

# Clinical★Service Excellence Programme

Recognising best practice in myeloma care

## Myeloma Best Practice Standards



These standards have been developed in consultation with patients, family members, carers and healthcare professionals, as a framework to support hospitals in the delivery of optimum, patient-focused treatment and care.

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# Myeloma Best Practice Standards

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## 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-centric 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 UK Clinical Service Excellence Programme (CSEP) to demonstrate their commitment to providing quality, patient-focused care. The CSEP accreditation recognises where these standards are already being met and identifies where improvements can be made to meet the needs of myeloma patients.

## Development of the Myeloma Best Practice Standards

The Myeloma Best Practice Standards have been developed following extensive feedback from a range of stakeholders 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

## Principles that guide 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 create change with limited time and resources. To reflect this, our standards have been developed with the following principles in mind:

- Myeloma-focused, tailored to the specific needs of patients living with this challenging and incurable cancer
- Achievable and realistic, yet aspirational to support continuous improvement of care
- Provides a reference point for patients and healthcare professionals
- Acts as a framework for hospitals to be awarded or work towards CSEP accreditation

# Why apply for the Clinical Service Excellence Programme?

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The Myeloma UK CSEP award will enable hospitals to recognise and celebrate their achievements in delivering the highest quality of treatment and care to their patients, as well as identifying any key areas for improvement.

Adhering to the Myeloma Best Practice Standards highlights that the hospital team understands the complex and challenging nature of myeloma and are able to provide high quality care for someone with this rare cancer. Likewise, CSEP accreditation will help reassure patients, family members/carers that their needs are being addressed and catered for which will, in turn, have a positive impact on their quality of life and wellbeing.

The CSEP award also provides clear evidence to commissioners on the quality of clinical service covered by the hospital and ongoing plans for improvement.



# Theme 1: Service Delivery

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## Rationale

All patients have differing and individual needs. It is 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 haemato-oncology outpatient clinic, which includes access to a clinical nurse specialist. Ideally a myeloma-specific clinic and myeloma clinical nurse specialist.

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- 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

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- 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

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- 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

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- 1.5 The service takes account of, and caters for, patient choice regarding their preferred setting of care e.g. provision of treatment at home or in a community clinic

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- 1.6 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

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## Supplementary references

Essence of Care 2010. Benchmarks for Care Environment, Department of Health

📄 [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/216691/dh\\_119978.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216691/dh_119978.pdf)

Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020

📄 <https://www.england.nhs.uk/publication/achieving-world-class-cancer-outcomes-a-strategy-for-england-2015-2020>

Beating Cancer: Ambition and Action (Scotland)

📄 <https://www.gov.scot/publications/beating-cancer-ambition-action>

Cancer Delivery Plan for Wales 2016-2020

📄 <http://www.walescanet.wales.nhs.uk/sitesplus/documents/1113/Cancer%20Delivery%20Plan%202016-2020.pdf>

Patient-led assessments of the care environment (PLACE)

📄 <https://www.england.nhs.uk/ourwork/qual-clin-lead/place>

## Theme 2: Multidisciplinary teamworking (MDT)

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### 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

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- 2.2 The MDT has a myeloma lead with a demonstrable interest and experience in the management and treatment of myeloma

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- 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

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- 2.4 Where input from other specialties (not part of the core MDT) is required, there is a nominated lead from each department who will review individual patients

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- 2.5 The MDT discusses patients at each critical time point in their myeloma; for example, at diagnosis, relapse, or when complications and/or side-effects require discussion and decisions from the team

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- 2.6 Patients are made aware of the existence and role of the MDT in their treatment and care

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- 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

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### Supplementary references

NICE guideline [NG47] Haematological cancers: improving outcomes (2016)

📄 <https://www.nice.org.uk/guidance/ng47>

Successful strategies in implementing a multidisciplinary team working in the care of patient with cancer: an overview and synthesis of the available literature (2018)

📄 <https://www.ncbi.nlm.nih.gov/pubmed/29403284>



## Theme 3: Testing, diagnosis and follow-up

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### 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

- 3.1 There is access to screening and diagnostic testing facilities in line with current guidance from the BSH Guideline Committee and NICE

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  - 3.2 Any diagnostic testing that takes place, e.g. bone marrow biopsy, 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)

