



MODULE 5: Care and Support

English Version





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1 Introduction

Intro

The MS Nurse is a supportive presence throughout the person's experience of living with MS; providing comprehensive, evidence-based information, responding to questions, clarifying (translating) communications to and from the physician, navigating to useful resources, and ensuring that the person with MS is a self-determined participant in his or her own care. The information and on-going support provided by the nurse is key in enabling the individuals' ability to make, share and agree with the goals of the multidisciplinary team.



The MS Nurse is a supportive presence throughout the person's experience of living with MS; providing comprehensive, evidence-based information, responding to questions, clarifying (translating) communications to and from the physician, navigating to useful resources, and ensuring that the person with MS is a self-determined participant in his or her own care.

This module examines the relationship of the person with MS and the MS Nurse. You will learn about the psychological and social impact MS can have on individuals and their families. This includes mental health issues such as depression, anxiety and cognition as well as the impact on employment and social activities. You will gain understanding of how the trained MS Nurse can optimise the outcomes for someone living with MS.

2 Importance of Communication and Trust

2.1 Learning Objectives



MS Nurses are often the key point of contact for people with MS and an invaluable source of information and long-term support; good communication skills are essential to fulfil this role. This section will explore the importance of establishing a trusting relationship that shares good communication with your MS patients and their families.

After review of this section, you will be better able to:

- Evaluate how best to counsel people with MS toward realistic expectations and achievable action plans
- Describe the social and emotional impact of caregiving and the importance of establishing a strong relationship with the carer

2.2 Building a Relationship of Trust with the Person with MS

Appropriate communications with the person with MS are vital for establishing a trusting relationship. Good communication may;

- Improve satisfaction and adherence with treatment plans/decisions
- Improve health outcomes (eg reduction in blood pressure, improved recovery from infection)
- Ensure time and opportunity for concerns to be voiced, heard and addressed

A number of studies looking at the experience of people with MS suggest they often feel professionals have an inappropriate attitude towards them, and that they feel deprived of the information and support they need¹. In addition, there may also be discrepancies in perception between what the person with MS feels are their healthcare needs and what the professional perceives their needs to be^{1,2}.



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The quality of the interaction between patients and healthcare professionals is an important factor in determining patient satisfaction. Dissatisfaction may occur as a result of poor communication. Nursing experience suggests that those healthcare professionals who demonstrate insightful awareness of patients' verbal and nonverbal communication needs, and are empathic to patients' feelings, facilitate patient satisfaction.

Information sharing is a challenging part of a consultation, and the more information that has to be communicated, the harder it is to assess how it is perceived or understood. Patients typically only retain 50% of the information given to them during a consultation – however, effective and timely communication may help to increase the amount of key information that a patient takes away.



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The MS Nurse should first establish the person's pre-existing knowledge, beliefs and experience with MS. Then the MS Nurse should consider the type and extent of information that the person wishes to receive and when. The MS Nurse should consider carefully the balance between the potential benefits and risks associated with all information, together with individual internal contextual factors such as cognitive ability and external contextual factors such as cultural and ethnic influences¹.



How would you begin to identify the pre-existing knowledge of someone who has just been diagnosed with MS?

I ask the person with MS how they received their diagnosis and how did it make them feel at that time? - This should normally happen in a face to face meeting with the doctor, but there have been cases where the person has received their diagnosis via a telephone conversation or by letter. I then ask the person what they already know about MS and where they got this information from. I also ask them if there are any specific questions they want to ask me. Asking these questions is a good starting point for discussion and enables me to find out the level and quality of information that the person already has.

Guidelines recommend that the information the MS Nurse provides is within their own area of knowledge/expertise and refers patients to others when necessary. It is important to clarify any specific options and choices the person with MS may need to make and the likely outcomes of each choice, with benefits and risks fully explained. It is essential to provide supporting written/audio material, web links, contact details, support groups, statutory advisory addresses, treatment plans and follow-up appointments¹.



Guidelines recommend that information the MS Nurse provides is within their own area of knowledge/expertise. It is important to clarify any specific options and choices the person with MS may need to make and the likely outcomes of each choice, with benefits and risks fully explained.

MS Nurses should also consider that many people with MS have depression, impairment of cognitive skills and/or visual impairment that can impact on processing of information. Therefore the delivery and pacing of information communication is as important as the content. Tips include:

- Use different types of questions (open, closed, focused) appropriately
- Active listening – pick up on verbal and nonverbal behaviour
- Give information in small portions, avoiding medical jargon
- Use a logical sequence
- Use diagrams and written materials to help explain the information
- Summarise and check regularly to ensure that both parties have communicated effectively
- Let the person ask, or ask him/her: what is the main issue in your mind right now?
- Be aware of fatigue and anxiety when giving new information; it may not be wise to give all materials during the first session
- Pace information carefully and always provide an opportunity for review and repetition

There are a number of challenges to effective communication that the MS Nurse might encounter:

- Telephone conversations: there are no non-verbal cues, therefore it is important to check the person can hear and understand; speak clearly and avoid using long sentences; check and summarise regularly to ensure that you have heard the person's story correctly and that they understand the information you have given them correctly; make sure you give enough time for the information to be heard and offer follow-up phone calls as necessary
- Listen to what is called the "sub text" and this means getting a feeling for what the person is not able to say outright but would like to be able to do so
- In some unfortunate occasions, the patient may even get the diagnosis by phone, which should not happen

When patients are faced with a complex array of treatment options, they have described six common themes they experience during the decision making process. These are:

- weighing up and deciding what's important
- acknowledging the illness as part of oneself
- playing the mental game
- seeking credible resources
- evaluating symptoms and fit with quality of life
- managing the roles and involvement of family.

These provide a greater understanding about the experience of making a therapeutic choice for people with MS and offer insights for nurses when supporting and communicating with patients faced with options about treatment.³

Establishing care is the first step toward building relationships and encouraging open communication with people with MS and their families or care partners. Components of establishing care include:

- Building trust
- Establishing partnerships
- Determining information needs
- Sharing information
- Assessing the individuals support network

2.3 Building a Relationship with the Caregiver

Around 30% of people with MS require assistance at home, with 80% of that support provided by informal (or family) caregivers. Looking after someone with a disability is demanding and not always easy to do. Carers may require financial, psychological and physical support to enable care at home. The burden of carers may be weighted by the age of the person they care for the unpredictability, complexity and variability of MS pathology, the absence of a cure, the episodic nature of disabling neurological symptoms and the presence of depression and or cognitive issues⁴.

The tasks performed by caregivers vary according to the patients' symptoms, the impact of their disease and what they can no longer do for themselves (table 1).

