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NURSING BEST PRACTICE GUIDE

# Fatigue

**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 when caring for myeloma patients with fatigue.**

After reading this, you should be able to:

- Define fatigue
- Understand the causes and consequences of fatigue in myeloma patients
- Be aware of the clinical testing and assessment tools for fatigue
- Understand the interventions for fatigue in myeloma patients
- Understand the nurse's role in the assessment, intervention and management of fatigue and in the patient education of this symptom

The information contained within this Guide should be used in conjunction with local policies, protocols and best practice guidelines in oncology.

## Background

Fatigue is a persistent sense of tiredness or exhaustion, typically resulting from physical or mental exertion, which interferes with normal daily activities. Whereas fatigue in a healthy individual can be improved by rest and refraining from strenuous activity, fatigue in myeloma and other cancer patients is much more severe and not alleviated by sleep and rest[1-5].

Fatigue is one of the most prevalent symptoms of myeloma affecting over 90% of patients at some point during the course of their myeloma, particularly those undergoing treatment[6]. For patients,

### KEY FACTS

- Fatigue affects almost all myeloma patients at some point
- It is considered to be one of the most distressing symptoms for myeloma patients impacting on all aspects of quality of life
- Fatigue is very treatable yet it remains under-recognised and under-reported
- Early intervention vastly improves functional capacity and quality of life

**This guide was last reviewed in December 2017.**

fatigue is often regarded as one of the most pervasive and distressing consequences of myeloma impacting not only on physical but also psychological and social aspects of their lives[7, 8]. Moreover, the way patients cope with fatigue can impact heavily on families and carers[9]. Typically, the consequences of fatigue include:

- Lethargy and diminished physical activity
- Difficulty in concentrating and decision-making
- Shortness of breath after only light activity
- Irritability
- Impatience
- Irrational behaviour
- Tearfulness
- Feelings of depression

There are many possible causes of fatigue in myeloma patients[5]. Of these, anaemia as a result of active suppression of the bone marrow by myeloma cells[10, 11] or as a side-effect of anti-myeloma treatment[12], both disrupting normal blood cell production, is common.

Other causes or contributing factors include:

- Pain
- Sedating properties of some treatments
- Disturbances in sleep or circadian rhythms
- Biochemical abnormalities caused by the myeloma itself, particularly an increase in cytokine levels
- Hormonal/endocrine changes
- Nutritional deficiencies
- Emotional distress, depression, anxiety
- Infection
- Comorbidities e.g. renal insufficiency, hepatic, cardiac pulmonary failure, thyroid dysfunction

The level of fatigue varies enormously from patient to patient; some may report only mild fatigue that has little impact on day-to-day life whereas others report severe debilitating fatigue that profoundly affects quality of life even a long time after treatment when in remission or plateau[13].

However, fatigue can be treated and managed with appropriate pharmacological[6] and/or non-pharmacological means[14, 15].

Unfortunately, fatigue is under-recognised by many healthcare professionals who underestimate the impact it has on quality of life of myeloma patients. Fatigue is also under-reported by many patients who consider it an unavoidable symptom of myeloma or side-effect of treatment and worry that reporting it may lead to a change in treatment.

It is vital therefore that patients and healthcare professionals, especially nurses, work together to reduce the impact fatigue has on patients so they can maintain the best possible quality of life.

The following describes the medical approach to the treatment of fatigue and provides best practice guidance for nursing interventions and nursing management of myeloma patients with fatigue.

### GENERAL RECOMMENDATIONS:

- Patients should be screened and assessed for fatigue on a regular basis regardless of the stage of their myeloma and whether they are having treatment or not
- The cause of the fatigue should be identified and treated accordingly
- Treatment-related fatigue may require dose modification or temporary cessation of treatment
- The consequences of fatigue should be managed appropriately to reduce the impact on quality of life

### NURSING RECOMMENDATIONS:

- Patients should be educated on the potential causes and consequences of fatigue and the various interventions for it
- Patients should be encouraged to talk openly about their fatigue and how it affects them
- The patient's level of fatigue and the impact it has on their ability to carry out activities of daily living should be assessed on a regular basis
- Family members should be involved in the fatigue management process

# Medical Approach

**Myeloma-related fatigue is a recognised complication of myeloma and a potential side-effect of treatment which relies on patients reporting the extent to which it affects their day-to-day living. It is, however, very treatable and the following general medical approach is taken to manage it effectively.**

