



Myeloma Best Practice Standards

supporting

Clinical Service Excellence Programme



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The Myeloma Best Practice Standards

Overview

The Myeloma Best Practice Standards have been developed by Myeloma UK, in consultation with patients, family members, carers and healthcare professionals, as a framework within which to support hospitals in the delivery of optimum, patient-focussed treatment and care.

The Standards comprise eight key themes, covering all aspects of myeloma, from referral and diagnosis to end-of-life care. Within each theme, optimum standards have been developed, reflecting the top priorities and needs of myeloma patients.

Our aim is that hospitals will apply for the Myeloma Best Practice Standards Award to demonstrate their commitment to providing quality, patient-focussed care. To recognise where these standards are already being met and identify where improvements can be made to better meet the needs of this unique group of patients.

How the Myeloma Best Practice Standards have been developed

The Myeloma Best Practice Standards have been developed following feedback from patients, family members, carers and healthcare professionals with relevant expertise in myeloma. The process of development has ensured that the standards:

- Have captured the views and opinions of what patients, family members and carers regard as the essential elements of Best Practice service provision in myeloma
- Are informed by experienced healthcare professionals, including consultants and nursing staff who have led service change and understand what constitutes optimum treatment and care
- Are evidence based, backed up by clinical guidelines
- Support, whilst not duplicating, existing government and local cancer policy

Key principles of the Myeloma Best Practice Standards

Myeloma UK understands the complexity and heterogeneity of myeloma, as well as the significant pressures facing the NHS and the consequent ability of healthcare providers to affect change with limited time and resources. To reflect this, our standards have been developed with the following principles in mind:

- They are myeloma focussed, tailored to the specific needs of patients living with this challenging and incurable cancer
- They are achievable and realistic, yet aspirational to support continuous improvement of care
- They have high impact for relatively little investment
- They add value for both patients and healthcare professionals
- They are simple and straightforward to apply for

Why apply for the Myeloma Best Practice Standards Award?

Achieving the standards will provide clear evidence that, above and beyond delivering good treatment and care, hospitals recognise the individual and challenging nature of myeloma and are able to provide for this. It demonstrates that the hospital fully understands the complexities relating to treating and caring for someone with this rare cancer.

The Myeloma Best Practice Standards Award will enable hospitals to recognise and celebrate their achievements in delivering the highest quality treatment and care to their patients, as well as identifying any key areas for improvement.

Patients, family members and carers will feel reassured that their needs are being addressed and catered for which will, in turn, have a positive impact on their quality of life and wellbeing.

It will also provide evidence to commissioners of the quality of treatment and care provided within the hospital and plans for improvement.

Theme 1: Service Delivery

Rationale

All patients have differing and individual needs and it is therefore essential that services are tailored to ensure these needs are understood, considered and catered for appropriately

Standards

- 1.1 New patient appointments are provided in a myeloma-specific outpatient clinic, which includes access to a myeloma nurse specialist
- 1.2 Feedback is sought from patients and families about their experience, which is used to inform the department's future planning. The results of this feedback and subsequent actions are communicated to patients and their families
- 1.3 Follow up appointments are tailored to each individual patient's circumstances in terms of timing and co-ordination of multiple appointments to minimise the need for frequent hospital attendance where possible
- 1.4 The outpatient clinic is well designed and provides a comfortable environment with appropriate facilities to meet the needs of patients and their families
- 1.5 There is evidence that time for staff education and training is specified in job plans, including attendance at external training events
- 1.6 The service takes account of and caters for patient choice regarding their preferred setting of care e.g. provision of IV treatment at home or in a community clinic
- 1.7 Upon arrival at an inpatient or day ward, patients and their families are greeted, orientated, and provided with an appropriately designed and comfortable environment in which to receive their treatment

Supplementary references:

[Essence of Care 2010. Benchmarks for Care Environment, Department of Health](#)

[CQC Essential standards of quality and safety. Outcome 10 Prompt: 10A, March 2010](#)

[Improving outcomes: a strategy for cancer 2011, Department of Health](#)

[Patient-led assessments of the care environment \(PLACE\)](#)

Theme 2: Multidisciplinary teamworking (MDT)

Rationale

Effective multidisciplinary team working is essential to ensure that treatment and care plans are delivered by those with the relevant disciplines, on an individual, patient-centred basis. New and follow-up cases need to be reviewed at critical time points, with complex cases receiving the breadth of experience necessary to deliver optimal treatment