Symptom	Possible support needs
Fatigue – an overwhelming sense of tiredness making physical or mental activity difficult and, for some, impossible	General support with day to day living; you may need to take on many of the tasks previously carried out by the person with MS
Balance problems and vertigo – walking difficulties, problems with co-ordination	Help with mobility; some people use a wheelchair to get around at times
Visual problems – blurred or double vision, temporary loss of sight in one eye or both	General support with day to day living; help with reading and general mobility; the person with MS may not be able to drive when experiencing this symptom
Numbness or tingling – commonly in the hands or feet	General support with day to day living; help with mobility
Pain – sometimes mild, sometimes severe	Help with medication; emotional support if the pain becomes debilitating
Loss of muscle strength and dexterity	General support with day to day living; many simple tasks such as dressing and washing will become very difficult; mobility may be affected
Stiffness and spasms – tightening or rigidity in particular muscle groups	General support with day to day living; help with mobility; help with medication
Anxiety, depression or mood swings	Emotional support; patience and understanding
Cognitive problems – difficulty with memory and concentration	Help with daily routines; patience and support when problems become frustrating
Speech problems – slurring, slowing of speech, or changes in pitch or tone	Assistance with communication; patience if communication becomes laboured
Incontinence – a lack of control over bladder or bowel functions	Help with toileting and personal care; possible assistance with catheter and stoma use if these options are chosen
Sexual problems – lack of libido, erectile difficulties	Support to explore solutions to sexual difficulties; patience and understanding

Table 1: MS symptoms and how they might impact on the caregiver role⁵

The tasks performed by caregivers

Some of the most common caregiver tasks include:

- Transport to social activities and medical appointments
- Assisting with activities of daily living (dressing, bathing, grooming, feeding)
- Physical assistance and support in bladder and bowel management, range of motion exercises and transferring
- Caring for children
- Other daily tasks (meal preparation, shopping, financial management, laundry and any special individual needs)
- Psychological and social support
- Financial management support and decision-making

The strain of balancing care with other responsibilities can lead to feelings of martyrdom, anger, depression and guilt. In some cases, it can cause caregiver burden. A systematic review of the needs and experiences of caregivers of MS patients showed that providing care for a person with MS can have a detrimental effect on the caregiver's psychological health⁶. Caregivers can experience high levels of distress and reduced quality of life. Psychiatric symptoms and cognitive impairment contribute significantly to caregiver distress, over and above the effect of disability due to neurological symptoms⁷. A recent study in Catalonia (Southern Europe) found that caregivers of people with MS have a HRQoL closer to population with chronic illness than to general population⁸. Caregiving can also have a negative impact on caregiver employment, forcing a reduction in hours worked, change in work schedules, refusal of promotions, or the need for a leave of absence. A recent study found that poorer cognitive ability by the care recipient to make decisions about daily tasks predicted reduced caregiver employment.⁹

caregiver burden

Caregiver burden is a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience. Caregivers who experience burden are more likely to have a higher risk of depression and a lower quality of life. Early recognition of caregiver burden is important in determining appropriate interventions.

Many caregivers often think they can handle everything alone. A recent "Carers Week" survey, undertaken in the UK, reported that two in five unpaid carers are sacrificing their own health by putting off medical treatment to care for an ill, frail or disabled loved one¹⁰. The survey, completed by 3,400 carers, also showed that caring had a negative impact on 83% of carers' physical health, with 36% of carers sustaining a physical injury (such as back pain) through caring. 87% said caring for a family member or friend has had a negative impact on their mental health. There is therefore a need for effective interventions towards helping caregivers continue their essential role but also maintaining themselves in the process.

Given the demanding role of caring for someone with MS, other supports for the caregiver are essential to prevent burnout. There are a number of things that can be suggested to the caregiver to help them avoid burnout⁵. These include:

- **Reaching out for practical and emotional support.** Sharing stress can help to alleviate stress.
- **Sleep.** Caring for another person takes a lot of energy. It is important to ensure the carer gets the rest they need.
- **Have fun.** Carers need to nurture their social side and give themselves an outlet to laugh and be with friends.
- **Be honest.** Carers should be encouraged to discuss their fears and concerns openly.

- **Have outside hobbies and interests.** Research shows that the emotional stress of caring is related to how "trapped" by their situation caregivers feel.
- **Exercise.** 20-30 minutes each day can help to clear the head, release endorphins, and care for the body.
- **Maintain a healthy diet.** It is important for the carer to take the time to eat the right foods. They will give energy, strength, and valuable vitamins and minerals that improve well-being.
- **Join an MS caregiver support group.** They can offer an outlet for emotions and provide practical information and support.
- **Watch out for resentment.** Anger is a common emotion for caregivers. The caregiving situation can feel (and often is) unfair. So it is important to deal with frustration in a healthy way, before angry encounters become physically and emotionally abusive.

Healthcare professionals, including the MS Nurse, should also support caregivers by having relevant information on available programmes and/or resources from the local MS Society, Carer's organisation or other community based support groups, by encouraging caregivers to attend support groups and access respite, and by being sensitive to the tremendous psychosocial issues caregivers face. Interventions designed and implemented to promote well-being in carers should consider support networks and coping processes as these shape positive and negative carer outcomes. Information, training and support must be offered using a paced and proactive approach rather than waiting until help is sought or a crisis occurs¹¹.



2.4 Summary

- Good communication provides the foundation for empowerment, hope and well informed decisions that will endure
- This contributes to the establishment of a strong, trusting relationship between MS Nurses and their patients.
- The MS Nurse-patient relationship can last for many years with shared confidence and trust evolving throughout the journey with MS.



Reflective learning points:

Thinking about the relationships you have with your patients, what are the different methods you use to communicate with them?

Are there any new methods that you will now try in order to improve communications?

3 Patient Education & Empowerment

3.1 Learning Objectives



MS Nurses play a central role in the education and support of newly diagnosed people with MS and their families; this section will outline the importance of the MS Nurse as educator and will discuss some approaches used to empower people with MS. After review of this section, you will be better able to:

- Evaluate the importance of patient and family education
- List and apply strategies for effective patient education
- Describe the role of the multidisciplinary team in MS care

3.2 Patient Education

To develop positive coping strategies for the diagnosis of MS and its implications, patients and families must have access to information. Today's patients are often very information-aware and will ask for information on many aspects relative to their MS. Although healthcare professionals remain the most trusted source of health information for people with MS, the Internet is the first source of health information for most of them. This has important implications for the dissemination of health information.¹²

Patient education has always been a central focus of the MS Nurse role, and a rapidly evolving environment heightens the need for evidenced-based information and education¹³⁻¹⁵. People with MS are faced with increasingly complex decisions, and need up-to-date, evidence-based information and decision-support systems in order to make informed decisions¹⁶.



