

MyelomaAcademy™



NURSING BEST PRACTICE GUIDE

End of life 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 provision of end of life care for myeloma patients.

After reading this, you should be able to:

- ★ Understand what end of life care entails
- ★ Recognise when a patient is approaching the end of life period of care
- ★ Understand the importance of good end of life care for myeloma patients and their families
- ★ Understand the nurse's role in the assessment and management of end of life care for myeloma patients

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 relapsing-remitting cancer that is characterised by periods of active disease when treatment is needed and periods of plateau or remission where treatment is not required. Although treatable, myeloma is not curable.

For most patients, treatment typically induces a response which results in a reduction of the myeloma and a relief of symptoms that can last months or years. However, relapse inevitably occurs and further treatment is necessary.

KEY FACTS

- ★ The period at the end of life is different for each patient and the signs and symptoms vary as their myeloma progresses
- ★ The general principles of end of life care should be part of a patient's care during their last months, days and hours of life
- ★ Communication about end of life care and decision-making is important as each patient has unique needs, wishes and preferences
- ★ Good end of life care enhances the quality of life for both patients and their families and helps meet their physical, practical, social, emotional and spiritual needs

This relapsing and remitting pattern continues until patients eventually become refractory to all treatment or their health deteriorates to a point where they can no longer tolerate further treatment.

In the absence of optimum treatment, myeloma progresses towards the end stages of the disease, which can, in some cases, manifest as plasma cell leukaemia or extramedullary plasmacytoma, and ultimately to death. Based on a joint decision by the multidisciplinary team, patient management at this point shifts from one of active treatment to end of life care. Some patients may continue some form of anti-myeloma treatment even until the last days of life but this is normally at a significantly reduced dose and intended to palliate rather than control disease^[1].

End of life care aims to help patients live as well as possible until they die and to enable them to die with dignity and with as little stress as possible. However, it is difficult to predict the period of end of life as the timeframe for each patient varies enormously depending on the extent of myeloma-related complications and/or the presence of other comorbidities. The most common cause of death in myeloma patients is infection^[2], often pneumonia or generalised sepsis, followed by renal failure^[3]. In other cases, patients simply decline slowly and there may not be any specific identifiable cause of death.

For a small number of patients death can happen swiftly but for the vast majority, the dying process begins many weeks or months before death occurs. Guidance from the National Council for Palliative Care defines patients 'approaching the end of life' as those that are likely to die within the next 12 months^[4]. During this time, treatment becomes predominantly palliative with care focused on identifying and supporting the needs, preferences and wishes of patients and their families. This process is sometimes referred to as advanced care planning and may involve different health and social care professionals including hospital doctors and nurses, general practitioners, community

nurses, hospice staff, counsellors, chaplains and social carers. Together, their role is to help control symptoms such as pain, nausea and fatigue, assist with any psychosocial, social and spiritual issues around dying, and agree goals of care (e.g. decisions about treatment and resuscitation) and preferred place of care during the last days of life with patients and their families.

As patients approach the last days and hours of life, they often have sequential organ failure and present with specific signs that are recognised as part of active dying. Signs and symptoms of impending death may include: worsening weakness, increased sleepiness, no appetite, difficulty swallowing, changes in breathing pattern, noisy/rattley breathing, restless movement, confusion and disorientation, cold extremities and complete loss of consciousness.

Once patients have been identified as having entered their last days of life, their care is coordinated and delivered in accordance with their personalised care plan to ensure they experience "a good death". The emphasis at this stage is on assisting the patient's physical comfort and in providing practical and emotional support for them and their families to avoid any undue distress and suffering. End of life care, however, does not end with the patient's death - healthcare professionals are also responsible for pronouncing death, notifying family members and providing bereavement support.

The period at the end of life is different for each myeloma patient and amongst the diversity of healthcare professionals involved during this stage, nurses play a crucial role in providing and coordinating high quality accessible care delivered in a respectful and sensitive manner. This guide describes the general approach to end of life care for myeloma patients and provides best practice guidance for nursing management at end of life.

Palliative care is an important component of supportive care at all stages of myeloma and is described in the **Myeloma Academy Nursing Best Practice Guide: Palliative Care**.