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  - 3.3 Patients receive test results and a confirmation of diagnosis (or otherwise) as quickly as possible, to avoid unnecessary anxiety during this time

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  - 3.4 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 patient's 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 patient and family once the consultant has delivered the news
    - The diagnosis is delivered in a suitable, confidential and caring environment, such as a consultation room
    - The patient is informed of their diagnosis in an honest, clear and sensitive manner and their treatment options are discussed, with the presence of family members or carers if requested
    - 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
    - A designated room should be available for patients and their family or carers to go to immediately after diagnosis
    - There is time given to ask questions following the diagnosis, both immediately and once the patient has returned home
    - Contact details for 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
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## Testing, diagnosis and follow-up (continued)

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**3.5** 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

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**3.6** The patient's GP is informed by letter, without delay, following diagnosis and information is given about next steps, including treatment and supportive care

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### Supplementary references

NICE guideline [NG35] Myeloma: diagnosis and management (2018)

📄 <https://www.nice.org.uk/guidance/ng35>

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

📄 [http://www.bcsghguidelines.com/documents/MYELOMA\\_GUIDELINE\\_Feb\\_2014\\_for\\_BCSH.pdf](http://www.bcsghguidelines.com/documents/MYELOMA_GUIDELINE_Feb_2014_for_BCSH.pdf)

National Cancer Patient Experience Survey 2018: National Results Summary

📄 <https://www.ncpes.co.uk/reports/2018-reports/national-reports-2018/4539-cpes-2018-national-report/file>

IMWG consensus recommendations on imaging in monoclonal plasma cell disorders (2019)

📄 [https://www.thelancet.com/pdfs/journals/lanonc/PIIS1470-2045\(19\)30309-2.pdf](https://www.thelancet.com/pdfs/journals/lanonc/PIIS1470-2045(19)30309-2.pdf)

Guidelines for the use of imaging in the management of patients with myeloma (2017)

📄 <https://onlinelibrary.wiley.com/doi/full/10.1111/bjh.14827>

## Theme 4: Treatment and supportive care planning

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### 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. This includes the 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

- 4.1 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

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- 4.2 Whilst based on published evidence and accepted best practice, it is acknowledged that the 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

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- 4.3 Patients should be given time to consider the treatment options available to them, notwithstanding the urgency of the situation

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- 4.4 Patients should be offered the opportunity to seek more than one opinion about their treatment options

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- 4.5 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, employment and financial advice

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- 4.6 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

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- 4.7 Before treatment is initiated, changed or stopped, patients are given information about the reasons, anticipated benefits and potential risks of these actions

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- 4.8 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

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## Treatment and supportive care planning (continued)

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**4.9** 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

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**4.10** Clinic and discharge letters including relevant test results and a summary of treatment are provided to the patient's GP 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 offered to the patient

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### Supplementary references

NICE guideline [NG35] Myeloma: diagnosis and management (2018)

📄 <https://www.nice.org.uk/guidance/ng35>

NICE guideline [NG47] Haematological cancers: improving outcomes

📄 <https://www.nice.org.uk/guidance/ng47>

Management of relapsed multiple myeloma: recommendations of the IMWG (2016)

📄 <https://www.nature.com/articles/leu2015356>

Guidelines for screening and management of late and long-term consequences of myeloma and its treatment (2017)

📄 <https://www.ncbi.nlm.nih.gov/pubmed/28107574>

Multiple myeloma: an overview of management (2019)

📄 <https://journals.sagepub.com/doi/full/10.1177/1178224219868235>

Guidelines for Supportive Care in Multiple Myeloma. British Committee for Standards in Haematology and the UK Myeloma Forum (2011)

📄 <http://www.ukmf.org.uk/wp-content/uploads/2012/11/MM-supportive-guidelines-20114.pdf>

## Theme 5: Research and clinical trials

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### 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

- 5.1 The department recruits and refers to the major national 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

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- 5.2 All newly diagnosed patients and relapsing patients are routinely told about relevant clinical trials, given information about the potential risks and benefits, and given the option to make an informed decision about whether or not to participate

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- 5.3 Where appropriate, patients are informed of the results of any clinical trials or other research they participate in

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- 5.4 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

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- 5.5 Doctors and CNSs are able to respond adequately to a request from a patient to participate in a clinical trial or other research study

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- 5.6 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

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### Supplementary references

