

MyelomaAcademy™



NURSING BEST PRACTICE GUIDE

Psychological support in myeloma

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 providing psychological support to myeloma patients.

After reading this, you should be able to:

- ★ Understand the factors that affect psychological wellbeing in myeloma
- ★ Recognise the psychological changes that can occur in myeloma patients
- ★ Understand the nurse's role in the assessment of patients' psychological needs
- ★ Be aware of intervention and management strategies to support patients' psychological needs
- ★ Understand the importance of recognising and supporting the psychological needs of those caring for someone with myeloma

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 remains incurable, despite improvements in survival in recent years. Most patients have not heard of myeloma at diagnosis and the disease process is complex and unpredictable. Uncertainty about the future can negatively affect emotional

and psychological resilience and impact on psychological wellbeing.

Plasma cell disorders include Monoclonal Gammopathy of Undetermined Significance (MGUS) and smouldering myeloma which require "watch and wait" care plans, causing significant fear and anxiety about the future.

KEY FACTS

- ★ A diagnosis of myeloma affects all patients psychologically, and the risk of anxiety and depression is increased
- ★ Screening for signs of psychological distress means interventions can be introduced early to promote and support wellbeing
- ★ Listening to concerns and providing information improves patients' ability to cope and feel more in control

In myeloma, the most common concerns related to the diagnosis include:

- ★ Incurability of myeloma
- ★ Delayed diagnosis
- ★ Impaired quality of life (QoL) due to impact of symptoms
- ★ Increasing awareness of vulnerability and management of future health needs
- ★ Worry about family and finances
- ★ Changes in self-perception and body image
- ★ Fear of recurrence and heightened concern about new symptoms

Patients experience fear as a direct result of their diagnosis and its unpredictability, with some describing myeloma as a 'time bomb'^[1]. This continued uncertainty is demonstrated in worsening health-related QoL scores at one year follow up, with over a third of patients worrying about their future health and one in five patients worrying about dying^[2]. Anxiety is common in myeloma patients, and depression can affect one in four patients^[3]. Of note, the risk of suicide in cancer patients is double that of the general population^[4].

Coming to terms with diagnosis of any cancer can cause distress, with associated symptoms of poor concentration, fatigue and insomnia. Rates of cancer-related distress have been reported to be around 30 – 40% in cancer generally and as high as 43% after high-dose therapy and stem cell transplant (HDT-SCT)^[5]. It is not uncommon for myeloma patients to experience feelings of low mood or depression several months

after treatment has been completed, particularly after a HDT-SCT. This can be particularly hard to manage as the patient and their family may feel that things should be 'back to normal' and they ought to be feeling better.

Treatments for myeloma are increasingly complex, and carry a range of side-effects that can also affect mood, wellbeing and the ability to cope. Symptoms and side-effects of treatment such as pain, reduced mobility, nausea and fatigue affect over 90% of myeloma patients^[6]. Steroid treatment can cause difficult mood swings and changes in energy levels. The impact of myeloma may also negatively impact on work and finances and cause changes in family relationships and roles, all of which can contribute to anxiety, fear and a feeling of loss of control. Loss of control and uncertainty are particularly concerning for patients with advanced disease^[7].

Family members also have psychological changes related to a diagnosis of myeloma. Anxiety has been reported to affect almost half of myeloma carers, with 14% showing signs of depression^[3]. Family members can neglect their own needs while providing practical and emotional support to patients. Patients and carers may conceal their stress in an effort to protect each other and this can also contribute to feelings of isolation.

It is important to recognise the signs of psychological distress as early as possible so that interventions can be introduced in a timely way to optimise QoL for the patient and their family.

GENERAL RECOMMENDATIONS:

- ★ Screen all patients for psychological distress at key points in the myeloma pathway. Ideally this should be at the time of diagnosis, when starting anti-myeloma treatment and when there is a change of treatment, or at transition to end of life care
- ★ Patients should be referred appropriately and in a timely manner if they require more specialist psychological support, urgently if they are at risk of suicide
- ★ Find out if a patient has a history of psychological problems such as anxiety or depression, and how these have been managed

NURSING RECOMMENDATIONS:

- ★ Listening, providing information and reassurance can provide invaluable emotional support to patients and families
- ★ Consider different support interventions and strategies to help manage psychological symptoms, for example complementary therapies, support groups, relaxation exercises
- ★ Guide patients towards reputable sources of information and support services that may help support psychological wellbeing
- ★ Help patients learn self-management strategies to build emotional resilience

Medical Approach

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Myeloma is a debilitating and challenging disease and all myeloma patients are at risk of psychological distress at any time during the course of their disease. Recognition of psychological problems through effective assessment, with appropriate interventions and management can prevent symptoms amplifying and promote psychological wellbeing.

The following section describes the general multidisciplinary approach to the assessment, prevention and treatment of emotional and psychological symptoms related to myeloma and its treatment.