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The role of the educator demands a comprehensive understanding of the disease process and the effect of MS on personal health and life status. The education MS Nurses provide must be constant, yet dynamic and **empower** patients to understand their illness and optimise their quality of life^{15,17,18}. The more patients know about their MS, the more empowered they are to take control of their lives.

Empower

Empowerment is essential for people with MS, families, and for healthcare providers in dealing with MS and its widespread implications¹⁹. Empowerment focuses on "what can be," not on "what was"²⁰. Self-efficacy, self-confidence, skill development, and effective communication are vital components and key features to promote successful coping with this chronic neurological condition.



How would you transfer the skills and knowledge to a person with MS so that they can ensure positive coping strategies, and effectively self-manage their MS?

I try to schedule regular appointments with the person so that I am able to pass the information to them in small, manageable pieces. This also gives me the opportunity to repeat information as necessary and also allows the patient to ask questions as required. It is also important to pass your full contact details to the patient – this enables the person to be able to contact you by telephone or e-mail when any problems occur, without them having to wait until the next scheduled face-to-face appointment.



Empowerment focuses on “what can be” not on “what was”.

MS patients may have cognitive impairment, and educating people with MS can be a challenging experience for nurses. Even in the absence of cognitive impairment, patients frequently ask the same questions repeatedly or fail to apply information to given tasks or self-procedures. Supporting material that can be taken home and referred to as necessary is helpful together with family or caregiver involvement. Patients should not be deemed able to perform a particular procedure until they have done so together with the MS Nurse²⁰.

It is very important for the MS Nurse to enable the individual to maintain active participation in managing their MS. The educated person will feel a sense of empowerment, acceptance, and well-being. The Nurse can assist in this process by referring people to a wide range of resources, including websites, leaflets and patient help groups.

The use of the Web varies widely according to personal characteristics, health role (MS patient or family member), and time from the diagnosis. A recent Italian study found some MS patients found the Internet useful for collecting information and learning about others' experiences (also using social networks), while others were cautious and preferred relying on information given by their neurologist. MS patients were mainly “on demand” users, searching on the Web before and/or after seeing the neurologist or when a new therapy or a new risk factor was proposed.²¹



It is very important for the MS Nurse to encourage the person to avoid a passive role and assume a proactive stance about their MS.

It is important for the MS Nurse to support reasonable expectations of proposed treatments and side effects, to educate and guide on self-care and promote living well with MS.

MS Nurses must assess the unique, individual information needs of each person to effectively provide the information required. This can be facilitated by:

- Giving clear, realistic interpretations of the information

- Checking the patient's understanding and expectations
- Supporting that understanding by referral to appropriate further information resources, providing literature to take away or contact details for additional help
- Providing a written and well understood management plan
- Ensuring there is appropriate follow-up booking/appointment in place
- Ensuring the patient has full contact details of their MS Nurse (e-mail address, mobile phone number) in order that the patient can reach that Nurse when support is needed
- Including the family or caregiver in all education

Information provision for people with MS seems to increase disease-related knowledge, with less clear results on decision making and quality of life. There are no negative side effects from informing patients about their disease²². Effectively achieved education enables patients to be autonomous, self-determined and motivated in managing diagnosis, treatments and healthy living. The MS Nurse's support, advice, education, and expertise will advance the person's potential pre-conception of MS from that of an incurable and uncontrollable disease to one of it being a manageable problem that is a part of his or her life (figure 1).



Successful education enables patients to remain autonomous, self-determined and motivated in managing diagnosis, treatments and healthy living. Support from the MS Nurse will facilitate the person's positive pre-conception of MS.

Strategies for effective patient education

- Pre-assessment to education
- Provide information in a clear and concise manner
- Provide a non-distracting, relaxing and comfortable learning environment
- Use a variety of educational tools (e.g. oral and written information, videocassettes, practice vials and syringes, and one-on-one demonstrations)
- Provide patients with reinforcement and acknowledge success
- Include family members in the teaching process (but assess if patient wants family involvement first)

Figure 1: Strategies for effective patient education

MS patients place inherent value on patient support programmes (PSPs). From a patient's viewpoint, PSPs provide real incremental benefit in patient-reported health status at all stages of MS²³. Encouraging self-management is consistent with recent moves in countries such as the

UK where the 'expert patient programme', aims that patients should give other patients the skills, knowledge and confidence to participate actively in all aspects of their own health care¹.

Self-management

The Chronic Disease Self-Management Course (CDSMC) is a lay-led self-management intervention that provides participants with a range of skills and strategies, which is currently being used in a number of countries (e.g. UK, US, Australia and Canada). The course is not disease-specific and participants with any chronic disease can attend together.

The focus of the CDSMC is the promotion of an individual's ability to select the self-management tool that will meet their individual needs at that time. CDSMC has been shown to be effective in randomised controlled trials among participants with arthritis, lung disease, heart disease and stroke²⁴.

A recent study aimed to assess the impact of the CDSMC on people with MS. It compared two groups of randomised individuals attending a CDSMC with additional data collected from a group of informed non-attendees²⁴. Results showed that the CDSMC had a statistically significant impact on self-management, self-efficacy and MSIS physical status, and showed a trend towards improvement in depression and MS self-efficacy, with all improvements being maintained over a 12-month period²⁴.

Overall the study concluded that the CDSMC provides some small positive effects for people with MS, and that the motivation to attend such a course may be related to the psychological distress of the individual and their disease duration. In particular, the authors felt that the CDSMC might be of value for those with mild anxiety/depression who need extra support, and they recommend attendance early in the disease course²⁴.

3.3 Developing Care Plans

Many centres use care plans, also known as clinical pathways or multidisciplinary action plans. These can apply to any aspect of managing MS and its symptoms. Care plans are shared by the person with MS and the MS Nurse as a prepared schedule of interventions; when, where, how and how long; and what the outcomes should be. Any necessary collaboration with other agencies or healthcare professionals that may be needed should also be included.



Many centres use care plans, shared by the person with MS and the MS Nurse as a prepared schedule of interventions.

A care plan on MS is an active partnership between the person with MS, their family, and the MS team. The care plan is established by agreed and shared realistic goals, consistent and constant support. Each care plan must be tailored to the individual needs of the patient and his or her family; MS is a NOT disease where "one size" fits all¹⁹. It has been recommended that healthcare professionals adopt an integrated model that encompasses therapeutic, rehabilitative, and palliative care; equal weight should be given to medical and psychosocial models of disability². MS Nurses should also be able to communicate this knowledge effectively to people and/or their families²⁵.



Each care plan must be tailored to the individual needs of the patient and his or her family.

