

# MyelomaAcademy™

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## The Myeloma Nursing Best Practice Guides

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# Aims of the Myeloma Nursing Best Practice Guides

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**The Myeloma Nursing Best Practice Guides have been developed to enhance nurse knowledge and inform nursing practice, to support nurses to deliver the highest quality of treatment, care and support to myeloma patients and their families.**

The Myeloma Nursing Best Practice Guides aim to:

- ★ Provide myeloma-specific nursing guidance outlining the key areas of nursing responsibility, interventions and management in the treatment and care of myeloma patients.
- ★ Provide nurses with the information required to play an informed and expert role in a multidisciplinary team and to better represent the patient needs.
- ★ Support nurses to help patients make informed decisions about their treatment and care.

## How to use the Myeloma Nursing Best Practice Guides

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The Guides have been developed in line with current clinical guidelines, position papers and consensus of expert opinion in the treatment and care of myeloma patients. The Guides are appropriate for use in all four UK home nations.

The Guides provide nurses with practical guidance on the:

- ★ treatment and management of common complications of myeloma
- ★ the management of treatment of side-effects
- ★ provision of holistic nursing support throughout the patient's myeloma pathway

The Guides should be used in conjunction with local policies, protocols and best practice guidelines but are appropriate for use by nurses at all levels, in any healthcare setting and throughout the patient's myeloma pathway including:

- ★ Diagnosis
- ★ Hospital care
- ★ Primary care
- ★ Treatment
- ★ Decisions about clinical trial participation
- ★ Management of symptoms and complications
- ★ Rehabilitation
- ★ Pre/post transplantation care
- ★ Palliative and end of life care

# The role of the nurse in myeloma treatment and care

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Nurses have the following important roles in the treatment and care of myeloma patients, to:

- ★ Be involved in the multidisciplinary team as a key member contributing to patient treatment, care and management
- ★ Ensure that nursing goals reflect the changing nature of myeloma as it progresses and as treatment, care and management are adapted to account for individual patient circumstances and characteristics
- ★ Provide targeted information in the right format at the right time to:
  - ★ Enable patients and their families to make informed decisions about their treatment and care
  - ★ Ensure patients are more in control of their situation
  - ★ Support patients to recognise the importance of treatment compliance and reporting of side-effects, to aid prompt resolution of any issues
- ★ Be the patient's main point of contact, coordinating treatment and care
- ★ Ensure continuity of treatment and care throughout all care settings
- ★ Use advanced skills in communication and education to support patients, their carers and families at all stages of myeloma
- ★ Have the experience and judgement to assess patients' physical and psychological responses to treatment and be able to take appropriate action in a timely way
- ★ Contribute to achieving the best outcomes for the patient
- ★ Act as a source of expertise for a wide range of clinical staff who are involved in the treatment and care of myeloma patients, but not necessarily myeloma specialists or routinely encountering myeloma patients

## MYELOMA: AN INTRODUCTION

Myeloma is a rare, complex and heterogeneous cancer of the bone marrow. It is characterised by a wide range of comorbidities and serious clinical complications including bone fractures, anaemia and kidney damage.

Myeloma comprises 2% of overall cases of cancer in the UK and is the second most common blood cancer with about 5,500 people diagnosed per year<sup>[1]</sup>, and is about 1½ times more common in men than women and twice as common in Afro-Caribbean groups compared to the Caucasian population.

There are approximately 17,500 people in the UK with myeloma at any one time<sup>[2]</sup>. Myeloma typically occurs in older people, with a median age at diagnosis of 70, meaning that many patients have comorbidities which may impact on their treatment, management and care plans<sup>[3]</sup>. There is no clear geographic distribution of

myeloma but there are marked variations in incidence between ethnic populations ranging from 3.9/100,000 in Chinese to 12.7/100,000 in African individuals<sup>[4]</sup>.

