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## About Myeloma UK

Myeloma UK is the only organisation in the UK dealing exclusively with myeloma, a bone marrow cancer for which there is no cure, but many very effective treatments.

Our broad and innovative range of services cover every aspect of myeloma from providing information and support, to improving standards of treatment and care through research and campaigning.

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.

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Aims of the Myeloma Nurse Best Practice Guides

The Myeloma Nurse 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 Nurse Best Practice Guides aim to:

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

How to use the Myeloma Nurse Best Practice Guides

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:

- Fatigue
- Gastrointestinal toxicities
- Myeloma bone disease
- Myeloma kidney disease
- Myelosuppression
- Pain
- Peripheral neuropathy
- Steroids
- Venous thromboembolic events

The Guides contain practical information and guidance to inform nursing practice when caring for myeloma patients, dealing with supportive care issues, complications and side-effects of myeloma and/or its treatment.

The Guides should be used in conjunction with local policies, protocols and best practice guidelines in oncology 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

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

- Be involved in the multidisciplinary team (MDT) 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 1.5% of overall cases of cancer in the UK and is the second most common blood cancer with 4,800 people diagnosed per year [1], 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 12,500 people in the UK with myeloma at any one time [2]. 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 care, treatment and management plans. 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 [3].

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 [4]. 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, care and management 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 Nurse 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 the Myeloma UK Myeloma Nurse Programme indicated 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 MDT 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 Nurse Best Practice Guide development

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 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 Best Practice Guide review committee included:

- Eric Low OBE
  Chief Executive, Myeloma UK
- Dr Maggie Lai
  Scientific and Medical Education Specialist, Myeloma UK
- Sue Perkins
  Service Development Manager, Myeloma UK
- Lois Lobban
  Healthcare Professional Programmes, Myeloma UK
- Dr Judith Behrens
  Consultant Haematologist
- Marvelle Brown
  Macmillan Haematology Senior Lecturer (Haematology), Thames Valley University
- Shirley Crofts
  Myeloma Clinical Nurse Specialist, Southampton General Hospital
- Flora Dangwa
  Clinical Lead for Specialist Nursing, Royal Free Hospital London
- Sophie Deppe
  Macmillan Myeloma Clinical Nurse Specialist, King's College Hospital, London
- Jeff Horn
  Macmillan Haematology Clinical Nurse Specialist, Aberdeen Royal Infirmary
- Mary Kelly
  Advanced Haematology Nurse Practitioner, Midland Regional Hospital, Tullamore, Ireland
- Tracy King
  Myeloma Clinical Nurse Consultant, Royal Prince Alfred Hospital, Sydney, Australia
- Monica Morris
  Macmillan Haematology/Oncology Clinical Nurse Specialist, St George's Hospital, London
- Dr Moira Stephens
  Lecturer, University of Wollongong, Australia
- Sharon West
  Myeloma Clinical Nurse Specialist, The Royal Marsden Hospital, London

Once the Guides were completed, they were peer reviewed and piloted by a group of myeloma nurses of various nursing bands.
Myeloma Nurse Best Practice Guides content

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 Nurse Best Practice Guides audience

The Guides have been developed with a patient-centred 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 Nurse Best Practice Guides

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, campaigning and raising awareness.

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

1. Leadership
We champion the importance of effective leadership and action. We are equipped with the knowledge of good governance. We encourage staff initiative and leadership, and strive to be a model organisation.

2. Integrity
We adhere to high ethical and professional standards in our work and relationships. We are fair and respectful in our interactions and are conscientious stewards of the resources that are entrusted to us.

3. Impact
We listen and understand the nature and needs of our stakeholders and create tailored, strategic solutions. We work closely with our stakeholders, partners and donors to achieve our objectives.

4. Focus
We are committed to ensuring that our work and its outcomes, and those of all our collaborators and partners, are firmly focused on patients, their families and carers.

5. Excellence
We promote collaboration and partnership to leverage knowledge and skills to continually improve our programmes and services for the benefit of our stakeholders. Whether working in partnership or independently, we endeavour to attain excellence in everything we do.

In addition to our core values we strive to ensure that all educational materials that we produce for both the patient and healthcare professional communities are current, unbiased, clear, peer reviewed and reflective of the latest policy and clinical data in myeloma.
Monitoring and evaluation

Each of the Best Practice Guides will be 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 an online evaluation system which will be developed and monitored by the Myeloma UK Nurse Programme Lead.

The evaluation will focus on five 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 will be used to modify and improve the Best Practice Guides. Myeloma UK staff will be responsible for updating them, in consultation with the review committee.

After the initial first-year evaluation is completed 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 Nurse Best Practice Guides

The Best Practice Guides will be available to download from the Myeloma Academy website (www.myeloma-academy.org.uk) which aims to adhere to W3C WCAG 1.0 level A. They will be 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.
References


Recommended reading


Royal College of Nursing (RCN) national Collaborating Centre for Nursing and Supportive Care (NCC-NSC) clinical guidelines. Available at: http://www.ncgc.ac.uk/


Royal College of Nursing (RCN) Principles of Nursing Practice. Available at: www.rcn.org.uk/nursingprinciples

Southern Derbyshire Shared Care Pathology Guidelines (2013) Diagnosis and Management of Myeloma Available at http://www.derbyhospitals.nhs.uk/easysiteweb/getresource.axd?assetid=8745&type=0&servicetype=1


Guidelines for the diagnosis and management of Myeloma within Anglia Cancer Network (2013) Available at http://www.angcn.nhs.uk/download/14f0a40e-0b08-4b6c-a7ad-0189fa15e1db


Your notes
This programme has been accredited by the RCN Centre for Professional Accreditation until 15 January 2016. Accreditation applies only to the educational content of the programme and does not apply to any product.