3.4 Role of the Multidisciplinary Team (MDT)

In most countries, the care and management of people with MS involves a multidisciplinary approach²⁶. This ensures continuity of care consistent with treatment goals and direction. The

hub of the comprehensive care team in MS is the knowledgeable patient, supported by family, relationship sphere, and care partners. The treatment team may consist of a neurologist and other physicians, as well as nurses, social workers, physical therapists, occupational therapists, speech language pathologists, recreation therapists, pharmacists, nutritionists, psychologists, neuro-psychologists, clergy, and others¹⁹ (figure 2). The overriding objective is to allow people with MS to reach their full potential to function independently¹⁸.



In most countries, the care and management of people with MS involves a multidisciplinary approach. The hub of the comprehensive care team in MS is the knowledgeable patient.

The MS Nurse functions as the key conduit for the team, providing information and feedback to team members about the person's physical, emotional, and cognitive state, and ability to be an active participant in his or her own care. Having identified the person's needs, the nurse acts to coordinate the necessary interventions, helping to ensure that these needs are adequately addressed²⁷. In order to maintain patient trust in the healthcare team's competence and commitment to the course of treatment, the nurse should ensure that all team members provide patients with consistent reliable information.

Physiotherapist  Assists the person with MS in improving or maintaining physical functioning through exercise, e.g. gentle, sustained stretching exercises to help relieve spasticity.	Occupational therapist  Provides support with activities of daily living, e.g. strategies for helping to minimise fatigue. They also provide aids and adaptations to enable the individual to maintain their maximum level of independence and health.
Social worker Assesses the overall living situation of the person with MS and their family and provides guidance with respect to financial arrangements and benefit entitlements, employment issues and alternative living situations. 	Psychologist Assesses the psychological status of the person with MS and their coping styles, problem-solving skills and cognitive function. They use counseling to help the person with MS strengthen their own ability to cope during periods of extreme stress. They may also help prepare the person with MS for active participation in rehabilitation. 
Speech and language therapist  Evaluates and treats those with speech and swallowing difficulties.	Continence advisor Assesses and implements a care plan for those people with MS affected by bladder or bowel problems. 
	Others  May include a dietitian, ophthalmologist, psychiatrist, psychiatric nurse, urologist, urology nurse.

Figure 2: The multidisciplinary team

It has been found that a multidisciplinary team approach is the most effective and efficient way of treating people with MS^{20,28}. A multidisciplinary approach to MS care facilitates coordination of services and continuity of care, while avoiding duplication and fragmentation for the patient and their family. It embraces a philosophy of empowerment – the person with MS is an active

participant in planning and implementing healthcare and self-care activities. He or she is a consultant to the team, which is important because MS, like all chronic illnesses, will last a lifetime²⁰.

Ideally, each member of the team should be familiar with patient's evolving needs and circumstances in order to create a realistic treatment programme. This should help the patient reach their fullest potential for independent functioning within the context of the life he or she chooses to lead. To achieve this, changes may need to be made as the team works with the patient, the family network, and, occasionally, within the vocational setting to advocate for patients and support their needs and wishes.



3.5 Summary

- The MS Nurse has an important role to play in ensuring the person with MS is well informed and well educated.
- There are a number of different strategies the MS Nurse can employ to achieve effective education.
- Care plans are an important tool to enable care to be tailored to meet the individual needs of the person with MS.
- Treating a person with MS often encompasses a multidisciplinary team approach which has been shown to be the most effective way of treating patients.



Reflective learning point:

How do you incorporate patient education into your role as MS Nurse?

4 Emotional and Psychological Support

4.1 Learning Objectives



The diagnosis of MS has emotional impact that can reverberate through their lifetime and many patients will require emotional support at various points throughout the journey of their condition. This section will discuss some of the more common emotional aspects of MS, along with how MS Nurses can help people cope and adapt to life with the condition. After review of this section, you will be better able to:

- Identify how MS can impact upon the emotional well-being of the person with MS
- Outline coping and adaptation strategies that can be implemented to assist the person with MS

4.2 Introduction



MS can cause emotional distress in many ways; people may experience fear, anger, denial, anxiety, depression, and hopelessness. These emotions may hinder motivation to take medications or perform complicated tasks designed to improve their well-being.



MS can cause emotional distress in many ways; people may experience fear, anger, denial, anxiety, depression, and hopelessness.

MS may start at a young age, at a time when individuals are developing expectations for their future. Furthermore, the course of the disease is unpredictable and causes a great deal of uncertainty¹. Many people have negative misconceptions about MS and their expectations may often be worse than the reality. There is no doubt that MS can lead to several cumulative losses over many years, resulting in feelings of loss of control. In addition, MS also affects family members, and the changing interactions between family members can also increase emotional distress¹.



Many people have negative misconceptions about MS and their expectations may often be worse than the reality.

Psychosocial support is a major category of treatment in MS, encompassing:

- Disease-related education (more recently termed psychoeducation — a supportive educational process designed to enhance people's understanding of the disease, adaptive coping strategies, and available resources)
- Diagnosis/treatment of emotional and/or cognitive problems
- Family interventions designed to support family members' efforts to cope with the intrusion of MS into the household
- Support for people's efforts to remain productively employed as long as they are able and interested, and to transition out of the workforce when, and if, it is necessary to do so
 - Helping people with MS and their families to access available resources

A study of people with MS and their satisfaction with care showed that the majority perceived a need for psychosocial support/counselling, with women experiencing a greater need for such services than men. However, the provision of this psychosocial support was one of the things the study participants were least satisfied with²⁹.



A study of people with MS and their satisfaction with care showed that the majority perceived a need for psychosocial support/counselling. However, the provision of this psychosocial support was one of the things the study participants were least satisfied with.

The provision of emotional support is still very much under debate. The NCCCC found limited evidence for the effectiveness of psychotherapy and no research into its cost-effectiveness¹. However they do acknowledge that a person with MS may benefit from emotional support, and recommend that this is considered on an individual basis¹.

4.3 Psychological Assessments

At present, there are no standardised, formal psychological assessment tools used by all countries. However, similar assessments are carried out throughout the world by MS Nurses using both paper-based and computerised tools.



At present, there are no standardised, formal psychological assessment tools used by all countries. However, similar assessments are carried out throughout the world by MS Nurses using both paper-based and computerised tools.