Recent advances in myeloma treatment mean that myeloma patients are living longer and can have a greater proportion of treatment delivered in an outpatient or community setting<sup>[5]</sup>. However, whilst treatment options and overall survival figures have improved considerably in the last decade, myeloma typically runs a course of multiple remissions and relapses and still has an ultimately fatal outcome for patients.

The complex clinical features of myeloma and the range of complications associated with it means that the treatment, management and care of myeloma patients is challenging, requiring input from a broad range of healthcare professionals in which nurses play a vital role.

# Background to the Myeloma Nursing Best Practice Guides

Myeloma UK identified that:

- ★ Nurse-specific myeloma best practice guides did not exist
- ★ There was growing evidence from patients, their families and carers in contact with Myeloma UK that there were inconsistencies in myeloma treatment and care across the UK
- ★ Feedback from nurses involved in Myeloma UK nurse programmes indicated that that Best Practice Guides would be valued as a resource

The development and implementation of the Best Practice Guides seeks to meet the needs of nurses but also to address several identified risks:

- ★ Risks to patients of not receiving high quality nursing care, which may impact on access to treatment, clinical outcomes and patient experience
- ★ Risks to nurses of operating within a field where they do not have sufficient knowledge or expertise
- ★ Risks for the wider multidisciplinary team and allied healthcare professionals of not having access to a nurse with expertise in myeloma, for advice
- ★ Risks to Myeloma UK of increased pressure on our patient and family services as a result of patients and families not receiving high quality treatment and care

# Myeloma Nursing Best Practice Guide development

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**Each individual Best Practice Guide has a full reference list outlining the evidence base used in developing the Guide.**

The Guides were developed by undertaking a thorough literature search and review of existing local guidance, position papers and guidelines, including the British Committee for Standards in Haematology (BCSH), RCN National Collaborating Centre for Nursing and Supportive Care (NCC-NSC) Clinical Guidelines, National Institute for Health and Care Excellence (NICE) guidelines and the Pan Birmingham Cancer Network – Guidance for the Management of Patients with Myeloma.

Based on the literature and evidence base review we assembled an expert review committee consisting of myeloma clinical nurse specialists and consultant haematologists who have an in-depth knowledge and understanding of myeloma as well as experts in cancer nursing and nurse education. Where evidence was lacking, a consensus of expert opinion was developed.

The original Best Practice Guide review committee included:

- ★ Myeloma UK Programme team
- ★ Dr Judith Behrens  
Consultant Haematologist
- ★ Marvelle Brown  
Macmillan Haematology Senior Lecturer  
(Haematology)
- ★ Shirley Crofts  
Myeloma Clinical Nurse Specialist
- ★ Flora Dangwa  
Clinical Lead for Specialist Nursing
- ★ Sophie Deppe  
Macmillan Myeloma Clinical  
Nurse Specialist
- ★ Jeff Horn  
Macmillan Haematology Clinical  
Nurse Specialist

- ★ Mary Kelly  
Advanced Haematology  
Nurse Practitioner
- ★ Tracy King  
Myeloma Clinical Nurse Consultant
- ★ Monica Morris  
Macmillan Haematology/Oncology  
Clinical Nurse Specialist
- ★ Dr Moira Stephens  
Lecturer
- ★ Sharon West  
Myeloma Clinical Nurse Specialist

All updates and newly published Guides are externally peer reviewed by nursing and clinical myeloma experts.

# Myeloma Nursing Best Practice Guide content

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**The Best Practice Guides aim to support nurses by providing practical information and guidance on the nursing interventions and management required in the treatment and care of myeloma patients.**

The Guides also support nurses to become specialists in their role and aid continuous improvement to patient care and nursing development.

# Myeloma Nursing Best Practice Guide audience

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**The Guides have been developed with a patient-centred holistic approach and consider the broad myeloma patient population, their families and carers.**

They are applicable to the treatment and care of all myeloma patients, irrespective of their race, gender, disability, sexual orientation, religion or age and as such are compliant with the RCN's Diversity Standard and Equality Impact Framework. They are also applicable to patients at all stages of the myeloma pathway from diagnosis through to end of life.