Standards

- 2.1 There is a multidisciplinary team (MDT) in place which includes members with the necessary range of expertise, in line with the requirements of the National Cancer Peer Review
- 2.2 The MDT has a myeloma lead with a demonstrable interest and experience in the management and treatment of myeloma
- 2.3 The MDT has a Clinical Nurse Specialist with a demonstrable interest in myeloma and a significant proportion of their caseload consisting of myeloma patients
- 2.4 Where input from other specialties that are not part of the core MDT is required, there is a nominated lead from each department identified who will participate in MDT meetings to review individual patients
- 2.5 The MDT discusses patients at each critical time point in their myeloma, e.g. at diagnosis, relapse, or when complications and/or side-effects require discussion and decisions from the team
- 2.6 Patients are made aware of the existence and role of the MDT in their treatment and care
- 2.7 In addition to the traditional MDT, there is a regional expert myeloma team that meets regularly to discuss protocols, access to treatment, research and challenging cases, either on a local or regional basis

Theme 3: Awareness education and referral

Rationale

Myeloma is a very challenging to diagnose and many patients present to primary care multiple times before being investigated and diagnosed. Delays in diagnosis can have a serious impact on a patient's prognosis and quality of life.

Haematology departments have a key role to play in advising primary care and other hospital departments about myeloma and raising awareness of myeloma to ensure that people suspected of having myeloma are referred without delay to their team for follow up.

Standards

- 3.1 There is evidence that the haematology department proactively engages with other departments and primary care to raise awareness of myeloma and share information on its presenting signs and symptoms
- 3.2 There is a protocol in place and communicated to other departments and primary care (e.g. a checklist) for delivering the news of a suspected diagnosis of myeloma. This protocol requires a CNS or equivalent member of nursing staff to be present during the delivery of any news suggesting myeloma as a possible diagnosis
- 3.3 There is a named consultant haematologist available to provide information to other hospital departments and primary care practitioners seeking advice about haematology referrals and suspected cases of myeloma
- 3.4 Urgent referrals are seen in line with the national two-week wait requirement. Any required tests or investigations are requested urgently and organised in a manner which avoids the need for multiple visits to hospital

Supplementary references:

[Essence of Care 2010: Benchmarks for Communication. Department of Health](#)

[Guidelines for the diagnosis and management of multiple myeloma 2014, British Committee for Standards in Haematology and the UK Myeloma Forum](#)

[Referral guidelines for suspected cancer \(2011\) National Institute for Health and Care Excellence](#)

Theme 4: Testing and diagnosis

Rationale

Access to appropriate diagnostic testing should ensure a rapid and accurate diagnosis of both stage and type of myeloma, which is delivered in a timely, appropriate and sensitively communicated manner to the patient and their family.

Standards

- 4.1 There is access to screening and diagnostic testing facilities in line with current guidance from the British Committee for Standards in Haematology
- 4.2 Any diagnostic testing that takes place, ie, bone marrow aspiration, is carried out after a basic health, pain and needs assessment of the patient to ensure optimum comfort and minimal distress during the tests/procedure(s)
- 4.3 Test results and a confirmation of diagnosis or otherwise is given to the patient and their family as quickly as possible to avoid unnecessary anxiety during this time
- 4.4 There is a current policy, written guidelines or checklist about informing patients of their diagnosis and staff are regularly trained in the delivery of diagnosis. As a minimum, the policy should state:
 - that a consultant haematologist should give the diagnosis, in-person
 - the patients' family members or carer should be present (if agreed to by the patient)
 - a clinical nurse specialist should be present, who allocates time to the family once the consultant has delivered the news
 - the diagnosis is delivered in a suitable totally confidential and quiet environment such as a consultation room or other caring environment
 - patients are informed of their diagnosis in an honest, clear and sensitive manner and an explanation of the options for treatment, if required, are given to the patient, family members and carers
 - time is given for the patient and their family members and carers to digest the information and make a decision on what treatment option they wish to pursue wherever possible
 - if patients wish, there is a designated room available for themselves and their family to go to immediately after diagnosis before going home

- there is time given to ask questions following the diagnosis, both immediately and once the patient has returned home
 - contact names and numbers of the patient's consultant and clinical nurse specialist are provided to the patient, their family members and carers following the relaying of diagnosis as well as an out of hours number to call in case of emergencies
 - the delivery of diagnosis in accordance with this policy should be recorded in the patient's notes
- 4.5 The concepts and terminology of supportive and palliative care are introduced as soon as possible after diagnosis as an integral part of the treatment and care patients will receive and should be clearly distinguished from end-of-life care
- 4.6 The patient's GP is informed by letter, without delay, following diagnosis and information is given about next steps, including treatment and supportive care