## Assessment

A diagnosis of fatigue is made based on a set of criteria defined by the World Health Organisation (WHO) International Classification of Diseases (ICD- 10)[16]. This states that the following must be present on most or all days during a two-week period in the preceding month:

- Significant fatigue, diminished energy or increased need to rest which is disproportionate to any recent change in activity level

Plus five (or more) of the following:

- Complaints of generalised weakness or limb heaviness
- Diminished concentration or attention
- Decreased motivation or interest in engaging in usual activities
- Insomnia or hypersomnia
- Experience of sleep as unrefreshing or non-restorative
- Perceived need to struggle to overcome inactivity
- Marked emotional reaction (e.g. sadness, frustration or irritability) to feeling fatigued
- Difficulty completing daily tasks attributed to feeling fatigued
- Perceived problems with short-term memory
- Post-exertional malaise lasting several hours

Fatigue can also be confirmed using the National Cancer Institute (NCI) Common Terminology Criteria for Adverse Events (CTCAE):

- The symptoms cause clinically significant distress or impairment in social, occupational or other important areas of functioning
- There is evidence from the history, physical examination or laboratory findings that the symptoms are a consequence of cancer or cancer therapy

Fatigue should be assessed for both severity and its impact on everyday life[5]. Communication with patients is vital and the routine use of some simple questions can often give an indication of the patient's level of fatigue and the impact it is having.

Questions such as the following should be frequently asked:

- Do you feel fatigued?
- If yes, how severe has it been, on average, during the past week on a scale of 0 – 10?
- How is the fatigue interfering with your ability to function?

If fatigue is suspected, a more formal assessment should be included; several assessment tools exist but there is no single recommended model.

Examples most frequently used include one of the following:

- Single item rating scales with numbers and/or descriptors e.g. the Likert scale (see Appendix I) where patients specify their level of agreement to a statement

- Multiple item scales embedded in other tools e.g. European Organisation for Research and Treatment of Cancer (EORTC) QLQ-C30 (see Appendix I)
- Multiple item multi-dimensional scales, such as the Brief Fatigue Inventory (BFI, see Appendix I)

Once fatigue has been confirmed, the possible causes of fatigue should be investigated.

These include the assessment of:

- Disease status and treatment
  - Exclude cancer recurrence or progression
  - Review current anti-myeloma treatments if appropriate
  - Review medication for comorbidities
  - Contributing factors and associated symptoms
  - Pain
  - Anxiety/depression
  - Anaemia
  - Poor nutrition or absorption
  - Fluid/electrolyte imbalance
  - Lack of physical activity
  - Infection
  - Comorbidities

## Treatment

Medical causes of fatigue can be treated directly[5].

Fatigue caused by anaemia may be treated either with blood transfusions or erythropoietin (EPO).

If the anaemia is a side-effect of anti-myeloma treatment, then doses and/or schedules should be reviewed and modified accordingly. **(See Myeloma UK Nursing Best Practice Guide on Myelosuppression).**

Where the anaemia is severe, treatment may need to be suspended temporarily until the anaemia resolves.

Any sign of infection must be treated quickly with broad spectrum antibiotics if it causes a rise in body temperature over 38˚C. If a viral infection is suspected patients should be given antiviral drugs.

Fatigue as a result of dehydration may be alleviated by correction of fluid and electrolytes. Likewise, anorexic patients may be given high carbohydrate supplements to boost calorie intake.

A review of pain management should be considered as some of the centrally acting opiates can affect mood and impair cognition. Where depression is suspected, antidepressant treatment may help improve mood and alleviate fatigue.

In severe cases of fatigue, psychostimulants such as methylphenidate (Ritalin®), pemoline (Cylert®) or dextroamphetamine (Dexedrine®) may be considered. Recent reviews have questioned the efficacy of psychostimulants in this setting[17].

## Monitoring

Patients receiving pharmacological intervention should be reassessed regularly to determine if treatment has been successful in alleviating fatigue. Non-pharmacological interventions should also be considered (see nursing management section).

# Nursing interventions and management

**Nurses play a central role in the management of fatigue in myeloma patients.**

The following provides best practice recommendations for nursing interventions related to the medical assessment, treatment and monitoring of myeloma patients with fatigue, and for nursing management related to the provision of knowledge, education and a more holistic approach to caring for myeloma patients with fatigue.