GENERAL RECOMMENDATIONS:

- ★ Recognising when a myeloma patient is approaching end of life should be a joint decision of the multidisciplinary team
- ★ All patients should receive individualised end of life care set out in a care plan following discussions about their wishes and preferences of where and how they would like to receive it
- ★ Regular, planned review and documentation of the care plan will ensure that the best care is given as the patient's condition changes
- ★ Effective communication between the hospital, community and primary care teams is essential for effective end of life care to be delivered

NURSING RECOMMENDATIONS:

- ★ The reasons for the withdrawal of active treatment should be explained to myeloma patients and their families
- ★ Patients and their families should be prepared for the transition to end of life care by being given appropriate information and support to facilitate decision-making and help them plan ahead
- ★ Advocacy and the ability to communicate on behalf of patients and their families forms an important part of end of life care

Medical Approach

End of life care forms an inevitable part of the supportive care for an incurable disease such as myeloma. The following section provides details of the general medical approach to caring for myeloma patients at the end of life.

Assessment

Recognising end of life

It is important to recognise when patients reach the end of life stage so that care can become focused on palliating symptoms and maintaining quality of life rather than on treating the myeloma. However, this is not always straightforward partly because of the increasing repertoire of novel myeloma treatment options and clinical trials available, and partly because some patients remain on treatment until their last few days of life. For some elderly myeloma patients, end of life care may even begin at the point of diagnosis^[5].

The following are potential clinical triggers of entry into the end of life stages of myeloma and where possible, it should be identified in a timely manner:

- ★ Multiply-relapsed with progressive shortening of length of remission/plateau
- ★ Refractory disease
- ★ Intolerance to further treatment
- ★ Worsening functional status

Once confirmed, patients and their families should be communicated with and offered information in a sensitive and accessible way according to their needs and preferences.

Holistic needs assessment and personalised care planning

Although holistic needs assessments are carried out throughout a patient's care, a comprehensive review should be made once they enter the end of life stage^[6]. This enables healthcare professionals to respond to any

changing needs and preferences patients may have, and to ensure they are getting the support they need for their circumstances.

The assessment should be documented and include patients' physical, emotional, social and spiritual needs alongside an assessment of their family and/or home situation. Cultural considerations must be taken into account as some faiths have specific beliefs/protocols surrounding death. Where appropriate, family and carers' views and needs should also be considered.

A holistic needs assessment at this time also provides the opportunity for patients to discuss their wishes and preferences about their care and create a personalised care plan. A Preferred Priorities of Care document^[7] may also be completed; this document gives patients an opportunity to think about, talk about and write down their preferences and priorities for end of life care, having weighed up the potential benefits, risks and burdens. Finding out what is and has been meaningful to patients in their life can help guide their care at the end of life^[8].

Planning may include patients thinking about:

- ★ How much information they want about their myeloma and/or prognosis
- ★ Any fears they have about the future e.g. being in pain or worried about being a burden to their family
- ★ What they would like to accomplish before they die
- ★ Where they want to receive end of life care e.g. hospital or community care
- ★ Where they want to be cared for when they die and where they want to die e.g. at home, in a hospice, care home or hospital
- ★ Who they want to be with when they die

Patients who do not discuss where they want to be when they die are more likely to die in hospital^[9].

With patients' agreement, discussions should be documented along with regular assessment to help meet changing needs and priorities. Information about any

changes should be disseminated to key persons involved in the patient's care.

Advance care decisions/directives

Unlike personalised care plans, advance care decisions or directives are legally binding documents which cover specific requests. It is important to discuss with patients what forms of care they do or do not wish to receive, since the time may come when they lose the capacity to communicate or make decisions.

Most advance care decisions relate to the refusal of treatment. For example, patients may wish to refuse intravenous antibiotics should they develop a life-threatening infection, or wish to refuse dialysis if they have renal failure. Priorities for pain control, clinically assisted hydration and nutrition, mechanical ventilation and a "do not attempt resuscitation" order can also be made within the document.