Supplementary references:

[Guidelines for the diagnosis and management of multiple myeloma 2014, British Committee for Standards in Haematology and the UK Myeloma Forum](#)

[Cancer Patient Experience Survey 2013 National Report 2013, NHS England](#)

Theme 5: Treatment and supportive care planning

Rationale

The multi-faceted nature of myeloma and the individual needs of patients mean that many factors need to be taken into consideration when agreeing a treatment and care plan for each case, including co-morbidities, age and social circumstances of the patient, type and stage of myeloma and patient preferences.

It is essential that patients have access to the most up-to-date treatment available, tailored to their individual needs and that optimum supportive care is delivered to ensure best quality of life both during and off-treatment

Standards

- 5.1 There are local clinical guidelines in place for treating myeloma which reflect national guidelines/best practice and a process to review and update these regularly
- 5.2 Whilst based on published evidence and accepted best practice, it is acknowledged that the very complex nature of myeloma requires an individual and responsive approach to patient need and there should be a degree of flexibility to deviate from national treatment guidelines when deemed appropriate for individual cases
- 5.3 Patients should be given time to consider the treatment options available to them, not withstanding the urgency of the situation
- 5.4 Patients should be offered the opportunity to seek more than one opinion about their treatment options
- 5.5 The patient's psychological, social and spiritual needs are assessed and documented in the patient notes at key decision points. Discussion will take place about the support services available to patients and referrals made with relevant services when a need is identified, including psychological support (counselling), employment and financial advice
- 5.6 Members of the haematology team are kept up-to-date with procedures for applying for treatment which falls outside of current National Institute for Health and Care Excellence, Scottish Medicines Consortium or All Wales Medicine Strategy Group guidance e.g. Cancer Drugs Fund or Individual Funding Request procedures
- 5.7 Before treatment is initiated, changed or stopped, patients are given information about the reasons, anticipated benefits and potential risks of these actions

- 5.8 For each treatment given, patients are provided with information about compliance, side-effects and a point of contact to report side-effects that may require intervention
- 5.9 Patients, family members and carers are given the contact details of their consultant haematologist, clinical nurse specialist and out-of-hours number throughout the duration of their treatment, with the role of each team member being clearly explained
- 5.10 Clinic and discharge letters including relevant test results and a summary of treatment are provided to the patient's general practitioner and any other community healthcare professionals involved in the patient's care (e.g. community palliative care team) after every appointment/hospital stay, with a copy provided to the patient

Supplementary references:

[Guidelines for Supportive Care in Multiple Myeloma, British Committee for Standards in Haematology and the UK Myeloma Forum, 2011](#)

[Guidance on Cancer Services. Improving Outcomes in Haematological Cancers. The Manual. NICE. 2003](#)

[Improving outcomes: a strategy for cancer 2011, Department of Health](#)

Theme 6: Research and clinical trials

Rationale

Data shows that patients who participate in a clinical trial have better outcomes, particularly in the relapsed/refractory setting. It is therefore essential that patients should have access to relevant clinical trials and be given the opportunity to participate in other research appropriate to them.

Standards

- 6.1 As a minimum, the department recruits to the major national trials such as the MRC myeloma trials and facilitates access to local clinical trials of novel agents/combinations, especially for patients with relapsed disease where there is an unmet clinical need. Patients are given the option to contribute to other national level research by donating tissue samples
- 6.2 All newly diagnosed patients and relapsing patients are routinely told about relevant clinical trials, given information about the potential risks and benefits of each of them and given the option to make an informed decision about whether or not to participate
- 6.3 Where appropriate, patients are informed of the results of any clinical trials or other research they participate in
- 6.4 For patients who are referred to another hospital to access a clinical trial, there are mechanisms in place to ensure appropriate continuity of care between the two hospitals
- 6.5 Doctors and CNS' are able to respond adequately to a request from a patient to participate in a clinical trial or other research study
- 6.6 Patient experience of participating in a clinical trial is evaluated to assess whether it has met the patient's expectations and to inform future communication and information about trials

Supplementary references:

[Guidelines for the diagnosis and management of multiple myeloma 2014, British Committee for Standards in Haematology and the UK Myeloma Forum](#)

Theme 7: End-of-life care

Rationale

All patients eventually reach the stage of their myeloma where discussions about end-of-life are appropriate and necessary. This is a potentially difficult and distressing time for patients and their families which, if mishandled can have a negative impact on their emotional wellbeing and preparedness for end-of-life.