We hope the Guides will also be of relevance to other healthcare professionals, including allied healthcare professionals who may form part of the wider multidisciplinary team.



# Core values underpinning the Myeloma Nursing Best Practice Guides

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**Myeloma UK is committed to improving information, emotional and practical support to people affected by myeloma and improving the standard of treatment and care through research, education and raising awareness.**

The work of Myeloma UK is underpinned by a series of core values and priorities that were put together by staff, the Board as well as service users, which include the following values of direct relevance to the Guides:

## **PATIENT-CENTRED**

We put patients at the heart of everything we do. We work with patients and their families to understand their needs and ensure they are listened to.

## **EXCELLENCE**

We believe that all patients and their families, should have timely access to the highest quality information and services, and to the most innovative treatments, no matter where they live in the UK.

## **INNOVATIVE**

We have a pioneering, problem-solving approach, and strive to overcome barriers through innovative ways of working.

## **We are COLLABORATIVE**

We collaborate efficiently and effectively in the implementation of our strategic goals.



# Monitoring and evaluation

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**Each of the Best Practice Guides is evaluated a year after publishing to allow sufficient time for the documents to be used in practice and to gather evidence and stakeholder feedback. Feedback will be gathered using an online and paper evaluation, sought from a broad range of nurses working in a range of different healthcare settings such as A&E, inpatient and outpatients, community clinics and transplant services.**

Initially, the Guides will not be applicable for use in a broader European or International arena, as they are developed in line with UK practice and policy. However, several guides address complications and side-effects of both myeloma itself and myeloma treatment. In this sense, although there may be some differences in treatment regimes across the European/International arena they are of relevance to nurses working in non-UK countries.

Ad hoc feedback from all stakeholders (UK and non-UK) is welcomed at any time via the existing Myeloma Academy programme feedback mechanisms.

## Evaluation focuses on these key areas

- ★ Structure and ease of use
- ★ Implementation
- ★ Clinical relevance
- ★ Relevance to the nursing role
- ★ Patient experience of impact on quality of care
- ★ Identified areas for improvement

## Ongoing review

Feedback from the evaluation process is used to modify and improve the Best Practice Guides. Myeloma UK staff are responsible for updating them, in consultation with expert reviewers.

The Guides will be reviewed on an annual basis. This annual evaluation process will repeat the stakeholder evaluation alongside an updated literature review to ensure that they remain clinically up-to-date.

# Use of the Myeloma Nursing Best Practice Guides

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**The Best Practice Guides will be available to download from the Myeloma Academy website ([www.myeloma-academy.org.uk](http://www.myeloma-academy.org.uk)), which aims to adhere to accessibility guidelines (W3C Web Accessibility Initiative - <https://www.w3.org/WAI/>). They are free to download and they are also available in print by contacting Myeloma UK. Large print versions available on request.**

All existing and future Intellectual Property Rights (IPR) (including without limitation, patents, copyright and related rights) of the Best Practice Guides belong to Myeloma UK.

We are not aware of any associated conflicts of interest in the production of the Best Practice Guides. If conflicts of interest arise as part of the implementation and evaluation process these will be assessed and addressed.

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## Recommended reading

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Kyle, R.A., et al., Monoclonal gammopathy of undetermined significance (MGUS) and smoldering (asymptomatic) multiple myeloma: IMWG consensus perspectives risk factors for progression and guidelines for monitoring and management. *Leukemia*, 2010. **24**(6): p. 1121-7.

### 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](http://www.myeloma-academy.org.uk)** or by email **[academy@myeloma.org.uk](mailto: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](http://www.myeloma.org.uk)** or contact us at **[myelomauk@myeloma.org.uk](mailto:myelomauk@myeloma.org.uk)** or **+44 (0)131 557 3332**.

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# Notes



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