Assessments might include the following:

- Assess which factors influence coping strategies such as support and education
- Assess how the individual is coping with the diagnosis and identify which adjustment stage they are currently in
- Assess the individual's level of dependence on others
- Assess type of coping skills – are they problem-focussed or emotion-focussed?
- Assess non-pharmacological health-maintenance behaviours such as exercise
- Assess whether employment, disability, financial or child care issues need to be addressed immediately
- Identify therapy options and make appropriate referrals.
- Assess social support available such as family or caregiver

Psychological tests assess a range of mental abilities and attributes, including achievement and ability, personality, and neurological functioning. Psychological testing, including neuropsychological assessment, allows for an assessment of a patient's cognitive and behavioural functioning and an analysis of changes related to mental or physical disease, injury, or abnormal development of the brain. Research has shown that the scores from these tests are reproducible and can be compared to those of normal persons of similar age, sex and demographic background to yield valid conclusions.

neuropsychological assessment

A neuropsychological assessment can provide detailed information on a patient's cognitive strengths and weaknesses, and the likely practical impact of this profile upon the patients' capacity to function in various aspects of their everyday life. Some of the more 'executive level' examples could include reporting on the likely impact of cognitive impairment on a patient's capacity to make important, complex decisions (eg appointing a power of attorney), to make reasonable judgments about risks and benefits of a potential course of action (eg taking an experimental drug, or giving up their job), or to be insightful about their capacity to perform certain tasks (eg deciding not to move into supported accommodation).

This sort of detailed neuropsychological assessment also usually leads to recommendations about the best practical strategies to use for managing any identified impairments.

Formal neuropsychological evaluation is not necessary for everyone, but in cases where cognitive impairment may impair a patient's capacity to function effectively in the workplace or at home, some form of screening to provide insight into the nature and extent of cognitive deficits is advised.

MS Nurses are unlikely to carry out this kind of formal assessment but they may notice some early warning signs which they can then follow-up with the relevant healthcare provider within the multidisciplinary team. If there is a need for a formal neuropsychological evaluation it must be done by an expert.

4.4 Depression

Clinically significant depression can affect up to 50% of people with MS over the course of their lifetime^{30,31} regardless of functional impairment, or physical disability. Evidence also suggests that many people with MS are undiagnosed or sub-therapeutically treated for their depression³². This highlights the need for increased systematic screening in MS for depression.



Significant depression can affect up to 50% of people with MS and many are not treated or are significantly undertreated. This highlights the need for increased systematic screening.

Recommendations for screening have included the use of self-report scales, such as the Beck Depression Inventory II, Patient Health Questionnaire, and Chicago Multiscale Depression Inventory³¹. NICE recommends asking two simple questions to identify those who might be depressed and to prompt further assessment³³:

- During the last month, have you often been bothered by feeling down, depressed, or hopeless?
- During the last month, have you often been bothered by little interest or pleasure in doing things?

If a patient with a chronic physical illness answers 'yes' to either question, the following three questions should be asked:

- During the last month, have you often been bothered by:
 - Feelings of worthlessness?
 - Poor concentration?
 - Thoughts of death?

Risk factors for clinical depression in the general population include a history of significant loss, a family history of mental illness, major trauma, loss or significant health problems. Depression is thought to be more common in women. It is also more prevalent in the 20-50 year old age range and in those of greater old age. These factors are relevant to people with MS, but include other specific risk factors³⁴. There seems to be an increased risk for people who have:

- Shorter disease duration
- Greater disease severity
- Lower education
- Lower age
- Less social support.

MS nurses play an important role in preventing or identifying depression by being aware of risk factors. These factors need to be considered in the early part of a person's care and any relevant risk factors recorded and shared with members of the MDT³⁵.



MS nurses can play an important role in preventing or identifying depression by being aware of risk factors.

Diagnosis of major depression is often missed by health professionals; however, since the suicide rate amongst people with MS has been shown to be 7.5 to 8.00 times higher than in an age-matched population, and since depression is responsive to treatment, the importance of diagnosis and active management cannot be overstressed^{36,37} (figure 3).

The Mnemonic below Can Be Useful in Highlighting Psychological Needs of People with MS		
D	Diagnosis	How are you dealing emotionally with the diagnosis?
E	Expression	Observe mood and facial expression
P	Pleasure	What things do you enjoy most?
R	Remorse	Do you feel guilty about things you have or have not done? Do you feel a burden to your family / friends?
E	Explore	Past personal or family history or psychiatric illness?
S	Sadness	How would you best describe your mood?
S	Stress	Do you experience stress and / or anxiety? How do you deal with this? What activities do you avoid due to stress / anxiety? Has your concentration decreased?
I	Insomnia	How well do you sleep? Do you experience early morning wakening? Do you experience initial insomnia / inability to sleep?
O	Others	How is illness perceived in your family? How do others perceive your mood?
N	Nutrition	How is your appetite?

	Do you taste and enjoy food? Have you gained / lost weight?
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Figure 3: Assessment of depression

Anyone with MS who is depressed may have a number of contributing factors (such as chronic pain and social isolation/deprivation) and identification of these means that interventions can be initiated to help resolve these where possible. Specific antidepressant medication and/or psychological treatments such as [cognitive behavioural therapy](#) should be considered but only as part of an overall programme of depression management¹.

Cognitive behavioural therapy

Cognitive behavioural therapy or CBT is commonly used in the treatment of conditions such as anxiety and depression. It is based on the belief that how we think about a situation influences how we act, and our actions subsequently influence how we think and feel. It encourages the adoption of new thinking and behavioural techniques. A CBT programme can be delivered in a number of ways and might be group-based, computer-based or telephone administered. It usually consists of a programme of once weekly hour long sessions. Psychotherapies have been shown to have a positive impact on MS-related depression with the results of CBT observed to be equivalent to the administration of *sertraline*³⁸. A review of intervention studies on depression in persons with MS showed that there is reasonable evidence that CBT is beneficial in the treatment of depression and in helping people adjust to (and cope with) living with the disease³⁹.

4.5 Anxiety

Regardless of specific medical problems, living with MS can be a source of strain. The loss of functions, altered life circumstances and not knowing how one will feel from day to day are significant causes of anxiety. Anxiety can be described as a feeling of unease, worry or fear that can become so persistent that it affects a person's ability to function normally. Anxiety can cause a physical response that produces symptoms such as tiredness, insomnia, weakness, the urge to go to the toilet and a blurring of vision.

Anxiety has been poorly studied in MS, although it is a common emotional impairment associated with the condition. Lifetime prevalence of anxiety disorders in people with MS is 36%⁴⁰. Anxiety symptoms are associated with fatigue, depression, sleep disturbance, problem-solving deficits, pain, and disability status^{41,42}.

People with MS with anxiety disorders are more likely to be female, and to have a lifetime diagnosis of depressive disorder or alcohol abuse. They are also more likely to report greater social stress, less social support and to have contemplated suicide⁴³. In one study, only 34% of those with an anxiety disorder had previously been given a documented psychiatric diagnosis; and none were given a specific diagnosis of anxiety disorder. Less than half of participants were receiving any treatment⁴³.