Staff must have appropriate training and experience to engage in conversations about stopping treatment, end-of-life care and the preferred place of care. Mechanisms must be in place to ensure these needs and preferences are carried out and managed appropriately.

Standards

- 7.1 When myeloma is diagnosed, the consultant haematologist explains that while myeloma is treatable, it is an incurable cancer and the concept of mortality is sensitively and carefully introduced
- 7.2 Discussions about what will happen when the benefits of treatments are likely to become outweighed by side-effects and impact on quality of life are held with patients well in advance of this occurring. This will allow them and their family to come to terms with and take any necessary steps to prepare for stopping treatment and make informed decisions about their own treatment and care
- 7.3 A documented holistic needs assessment is undertaken of patients approaching the late stage of disease and end-of-life so that their needs are adequately met when the time comes
- 7.4 In appropriate cases an Advanced Care Plan is also put in place
- 7.5 Communication with other services involved with the patient's care towards end-of-life is well co-ordinated, ensuring that roles and responsibilities of the various teams, including primary care, secondary care and hospice care, are clearly defined with a clear treatment plan agreed and adhered to
- 7.6 Patients and family members/carers are given clear and accurate information about what to expect in the lead up to end-of-life and this should be conducted in a sensitive manner. This information covers the role of carers and how they can assist in supporting the patient practically and emotionally
- 7.7 There is a mechanism in place that offers bereavement support to the late patient's family member or main carer, be it through secondary or primary

care services, and the opportunity for follow up with the patient's consultant if requested

Supplementary references:

[End of Life Care Strategy: Quality Markers and Measures. June 2009](#)

[Improving Supportive and Palliative Care for Adults with Cancer. NICE, 2004](#)

[Guidelines for Supportive Care in Multiple Myeloma, British Committee for Standards in Haematology and the UK Myeloma Forum, 2011](#)

[Improving outcomes: a strategy for cancer 2011, Department of Health](#)

[A Practical Guide for Holistic Needs Assessment](#)

[Leadership Alliance for the Care of Dying People](#)

Theme 8: Information and support

Rationale

Provision of information and support for patients and their carers is essential if a patient is to come to terms with their diagnosis and make informed decisions about their own treatment and care. .

Myeloma is an individual cancer which has an impact on patients, and their family members, physically, emotionally and socially. Therefore, information and support must be tailored to individual needs.

Standards

- 8.1 At the point of diagnosis the information and support needs of the patient, family members and carers are assessed so that these can be met appropriately. This is carefully monitored throughout the patient's myeloma so that any change in circumstances can be catered for
- 8.2 Patients are referred to patient organisations or other specialist information providers at the point of diagnosis and throughout the course of their myeloma
- 8.3 Written information that specifically addresses myeloma, its diagnosis, treatment, living with the disease, management of pain and other concerns is given to the patient, family members and carers at key stages
- 8.4 When providing information actions are agreed which are followed up at subsequent appointments or any other contact with the patient
- 8.5 Written information provided is concise, non-technical, and in plain language, containing accurate, reliable and sufficiently detailed information to help patients make treatment choices
- 8.6 Alternative types of information, such as online, audio and visual are signposted to the patient, family members and carers
- 8.7 Information is provided to patients, family members and carers about local support groups as well as reputable websites from which to seek information
- 8.8 Information is provided to patients, family members and carers on the support services available to them within the NHS, including palliative care services, counselling and benefits advice, where appropriate by their nursing team

- 8.9 There is written information provided, and practical advice or demonstrations to patients, family members and carers on the administration of medicines, including instructions on their storage, use and side-effects, when appropriate
- 8.10 As part of the delivery of information patients are encouraged to contact their CNS at any point during their myeloma
- 8.11 There is a system in place to make available literature on myeloma and information about relevant patient organisations in the patient waiting room. This information is regularly reviewed with a member of the haematology team taking responsibility for ensuring stock levels are maintained
- 8.12 Patients have a point of contact for information or reassurance at all times, including when they are not receiving treatment, including a contact available out of hours

Supplementary references:

[Guidelines for Supportive Care in Multiple Myeloma, British Committee for Standards in Haematology and the UK Myeloma Forum, 2011](#)

[Guidelines for the diagnosis and management of multiple myeloma 2014, British Committee for Standards in Haematology and the UK Myeloma Forum](#)

[Improving outcomes: a strategy for cancer 2011, Department of Health](#)