Management

The focus of end of life care is to help patients manage their symptoms so that they are experiencing the best possible quality of life. The most common symptoms at this stage include pain, fatigue, loss of appetite/anorexia, constipation, nausea and vomiting. Referral to the specialist palliative care at this stage is appropriate if this has not been done already where psychological, social and spiritual support can also be provided to patients and their families.

Several **Myeloma Academy Nursing Best Practice Guides** are available on the nursing management of such symptoms and should be referred to for guidance on specific treatment and management issues. Relevant guides include those on: pain, gastrointestinal (GI) toxicities and psychological support.

It is also important to be aware that there are different ways of managing pain and other symptoms without using drugs, such as physiotherapy and complementary therapies.



There is a **Myeloma Academy Nursing Best Practice Guide** on complementary therapies and myeloma.

Blood products are commonly required by myeloma patients who are approaching the last weeks of life and often crucial in maintaining quality of life in the last days of life. However, the need for blood or platelet transfusions can sometimes make it difficult for patients to be transferred to a hospice as not all of them have the facilities to administer blood products. It is also important to recognise when transfusions no longer benefit patients and discussions with patients and their families about their withdrawal should be made where appropriate.

For patients with implantable cardioverter defibrillators (more common in patients with cardiac AL amyloidosis) there is a risk that unexpected shocks may be delivered during the dying process. Therefore, discussions regarding their deactivation should be made with patients and clear information provided on the potential problems if it is not done.

If patients are to be discharged to home or hospice care, it is necessary that a detailed plan for liaison with the primary care team or hospice staff is made. A referral to the community palliative care team should be a priority and the plan should include a method for information sharing, agreement on who is responsible for which aspects of care and communication to ensure follow-up takes place. A further medication review may also be needed, with a focus on practical issues such as the supply of pain relief. A patient being discharged to home or hospice care may qualify for NHS funding

of care outside of hospital^[10]. As myeloma patients are typically under hospital care for many years, it is common for carers to continue seeking support from the hospital staff during this period. Liaison between hospital and community teams is therefore important to help meet the needs of families and carers.

It is important to provide information and support to families and carers throughout the end of life stage, including how symptoms are managed, what help is available for them, what to expect at the time of death, the procedures following death and that bereavement support is available. The **Myeloma UK Planning Ahead Infopack** covers the key questions and topics that patients and families may ask about end of life care^[11]. Having information will help patients and families feel better prepared and able to cope, especially if the patient wishes to be cared for at home.

There is specific clinical guidance for management of patients in the last 2 - 3 days of life set out by the National Institute for Health and Care Excellence (NICE)^[12]. These recommendations cover recognition of the signs of last days of life, shared decision-making, communication and symptom management. In addition, priorities for care in the last few days or hours of life are set out by the Leadership Alliance for the Care of Dying People^[13] and shown in Appendix I.

Nursing interventions and management

The following provides best practice recommendations for nursing interventions related to the assessment, treatment and monitoring of myeloma patients at end of life and for nursing management that encompasses a holistic approach to care.

Interventions

- ★ Carry out an assessment of holistic needs when a patient may be entering the end of life stage
- ★ Ensure symptoms are assessed regularly and medications reviewed accordingly
- ★ Ensure that a patient's "do not attempt resuscitation" order is discussed in a timely way and clearly communicated within the team
- ★ Be aware of any advanced care decisions/directives in place
- ★ For patients who are blood product dependent, regularly assess the benefit the patient receives from transfusions against the potential burden the procedure may incur
- ★ Consider use of complementary therapies to help with symptom control and promote physical and psychological wellbeing
- ★ Be alert for signs that the patient is entering the last days of life and ensure recommendations for care in the last

days of life are followed

Management

- ★ Provide the opportunity for patients to discuss their situation, talk about particular fears and anxieties, ask questions and begin to make plans which reflect their wishes for end of life, including where they want to be when they die
- ★ Use principles of good communication to help patients express their wishes and concerns
- ★ Provide written information to help patients and families prepare for the end of their life so that they can begin to make necessary arrangements and fulfil personal wishes
- ★ Provide details of contact numbers for help and advice, including out of hours numbers
- ★ Make relevant referrals to ensure a support package is in place for patients discharged to home, this may include palliative care team; allied healthcare professionals, social services, and primary care team
- ★ Maintain communication with the community teams as appropriate to promote continuity of care and emotional support, particularly for family members
- ★ When appropriate, provide family members with access to written information on bereavement support facilities, both local and national



Summary

End of life care is an important element of myeloma nursing. Nurses have a role in providing education and support to patients and families about end of life care and in relieving symptoms and promoting patients' quality of life during the last months, weeks and days of life.