Social anxiety has also been found to be common. In one study, 31% of clinic patients met criteria for social phobia (fear and avoidance of social situations) on the Social Phobia Inventory. This was not associated with severity of disability. The presence of social phobia was associated with reduced health-related quality of life⁴⁴. To date, no pharmacological treatments for social phobia in MS have been reported in the literature.

A counsellor, psychologist or MS Nurse can help with these problems through encouraging the individual to develop self help strategies such as relaxation techniques, discussing fears or

distraction techniques. Cognitive behaviour therapy may also help to ease anxiety. In more severe cases medication may be prescribed.

4.6 Stress

It is widely believed by people with MS, relatives and some professionals, that stress of almost any type may precipitate a relapse and worsen the symptoms of MS. Some patients are even advised to avoid certain stressors, e.g. **emotional stress, trauma** and certain medical interventions. The evidence for an association is limited and/or conflicting. However, a recent national cohort study in Denmark provides little evidence for a *causal* association between major stressful life events (as exemplified by divorce or the loss of a child or a spouse) and subsequent MS risk.⁴⁵ But there are NO certainties about relationships between the pathological response to stress, its' role within the auto-immune system and subsequent auto-immune mediated disease.

Emotional stress, trauma

Emotional stress – evidence is conflicting regarding an association between stress and MS relapses. Several studies have shown no significant association between stressful life events or psychological stress, and MS relapses. However, increased conflict and disruption in routine daily hassles have been reported to increase relapse rates. There is also a significantly increased risk of MS progression when the rate of reported stressful events is higher⁴⁶.

Trauma – evidence to support a relationship between trauma and MS relapse is sparse and no association has been found between head injury or lumbar disc surgery and the onset of MS¹.

Nevertheless, in a meta-analysis review, the majority of studies were found to suggest that stress was associated with an increased risk of relapse⁴⁶. For example, a 2-year prospective study in RRMS found that patients who reported significant negative stressful life-events were 3.7 times more likely to have a relapse than those unexposed to stress⁴⁷.

Higher stress levels also appear to increase the risk of development of gadolinium-enhancing lesions. A recent randomized trial shows that reducing stress using stress management therapy (SMT), a cognitive-behavioural therapy approach, results in a statistically significant reduction in new magnetic resonance imaging lesions.⁴⁸

4.7 Coping Strategies

Coping strategies are psychological defence mechanisms that assist in adaptation to a variety of stressful life problems, including chronic disease. Many coping strategies exist, including mechanisms such as escape-avoidance, problem solving, seeking social support, positive reappraisal, and more. How an individual with MS copes depends on factors such as personality, past experiences, social support, their economic situation as well as their MS course.



Coping strategies are psychological defence mechanisms that assist in adaptation to a variety of stressful life problems, including chronic disease. How an individual with MS copes depends on factors such as personality, past experiences, social support, their economic situation as well as their MS course.

For many people with MS, the unpredictability of exacerbations, extent of recovery, and impact of residual symptoms on daily life can challenge coping mechanisms. McCabe and colleagues noted that people who engaged in more emotion-focused coping styles (wishful thinking) were more likely to experience poor psychological adjustment than those who employed more problem-focused strategies. They demonstrated that women in general, both with and without MS, were more likely to focus on the positive and seek social support than were men, and that levels of fatigue and medication impact were factors in psychological adjustment and coping⁴⁹.

Aside from MS-related variables such as fatigue, cognition, depression, and medication effects, there are factors related to family of origin which may affect coping strategies. Some of these include cultural, ethnic, spiritual, and socioeconomic backgrounds, as well as family support. All of these factors need to be considered when generating an effective care plan for optimising quality of life in MS.

Joining a support group, where the person with MS can share experiences and feelings with other people who are likely to have had similar experiences, may be helpful. In Finland, the benefit of meeting people who have the similar situation in their lives has been reported to be the most important issue regarding coping and adaptation to a new life situation. Furthermore, in groups it is possible to express difficult feelings that a person may not want to share with their family. Support groups often provide information and advice about coping strategies as well as practical issues such as technical aids, civil rights and so on. The creation of new adjustment groups whereby nurses can introduce cognitive behavioural principles for people with MS could be an effective way for individuals to learn new skills, new means of managing their emotions, and new behavioural techniques to improve existing mood disorders and aid adjustment to the condition that they can use throughout their lives.⁵⁰ Hope is also an important protective coping resource for coping with MS and should not be neglected.⁵¹

4.8 Spirituality

Spirituality is defined as an individual's sense of peace, purpose, and connection to others, as well as a person's beliefs about the meaning of life. Spirituality can be expressed in an organised religion or in other ways. Some people find spirituality in religion, others through music, art, or an appreciation of nature.

Spirituality may have an important impact on the well-being of the chronically ill. The impact of spirituality may be evident in its capacity to supply the coping resources that can be valuable tools in promoting hope and managing depression. The ability to cope with illness is an important factor in improving physical and mental health status. Successful coping may also aid in the promotion of family health, another measure of overall well-being⁵².

Some research suggests that having a sense of spirituality may make an individual with an illness feel better. Spiritual and religious well-being may be associated with improved quality of life by reducing anxiety and depression, reducing a sense of isolation, and bestowing others with a feeling of personal growth, despite having an illness⁵³.

Spiritual practices include meditation, [prayer](#) and contemplation. Spirituality has been shown to have some effectiveness as a symptomatic treatment, but it has yet to be determined whether these effects go beyond those of a placebo. A study looking at the effects of mindfulness meditation in patients with MS found improvements in the measures of fatigue, depression, anxiety and quality of life, while those who received usual medical care declined slightly on most

of the measures. Those who took mindfulness training saw their depressive symptoms drop by more than 30% than those study participants who took no training⁵⁴.

Prayer

There is limited research on how prayer and spirituality affect people with MS. One large, formal clinical study currently being conducted in the US is examining how intercessory prayer affects disability and quality of life. Over 200 people with MS are participating in this study, where they are randomly assigned to either a treatment group which receives prayers, or a control group which does not. The findings from this research have yet to be published.

4.9 Adaptation

People with MS need to initiate and respond to changes in their lives to ensure a positive response shift. This will involve

- Recognising the need to respond to change
- Identifying and evaluating options for change
- Setting, re-evaluating, and achieving flexible goals.

In a large systematic review of 72 studies⁵⁵, adjustment to a diagnosis of MS and disease progression was found to depend on a wide range of factors; the most strongly correlated being perceived stress and emotional-coping strategies while uncertainty over future health was robustly associated with a worse adjustment to diagnosis. Other factors were similar to those for other major disease diagnoses such as social support, interactions with others, cognitive psychopathology, illness and symptom cognitions, perception of control and self-efficacy, positive psychology and health behaviours.

