families about the role of palliative care in relieving symptoms and promoting quality of life at all stages of myeloma.

Abbreviations

★ **ACD** Advance care directive

★ **DNAR** Do not attempt resuscitation

★ **SPARC** Sheffield profile for assessment and referral for care



Appendix I

Useful resources

- ★ **Myeloma Academy Nursing Best Practice Guide: End of Life**
- ★ **Myeloma UK Planning Ahead: an Infopack for myeloma patients**
- ★ **NICE - Improving supportive and palliative care for adults with cancer**
www.nice.org.uk/guidance/csg4 (2004)
The NICE clinical guidance on supportive and palliative care (CSG) advises those who develop and deliver cancer services for adults with cancer about what is needed to make sure that patients, and their families and carers, are well informed, cared for and supported.
- ★ **National Council for Palliative Care**
www.ncpc.org.uk/
The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland.
- ★ **Scottish Partnership for Palliative Care**
www.palliativecarescotland.org.uk/
The Scottish Partnership for Palliative Care is an umbrella and representative organisation which, through a collaborative approach, supports and contributes to the development and strategic direction of palliative care in Scotland.
- ★ **BMJ Supportive and Palliative Care journal**
<http://spcare.bmj.com/>
An international journal that aims to improve supportive and palliative care for patients through research, evidence and innovative practice



References

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6. National Cancer Institute, *Common Terminology Criteria for Adverse Events v4.0*. 2009.
7. Green, M.J., et al., *Advance Care Planning Does Not Adversely Affect Hope or Anxiety Among Patients With Advanced Cancer*. J Pain Symptom Manage, 2015. **49**(6): p. 1088-96

ABOUT THE NURSING BEST PRACTICE GUIDES

The Nursing Best Practice Guides have been developed by Myeloma UK and an expert nursing advisory group, with input from relevant specialist healthcare professionals. They have been developed to enhance nurse knowledge, inform nursing practice and support nurses in the delivery of high quality treatment and care to myeloma patients and families.

Nursing Best Practice Guide series:

- ★ Complementary therapies
- ★ Fatigue
- ★ Gastrointestinal toxicities
- ★ End of life care
- ★ Myeloma bone disease
- ★ Myeloma kidney disease
- ★ Myelosuppression
- ★ Oral mucositis
- ★ Pain
- ★ Palliative care
- ★ Peripheral neuropathy
- ★ Psychological support
- ★ Steroids
- ★ Venous thromboembolic events

ABOUT THE MYELOMA ACADEMY

The Myeloma Academy provides healthcare professionals involved in the treatment and care of myeloma patients with access to comprehensive accredited learning resources and tools in an innovative online environment and through educational events.

It supports the education and continual professional development of myeloma healthcare professionals so they can provide optimum patient-centred treatment and care within the current UK health and policy environment.

For more information visit:

www.myeloma-academy.org.uk or by email **academy@myeloma.org.uk**

ABOUT MYELOMA UK

Myeloma UK is the only organisation in the UK dealing exclusively with myeloma.

Our mission is to provide information and support to people affected by myeloma and to improve standards of treatment and care through research, education, campaigning and raising awareness.

For more information about Myeloma UK and what we do, please visit **www.myeloma.org.uk** or contact us at **myelomauk@myeloma.org.uk** or **+44 (0)131 557 3332**.



Notes



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