Assessment

As with all aspects of myeloma care, a multidisciplinary approach is vital. Nurses frequently form a close rapport with patients and their families that helps to facilitate accurate assessment of psychological and support needs.

While psychological distress can surface at any stage, potential trigger points for anxiety and depression in myeloma are typically at:

- ★ Diagnosis
- ★ End of a course of treatment
- ★ Relapse or acceleration of disease

It is important to be aware of any history of anxiety or depression and how this was treated or managed. Patients' concerns are likely to change over time, so assessments need to be repeated at key points in the myeloma pathway^[8]. The National Institute for Health and Care Excellence (NICE) has developed a four level model for psychological assessment and support in people with cancer as shown in Appendix I^[9]. All nurses should be able to perform Level 1 assessment and many clinical nurse specialists have been trained and have the advanced communication skills to assess at Level 2.

Signs of depression in patients and carers^[10] include:

- ★ Low mood and lack of enjoyment of life and usual pursuits
- ★ Tearfulness, irritability or impatience
- ★ Feelings of guilt, self-blame and low self esteem
- ★ Isolation and avoiding social events
- ★ Unexplained physical symptoms such as insomnia or excessive sleeping, poor appetite, weight loss and lack of energy
- ★ Suicidal thoughts

Signs of anxiety include:

- ★ Restlessness or agitation
- ★ Poor concentration
- ★ Headaches, sweating and dizziness

The severity and duration of symptoms are important factors in assessment. Generally symptoms of depression will have lasted for more than two weeks.

Using a formal assessment tool will help to ensure consistency of the assessment process for patients, particularly where different teams are involved in a patient's care. There are several tools available for carrying out psychological, holistic and QoL assessment in people with cancer. These include:

Anxiety and depression screening tools

- ★ The Hospital Anxiety and Depression Scale (HADS)^[11]. This is a 14 question tool based on the frequency of symptoms of anxiety or depression over the preceding week. A licence must be purchased in order to use it
- ★ Generalised Anxiety Disorder assessment (GAD-7)^[12]. This tool has 7 questions which assess frequency of anxiety over previous two weeks. It is free to use
- ★ Patient Health Questionnaire (PHQ-9)^[13]. This is a 10 question tool, assessing severity of symptoms of depression over the previous two weeks. This tool is also free to use

Guidance on using the tools is important, including how to interpret the scores and the appropriate interventions and action required.

Holistic needs assessment (HNA) tools

- ★ The distress thermometer and concerns checklist is a checklist and rating tool designed to enable patients to rate and prioritise their concerns
- ★ The Sheffield Profile for Assessment and Referral for Care (SPARC) is a 45 question tool designed to facilitate the referral of those with advanced illness to palliative care
- ★ The Pepsi cola 'aide memoire' is a checklist for healthcare professionals aimed at supporting best practice in end of life care

Most centres will have identified and recommend the use of a specified HNA tool. More information on the above HNA tools can be found in an NHS guide for healthcare professionals^[14].

Evidence shows that a greater range of needs will be uncovered during HNAs carried out in outpatients, rather than during inpatient care, with post-treatment assessments more likely to focus on emotional and social wellbeing and spiritual issues. This has relevance to myeloma patients who are largely managed in outpatient settings and usually will have several treatment episodes.

Quality of life assessment (QoL) tools

- ★ The EORTC QLQ C30 MY20. This questionnaire is designed to assess QoL in myeloma patients taking part in research
- ★ The MyPOS questionnaire^[15]. This tool is designed for clinical use and focuses on the issues myeloma patients report as most important. It helps to assess the impact of symptoms on QoL, rather than measuring the symptom itself. For example, a question would be phrased "How much is your pain interfering with your daily life on a scale of 1 - 10" rather than "How would you rate your pain"

Further information about QoL assessment tools can be found on the resources section of the Myeloma Academy website.

The MyPOS tool can be downloaded at <http://pos-pal.org/maix/mypos.php>



Treatment

It is important to recognise the value of the psychological support that every nurse can provide to patients, by using good communication skills such as listening, picking up on patient cues and showing kindness and compassion.

Listening and counselling skills may reveal concerns and are fundamental in helping patients and families to feel more supported throughout the course of their disease. The value of simply being with a patient and listening can make a significant difference to patients who are struggling to cope emotionally. Providing information about myeloma and its treatments, and contact details if they have concerns, can reduce fear and help patients to feel more in control.

It is crucial to recognise when further interventions and specialist referrals are required. Some patients may need referral to a counsellor or psychologist for ongoing support. Counselling services and psychological support services may be available within hospitals, cancer support centres, palliative care services or via the patient's GP. Interventions may include talking therapies, techniques such as cognitive behavioural therapy (CBT) and mindfulness approaches. For some patients anti-depressants may be appropriate. It is important to ask cancer patients about suicidal feelings or intent^[4]. Although it requires skill and confidence, simply asking a patient if they feel suicidal will not put the idea into their head. Patients at suicidal risk need urgent referral for specialist psychological support.