Patients may have to adjust to life changes and limitations in their ability to work, travel, and pursue recreational and social activities. The ability to adapt to change allows people with MS to continue to function as valuable members of society.

Nurses can help patients do this by shared exploration of all options, and validation, or affirmation, of good choices. These options may include choices regarding treatment and physical therapy regimens, as well as employment and recreational activities.



What might you be able to do that will enable a person with MS to make positive adjustments that ensures they live well with MS – what are the options available?

I underline the importance of the things the person with MS is still able to do, and try to ensure that the person maintains these activities. It is important to try and make sure the person does not focus on the losses that might have occurred from having MS



4.10 Summary

- Most people with MS will require some kind of emotional support at different stages during the course of their condition.
- Anxiety and depression are frequently present in people with MS but are often under recognised and under treated.



Reflective learning points:

Describe some of the ways that MS might impact upon a person's emotional well-being?

In your current role as MS Nurse, how might you try and help a person diagnosed with MS cope and adapt following their diagnosis?

5 Non-Pharmacologic Management of Symptoms

5.1 Learning Objectives



MS is associated with multiple symptoms which will have a huge impact on the well-being of the person with MS, their families and their quality-of-life. This section will review the non-pharmacologic therapies recommended to manage the symptoms of MS, with the goal of improving or maintaining function and preserving the person's quality-of-life. After review of this section, you will be better able to:

- Implement non-pharmacologic interventions for the management of common symptoms
- Outline the MS Nurse's role in symptomatic assessment and management

Please refer to module 2 for an in-depth explanation of each of the symptoms and to module 4 for a detailed review of the pharmacologic management of some of these symptoms.



5.2 Introduction

The MS Nurse can enhance the individual's capacity to self-manage through a therapeutic partnership, within the patient centred team,,: educating patients and caregivers, helping to enhance the patient's support network, and setting realistic goals^{56,57}.



The MS Nurse can help an individual's self-care through therapeutic partnership, fostering treatment in a team–patient relationship, educating patients and caregivers, helping to enhance the patient's support network, and setting realistic goals.

During initial consultations with the person with MS, it is important that the MS Nurse completes a comprehensive review of physical and emotional symptoms (see module 2 for detailed definitions of some of these symptoms). Information should be sought on the effects of MS on mobility, vocational ability, the need for aids or adaptations and the availability of personal support. It is important for the MS Nurse to look beyond the perceived need of an individual to their actual need.

5.3 Fatigue

The management of MS fatigue can help improve quality of life for people with MS at any stage of life. Other symptoms, such as depression, being in pain, or sleep disturbance from bladder problems or spasms, can all worsen fatigue. Fatigue may also be the result of inactivity, poor diet, stress or an infection. Some medications can increase drowsiness and worsen fatigue. This applies to all types of treatments - prescription, over the counter, alternative and illicit - regardless of whether they are being used to treat MS or not. Of the drugs for MS symptoms, treatments for spasms, stiffness and pain can be associated with an increase in fatigue.

A thorough assessment by the nurse must include assessment of diet, fitness, sleep, activity, depression and stress, heat, thyroid function, blood counts and MS status (exacerbation or worsening of MS) (Table 2).

Assessment of Fatigue	
1.	Determine: <ul style="list-style-type: none"> ▪ The nature of fatigue ▪ If fatigue is a new symptom ▪ If symptoms of fatigue are continuous or intermittent, acute or chronic
2.	Identify possible contributing factors, such as: <ul style="list-style-type: none"> ▪ Relapse ▪ Medications ▪ Concurrent illness (eg infection) ▪ Level of activity ▪ Heat ▪ Lifestyle patterns such as <ul style="list-style-type: none"> sleep (exclude primary sleep disorders) diet exercise (types and levels of tolerance and endurance) ▪ Psychosocial issues ▪ Pain
3.	Assess the severity of fatigue
4.	Determine its effect on daily activities
5.	Determine the impact of fatigue on other MS-related symptoms
6.	Identify existing management strategies and coping behaviours

Table 2: Assessment of fatigue

The next step is to implement strategies that will help manage the effects of fatigue (table 3). Fatigue management and energy conservation have been proposed as effective acute and long-term strategies to minimise fatigue in MS^{58,59}. Both approaches rely on a person reflecting on their own fatigue and the way that it affects their daily life. It does not take the fatigue away but aims to make living with fatigue easier:

Take frequent rests – The person with MS should try to balance activities with rests and learn to allow time to rest when planning a day's activities. Rest means doing nothing at all; frequent short rests are preferable to one long one. Also some people find relaxation helpful.

Prioritise activities – Suggest to the person that they try to put activities in order of priority so that those that must be done are completed before the person runs out of energy. Decide if jobs could be done by other people, consider outside help, and consider jobs that could be cut out of the daily routine or done less often, eg ironing.

Plan ahead – The person may find it helpful to make a daily or weekly timetable of activities that need to be done. Spread heavy and light tasks throughout the day. Set realistic targets and breakdown large complicated tasks into smaller stages that can be spread throughout the day.

Organise tools, materials and work area – This involves organising the work area for example the kitchen so that tools and objects that are in continual use like tea, coffee and crockery are placed at a height between hip and shoulder and heavy objects and less used items are placed from the hip to the floor.

Adopt a good posture – Activities should be carried out in a relaxed and efficient way minimising stress on the body, which will in turn save energy. Maintaining an upright and symmetrical posture during all tasks and resting on a perching stool while carrying out tasks if necessary. Avoid excessive twisting and bending.

Lead a healthy lifestyle – Exercise is essential but exercise should be balanced with rests. Physiotherapists can advise on specific exercises that may be relevant. Eat a well-balanced diet; further advice is available from dieticians. Avoid heavy meals or only plan a light activity afterwards⁶⁰.

When appropriate referral to a sleep specialist

Table 3: Management strategies for fatigue

Several additional nonpharmacological/complimentary approaches have been proposed (table 4), including physiotherapy⁶¹, aerobic exercise⁶², yoga⁶³ or cooling⁶⁴. The observed positive effects have been small, although these approaches did benefit from having no adverse side effects. More recently, a controlled trial has demonstrated that progressive resistance training can improve muscle strength and functional capacity in MS, and this is associated with improvement in fatigue, mood and quality of life⁶⁵.