## Interventions

- Screen patients for symptoms of fatigue on an informal basis at each visit regardless of whether they are on treatment or not
- Inform the haematologist if patients report new or worsening symptoms of fatigue
- Check patients' hydration status regularly and encourage them to drink the daily recommended amount (3L) of fluid
- Be vigilant for signs of infection
- Take patients' weight on a regular basis. Be vigilant for signs of anorexia, enquire about patients' diets and coordinate referral to a dietician if necessary
- Coordinate referral to other members of the multidisciplinary team e.g. physiotherapist, palliative care team, where necessary

## Management

- Inform and educate patients on the different causes of fatigue, the possible consequences and the interventions available including giving written information
- Make sure patients understand the importance of reporting signs of fatigue as early as possible
- Help patients make adjustments to their life if fatigue is impacting on their activities of daily living such as bathing, eating, dressing and mobility. Coordinate referrals to the occupational therapist or physiotherapist where appropriate
- Help patients understand that they may not be able to do everything they used to do before their diagnosis
- Advise patients on things to do to lessen the impact fatigue has on their daily living e.g. recommend the use of a diary to determine if there is a pattern to the fatigue or to identify specific activities associated with increased levels of fatigue
- Help patients devise a plan to modify specific activities to coincide with greater energy levels. Advise them to plan ahead, use labour saving techniques and equipment, delegate tasks to others etc.
- Encourage patients to take appropriate periods of rest but discourage prolonged periods of sleep during the day
- Educate patients about sleep hygiene if they are finding it difficult to sleep at night e.g. establish a routine sleep pattern, avoid stimulants prior to sleep, ensure symptoms e.g. pain, are controlled at night

- Encourage patients to take appropriate regular exercise. Coordinate referral to the physiotherapist where appropriate
- Ensure patients are eating a well-balanced diet. Coordinate referral to the dietician where appropriate for nutritional guidance
- Discuss with patients the potential benefits of complementary therapies such as relaxation techniques, aromatherapy, reflexology and gentle exercises such as yoga and Tai-Chi
- Give patients the chance to discuss and explore issues surrounding their fatigue
- Ensure that carers and families are included in any management strategies for the patient and that they understand their role in supporting the patient
- Be knowledgeable about the different management strategies. Understand that fatigue is very subjective and measures that benefit some patients may not help others. Examine potential ways of improving skills in recognising, assessing and managing fatigue

# Summary

Fatigue is a common, complex and distressing symptom of myeloma which can affect patients physically, psychologically and socially. Treatment and management of fatigue is essential to reduce the impact on patients' quality of life.

By taking a proactive approach, nurses greatly assist patients and their families to reduce the impact of this debilitating symptom and help to improve quality of life and outcomes for patients.

## Abbreviations

- **BFI** Brief fatigue inventory
- **CTCAE** Common terminology criteria for adverse events
- **EORTC** European Organisation for Research and Treatment of Cancer
- **EPO** Erythropoietin
- **ICD** International classification of diseases
- **NCI** National Cancer Institute

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## 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.**

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# Appendix I

## Fatigue assessment tools

### Likert scale

| | | | | |
|---|---|---|---|---|
| Very interested | Somewhat interested | Neutral | Not very interested | Not at all interested |
| 5 | 4 | 3 | 2 | 1 |
| Very much | Somewhat | Undecided | Not really | Not at all |
| 5 | 4 | 3 | 2 | 1 |
| Very much like me | Somewhat like me | Neutral | Not much like me | Not at all like me |
| 5 | 4 | 3 | 2 | 1 |
| Very happy | Somewhat happy | Neutral | Not very happy | Not at all happy |
| 5 | 4 | 3 | 2 | 1 |
| Almost always | Sometimes | Every once in a while | Rarely | Never |
| 5 | 4 | 3 | 2 | 1 |