Complementary therapies are commonly used by myeloma patients to help manage their symptoms. Complementary therapies can improve psychological wellbeing by reducing stress and tension, and promote a sense of control and self-determination. Relaxation therapies, meditation and breathing exercises can all be taught to

patients to help manage tension, improve sleep and self-manage stressful situations promoting resilience. Hypnotherapy can help with anxiety related to particular situations or procedures.

See the Myeloma Academy Nursing Best Practice Guide on Complementary Therapies for more information.

Meeting other myeloma patients can be a valuable source of support, whether that is through a chat in the waiting room or in a more structured way, such as a Support Group or online discussion forum. Myeloma patients have a unique disease trajectory compared to other cancer patients and often report feeling isolated. Thus they may feel more supported and comfortable in a myeloma specific group. Patients may also benefit from being introduced to other patients who are willing to talk through certain treatments to provide support; this may be particularly useful for patients who are planned to have a HDT-SCT.

Many patients will derive a vast amount of support from their family and friends. However, family members are vulnerable themselves to anxiety and depression and need their own source of support. This is often provided within the cancer support services at the hospital. Other sources of support include cancer information and support centres and through the family member's GP. A carer review can help identify areas where extra support might be available, but many family carers are not aware this is available.

Nursing interventions and management

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The following section provides best practice guidance for nursing interventions related to the assessment, prevention and provision of psychological support in myeloma, and nursing management strategies to ensure timely, holistic and patient focused care.

Interventions

- ★ Assess patients' holistic needs at all stages of myeloma, being aware of potential trigger points for anxiety and depression, such as relapse, or following a period of treatment, such as HDT-SCT
- ★ Use communication skills that include:
 - ★ Creating an environment that encourages patients to open up and seek help when they need it
 - ★ Active listening, picking up on cues and hearing the patient's concerns
 - ★ Open explorative questions to find out how symptoms impact on a patient's QoL
 - ★ Enabling patients to explore own needs, avenues of support and solutions
- ★ Use appropriate assessment tools to screen for psychological changes and signs of depression
- ★ Be aware of or find out if a patient has any previous psychological problems and how these were managed
- ★ Be alert to signs of anxiety and depression in both patients and carers and seek specialist advice and referral for patients who have symptoms of anxiety and depression
- ★ Screen for suicide risk. Urgent referral is needed for patients who express suicidal thoughts
- ★ With patient's permission, psychological assessment and support can involve input from the family and include consideration of available family support

- ★ Where appropriate, and with individual needs acknowledged, reinforce events and emotions as common to others with myeloma, providing reassurance that patients are not alone in what they are going through

Management

- ★ Provide patients with a contact number for their key worker and advise on reporting psychological symptoms that are persistent and difficult to manage
- ★ Provide indirect support to patients through providing support and information to patient's family or carer
- ★ Be aware of local and available counselling and psychology services to enable swift and seamless referral if a patient is in need of further support
- ★ Provide all myeloma patients and families with information about available support, including local myeloma support groups, peer support, discussion forums, complementary therapy services, local cancer support centres and national organisations
- ★ Help patients' understanding of myeloma by providing information tailored to individual needs in terms of complexity, level of detail, language used and timing of information giving
- ★ Promote interdisciplinary communication to highlight any psychological problems early and provide appropriate support early on

Summary

All patients will need some form of psychological support during the course of their disease. Nurses play a vital role in promoting psychological wellbeing and providing relevant information and guidance about self-management strategies and available support.

In myeloma, nurses typically form long and close relationships with patients and thus have a central role in assessing levels of coping, including signs of anxiety and depression, and recognising when further support and interventions are needed.

Abbreviations

★ CBT	Cognitive behavioural therapy	★ HNA	Holistic needs assessment
★ GAD	Generalised anxiety disorder	★ PHQ	Patient health questionnaire
★ HADS	Hospital anxiety and depression scale	★ SPARC	Sheffield profile for assessment and referral for care
★ HDT-SCT	High-dose therapy and stem cell transplant		

Appendix I

Adapted from the National Institute for Health and Care Excellence (NICE) recommended model of professional psychological assessment and support

Level	Group	Assessment	Intervention
1	All health and social care professionals	Recognition of psychological needs	Effective information giving compassionate and general psychological support
2	Health and social care professionals with additional expertise	Screening for psychological distress	Psychological techniques such as problem solving
3	Trained and accredited professionals	Assessed for psychological distress and some diagnosis of psychopathology	Counselling and specific psychological interventions such as anxiety management and solution focused therapy, delivered according to an explicit theoretical framework
4	Mental health specialists	Diagnosis of psychopathology	Special psychological and psychiatric interventions such as psychotherapy including cognitive behavioural therapy (CBT)

Self help and informal support



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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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