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

▣ <https://www.ukmf.org.uk/wp-content/uploads/2014/10/Updates-to-the-guidelines-Oct-2014.pdf>

NIHR: The Role of the Clinical Research Nurse

▣ <https://www.nihr.ac.uk/documents/the-role-of-the-clinical-research-nurse/11505>

Patients' willingness to participate in clinical trials and their views on aspects of cancer research: results of a prospective patient survey (2016)

▣ <https://trialsjournal.biomedcentral.com/articles/10.1186/s13063-015-1105-3>

## Theme 6: Palliative and end of life care

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### Rationale

Discussing palliative and end of life care can be a potentially difficult and distressing time for patients and their families. If mishandled it 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 active 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

- 6.1 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

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- 6.2 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 help patients and their family come to terms with and take any necessary steps to prepare for stopping treatment and make informed decisions about their own treatment and care

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- 6.3 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

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- 6.4 In appropriate cases an advance care plan is also put in place

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- 6.5 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

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- 6.6 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

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- 6.7 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

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## Supplementary references

A Practical Guide for Holistic Needs Assessment

▣ <http://www.ncsi.org.uk/what-we-are-doing/assessment-care-planning/holistic-needs-assessment/>

Preferred and actual place of death in haematological malignancy (2017)

▣ <https://spcare.bmj.com/content/7/2/150>

NICE guideline [NG31] Care of dying adults in the last days of life (2015)

▣ <https://www.nice.org.uk/guidance/ng31>

NICE guideline [NG142] End of life care for adults: service delivery (2019)

▣ <https://www.nice.org.uk/guidance/ng142>

Treat patient, not just the disease: holistic needs assessment for haematological cancer patients (2018)

▣ <https://www.oncologyreviews.org/index.php/or/article/view/374>

Guidelines for Supportive Care in Multiple Myeloma. British Committee for Standards in Haematology and the UK Myeloma Forum (2011)

▣ <http://www.ukmf.org.uk/wp-content/uploads/2012/11/MM-supportive-guidelines-20114.pdf>



## Theme 7: Awareness education and referral

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### Rationale

Myeloma can be very challenging to diagnose and many patients present to primary care multiple times before being investigated for myeloma 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 to ensure people with suspected myeloma are appropriately referred for further investigations.

### Standards

- 7.1 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

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- 7.2 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

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- 7.3 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

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- 7.4 There is evidence that time for staff education and training is specified in job plans, including attendance at external training or education events

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### Supplementary references

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

📄 [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/216691/dh\\_119978.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216691/dh_119978.pdf)

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

📄 <https://www.ukmf.org.uk/wp-content/uploads/2014/10/Updates-to-the-guidelines-Oct-2014.pdf>

NICE guideline [NG12] Suspected cancer: recognition and referral (2017)

📄 <https://www.nice.org.uk/guidance/ng12>

NICE guideline [NG148] Acute kidney injury: prevention, detection and management (2019)

📄 <https://www.nice.org.uk/guidance/ng148>

The interface between primary and secondary care: key messages for NHS clinicians and managers. Department of Health (2017)

📄 <https://www.england.nhs.uk/publication/the-interface-between-primary-and-secondary-care-key-messages-for-nhs-clinicians-and-managers/>

## Theme 8: Information and support

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### 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

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- 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

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- 8.3 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

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- 8.4 Written information provided is concise, non-technical, and in plain language, containing accurate, reliable and sufficiently detailed information to help patients make treatment choices

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- 8.5 Alternative types of information, such as online, audio and visual are signposted to the patient, family members and carers

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- 8.6 Information is provided to patients, family members and carers about local support groups as well as reputable websites from which to seek information

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- 8.7 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

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- 8.8 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

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## Information and support (continued)

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- 8.9** As part of the delivery of information, patients can easily contact their CNS at any point during their myeloma care
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- 8.10** There is a system in place to make literature on myeloma and information about relevant patient organisations available 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
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- 8.11** Patients always have a point of contact for information or reassurance, including periods when they are not on active myeloma treatment
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### Supplementary references

Patient Information Forum: 'How to Guides'

<https://pifonline.org.uk/resources/how-to-guides/>

The Information Standard Principles: The Information Standard for Health and Care Information Production Quality Statements

<https://www.england.nhs.uk/tis/about/the-info-standard/#review>



### Clinical ★ Service Excellence Programme

Recognising best practice in myeloma care

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