Nurses play a crucial role in helping patients and families prepare for this last stage of life and in achieving the best possible quality of life. Good communication helps nurses to understand patients' needs and wishes so patients can make decisions which are right for them and their family. Expert management of symptoms throughout this period can promote comfort and ensure dignity in life and in death.



Appendix I

.....

Leadership Alliance for the Care of Dying People - Five Priorities for Care^[13]

The possibility that a person may die within the coming days and hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
Sensitive communication takes place between staff and the person who is dying, and those important to them.
The dying person, and those identified as important to them, are involved in decisions about treatment and care.
The people important to the dying person are listened to and their needs are respected.
Care is tailored to the individual and delivered with compassion – with an individual care plan in place.

Appendix II

.....

Useful resources

- ★ **Myeloma Academy Nursing Best Practice Guide: Palliative Care**
- ★ **Myeloma Academy Tutorial Communication Skills: – Discussing end of life care**
<https://academy.myeloma.org/cpd-learning/tutorials>
- ★ **Myeloma UK Planning Ahead: an Infopack for myeloma patients**
- ★ **NICE – Care of Dying Adults in the Last Days of Life**
www.nice.org.uk/guidance/ng31?unlid=8299497420161285432 (2015)
This NICE clinical guidance aims to improve end of life care for people in their last days of life by communicating respectfully and involving them in decisions, maintaining comfort and dignity and how to manage common symptoms and reduce unacceptable side effects
- ★ **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

1. Snowden, J.A., et al., *Guidelines for supportive care in multiple myeloma 2011*. Br J Haematol, 2011. **154**(1): p. 76-103.
2. Nucci, M. and E. Anaissie, *Infections in patients with multiple myeloma*. Semin Hematol, 2009. **46**(3): p. 277-88.
3. Dispenzieri, A., M.Q. Lacy, and P.R. Greipp, *Multiple Myeloma, in Hematologic Malignancies: Multiple Myeloma and Related Plasma Cell Disorders*, M.A. Gertz and P.R. Greipp, Editors. 2004, Springer Verlag: Berlin Heidelberg. p. 53-109.
4. Commissioning End of Life Care National Council for Palliative Care 2011
5. Willan et al. (2016) *Multiple myeloma in the very elderly patient: challenges and solutions*. Clin. Interv. Aging 11: 423-435
6. Boland, E.G., et al., *Holistic needs assessment in advanced, intensively treated multiple myeloma patients*. Support Care Cancer, 2014. **22**(10): p. 2615-20
7. Department of Health, Preferred Priorities for Care, National End of Life Care Programme 2011
8. Gawande A, *Being Mortal*, Metropolitan Books, New York 2014
9. Howell, D.A., et al., *Preferred and actual place of death in haematological malignancy*. BMJ Support Palliat Care, 2015
10. Department of Health, *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care November 2012 (Revised)*. 2012, NHS Continuing Healthcare Policy Team: Leeds.
11. Myeloma UK and Marie Curie, Planning Ahead: an Infopack for myeloma patients, Myeloma UK, 2015
12. National Institute for Health and Care Excellence, *Care of dying adults in the last days of life, in NICE Guidelines. 2015*, NICE: London
13. Leadership Alliance for the Care of Dying People, *One chance to get it right; Improving people's experience of care in the last few days and hours of life*. 2014 <https://www.england.nhs.uk/ourwork/qual-clin-lead/lac/>

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**.

Published by: Myeloma UK

Publication date: November 2016

Last updated: December 2017



Notes



MyelomaAcademy™



www.myeloma-academy.org.uk



Myeloma UK 22 Logie Mill,
Beaverbank Business Park, Edinburgh EH7 4HG
Myeloma Infoline: 0800 980 3332
www.myeloma.org.uk Charity No: SC 026116