### EORTC QLQ-C30

| | Not at all | A little | Quite a bit | Very much |
|---|---|---|---|---|
| Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase? | 1 | 2 | 3 | 4 |
| Do you have any trouble taking a long walk? | 1 | 2 | 3 | 4 |
| Do you have any trouble taking a short walk outside the house? | 1 | 2 | 3 | 4 |
| Do you need to stay in bed or a chair during the day? | 1 | 2 | 3 | 4 |
| Do you need help with eating, dressing, washing yourself or using the toilet? | 1 | 2 | 3 | 4 |
| During the past week | | | | |
| Were you limited in doing either your work or other daily activities? | 1 | 2 | 3 | 4 |
| Were you limited in pursuing your hobbies or other leisure time activities? | 1 | 2 | 3 | 4 |
| Were you short of breath? | 1 | 2 | 3 | 4 |
| Have you had pain? | 1 | 2 | 3 | 4 |
| Did you need to rest? | 1 | 2 | 3 | 4 |
| Have you had trouble sleeping? | 1 | 2 | 3 | 4 |
| Have you felt weak? | 1 | 2 | 3 | 4 |
| Have you lacked appetite? | 1 | 2 | 3 | 4 |

## EORTC QLQ-C30 (continued)

| | Not at all | A little | Quite a bit | Very much |
|---|---|---|---|---|
| Have you felt nauseated? | 1 | 2 | 3 | 4 |
| Have you vomited? | 1 | 2 | 3 | 4 |
| Have you been constipated? | 1 | 2 | 3 | 4 |
| Have you had diarrhoea? | 1 | 2 | 3 | 4 |
| Were you tired? | 1 | 2 | 3 | 4 |
| Have you had difficulty in concentrating on things, like reading a newspaper or watching television? | 1 | 2 | 3 | 4 |
| Did you feel tense? | 1 | 2 | 3 | 4 |
| Did you worry? | 1 | 2 | 3 | 4 |
| Did you feel irritable? | 1 | 2 | 3 | 4 |
| Did you feel depressed? | 1 | 2 | 3 | 4 |
| Have you had difficulty remembering things? | 1 | 2 | 3 | 4 |
| Has your physical condition or medical treatment interfered with your family life? | 1 | 2 | 3 | 4 |
| Has your physical condition or medical treatment interfered with your social activities? | 1 | 2 | 3 | 4 |
| Has your physical condition or medical treatment caused you financial difficulties? | 1 | 2 | 3 | 4 |

| For the following questions please circle the number between 1 and 7 that best applies to you: | | | | | | |
|---|---|---|---|---|---|---|
| How would you rate your overall health during the past week? | | | | | | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Very poor | | | | | | Excellent |
| How would you rate your overall quality of life during the past week? | | | | | | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Very poor | | | | | | Excellent |

## Brief Fatigue Inventory (BFI)

| | | | | |
|---|---|---|---|---|
| Throughout our lives most of us have times when we feel tired or fatigued. Have you felt unusually tired or fatigued in the past week? | Yes | | No | |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 1. Please rate your fatigue (weariness, tiredness) by circling the one number that best describes your fatigue right now. | | | | | | | | | | |
| **0** | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **9** | **10** |
| No fatigue | | | | | | | | | | As bad as you can imagine |
| 2. Please rate your fatigue (weariness, tiredness) by circling the one number that best describes your usual level of fatigue in the past 24 hours. | | | | | | | | | | |
| **0** | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **9** | **10** |
| No fatigue | | | | | | | | | | As bad as you can imagine |
| 3. Please rate your fatigue (weariness, tiredness) by circling the one number that best describes your worst level of fatigue in the past 24 hours | | | | | | | | | | |
| **0** | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **9** | **10** |
| No fatigue | | | | | | | | | | As bad as you can imagine |
| 4. Circle the one number that describes how, during the past 24 hours, fatigue has interfered with your: | | | | | | | | | | |
| A. General activity | | | | | | | | | | |
| **0** | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **9** | **10** |
| Does not interfere | | | | | | | | | | Completely interferes |
| B. Mood | | | | | | | | | | |
| **0** | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **9** | **10** |
| Does not interfere | | | | | | | | | | Completely interferes |
| C. Walking ability | | | | | | | | | | |
| **0** | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **9** | **10** |
| Does not interfere | | | | | | | | | | Completely interferes |
| D. Normal work (includes work outside the home and daily chores at home) | | | | | | | | | | |
| **0** | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **9** | **10** |
| Does not interfere | | | | | | | | | | Completely interferes |
| E. Relations with other people | | | | | | | | | | |
| **0** | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **9** | **10** |
| Does not interfere | | | | | | | | | | Completely interferes |
| F. Enjoyment of life | | | | | | | | | | |
| **0** | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **9** | **10** |
| Does not interfere | | | | | | | | | | Completely interferes |

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