Non-Pharmacological Interventions for Fatigue	
1.	Promote patient understanding of MS-related fatigue: <ul style="list-style-type: none"> • Provide written information sources as appropriate
2.	Implement energy conservation strategies through: <ul style="list-style-type: none"> • Referral to an occupational therapist • Adaptations to home and work environments
3.	Encourage appropriate lifestyle modifications with regards to: <ul style="list-style-type: none"> • Nutrition and fluid balance • Sleep patterns • Activity and rest patterns • Temperature control <ul style="list-style-type: none"> cooling techniques environmental temperature control (eg air conditioning) avoiding temperature extremes • Refer patient to a physiotherapist for: <ul style="list-style-type: none"> assistive devices
4.	Inform patient of the following therapies that may contribute to fatigue as well as their side effect profiles: <ul style="list-style-type: none"> • Antispasticity medications • Anticonvulsants • Antidepressants • Certain alternative medicines (eg chamomile, ginseng and sage)
5.	Advise patient to discuss ongoing evaluation of fatigue-management strategies with their doctor

Table 4: Non pharmacologic approaches for managing fatigue

In addition to teaching these techniques, a fatigue management programme often involves careful listening, liaison with statutory services and advice regarding access to disability resources. An occupational therapist can offer education regarding both fatigue management

principles as well as practical problem solving which aims to address fatigue related distress at the level of activity and participation. Fatigue management education delivered in a face to face format in community settings has been found to significantly reduce impact of fatigue on daily life, improve QOL and increase self-efficacy in randomised trials⁵⁹. Other ways of delivering the course such as by teleconference were also successful⁶⁶.



A fatigue management programme often involves counselling, liaison with statutory services and advice regarding access to disability resources.

A recent meta-analysis found that rehabilitation interventions (exercise and educational) appeared to have stronger and more significant effects on reducing the impact or severity of patient-reported fatigue compared to medication.⁶⁷ It is therefore important that healthcare providers should consider a full spectrum of effective fatigue management interventions, from exercise to educational strategies in conjunction with medication, to successfully manage the challenge.



In what way might you work together with someone who has MS to assess the impact of their fatigue?

To begin with, I usually use a fatigue scale to confirm the presence and severity of the fatigue. I try to determine if it is physical (occurring after physical activity) or if it is more prominent after psychological efforts (for example, following tasks that demand concentration).

How would you then enable them to effectively self-manage fatigue– what approaches would you suggest?

I ask the person to keep a fatigue diary for several weeks, listing all activities undertaken with a fatigue rating (eg. rating scale from 0-10, using a visual analogue scale that is simple and practical). I recommend patients make a clear plan for the day, to avoid trying to do too many things at one time. Eating small meals several times a day rather than one big meal later in the day can help lessen the effects of fatigue. It is also important to remember to drink regularly to avoid dehydration.

5.4 Cognition

As the healthcare professional with the most regular contact with people with MS, the MS Nurse plays a pivotal role in recognising potential signs of cognitive problems, identifying the need for referral for formal evaluation, and regular recall and review of interventions.



The MS Nurse plays a pivotal role in recognising the signs of cognitive problems, identifying the need to refer individuals for formal evaluation, and monitoring progress of these deficits and effectiveness of interventions.

Although cognitive dysfunction is a sensitive area to broach with people with MS and their families, it is now generally accepted that openly recognising the problem is considerably more helpful than pretending it does not exist. Recognition allows constructive discussion and the learning of compensatory strategies⁶⁸.

Cognitive impairment is caused by MS lesions; however, secondary factors, such as depression, fatigue, medication effects, or comorbid conditions including thyroid, cerebrovascular, cardiopulmonary disease or sleep disorders may also contribute⁶⁰. People with MS may complain of having trouble concentrating, remembering daily job or home routines, and making decisions⁶⁰. However, an individual may not recognise subtle cognitive symptoms and should be asked whether they are having difficulty remembering appointments or conversations, understanding written material, or being easily distracted and having difficulty focusing on tasks⁶⁹.

Several different questionnaires and testing batteries have been proposed for screening and evaluation of cognitive deficits in people with MS^{70,71}, but there is no general consensus on which questionnaires and tests are most beneficial. BICAMS (Brief International Cognitive Assessment for MS) is an international initiative to recommend and support a cognitive assessment that is brief, practical and universal. It includes tests of mental processing speed and memory. Preliminary validation studies are currently underway in a number of countries.

Cognitive impairment may be improved by addressing secondary causes and comorbid conditions, and by limiting distractions and organising tasks at home or work⁶⁰. Recent evidence suggests that a "mentally active lifestyle" could potentially prevent or slow further cognitive decline⁷². It may be beneficial for patients and family members to be aware of, and understand, cognitive issues, to develop coping strategies, and begin to take advantage of individual strengths that compensate for impairments, and adjust expectations⁷³.



What might you look for, and what questions might you ask, when assessing for signs/ indicators of difficulties with cognition?

There are a number of things I look out for in my patients including:

- Are they following my instructions regarding their medication?
- Are they missing any of our scheduled appointments?
- Are they having any difficulty taking part in our discussions?

Has the carer/patient reported any changes in behaviour (memory, concentration, ability to follow instructions)?

When discussing cognitive problems with my patients, I explain some of the things that MS patients report (for example, memory problems and problems with concentration). I then ask the person if they have experienced any of these things. In normal circumstances, the discussion will lead on from here and I am able to ask, for example, about any possible problems at work / household issues etc.

I also explain that fatigue can sometimes cause cognitive problems, but that these problems disappear after rest; heat can also have a similar effect - for example, in Finland people love

saunas and afterwards there can be fatigue and some cognitive problems which will resolve with time.

MS Nurses may help people with MS and their families adjust to cognitive deficits. Figure 4 lists strategies that have proved helpful in the management of cognitive problems. Nurses could suggest these strategies to patients and their families and work with them to overcome some of the problems presented by cognitive impairment.



MS Nurses may help people with MS and their families adjust to cognitive deficits
Nurses could suggest strategies to patients and their families and work with them to overcome some of the problems presented by cognitive impairment.

Strategies to Help Cope with Cognitive Deficits

1. Make lists (eg, shopping, “to do”)
2. Use calendars for appointments and reminders for events; develop a consistent daily routine
3. Develop a memory notebook to log daily events, reminders, messages, driving directions
4. Organise the environment so that items used regularly remain in familiar places
5. Modify the learning environment for patients’ comfort (eg, heat, light, etc)
6. Schedule the teaching session for early in the day, and limit it to a short period of time to minimise fatigue
7. Conduct conversations in quiet places to minimise distractions
8. Repeat information, and write down important points
9. Use simple, step-by-step instructions—include the obvious
10. Follow verbal instructions with written backup, and use visuals (ie, diagrams, pictures) when possible
11. Involve care partners in instructions (ie, follow-up phone call to care partner, family at home)
12. Teach basic organisation skills
13. Openly discuss concern about cognitive dysfunction
14. Have the care partner monitor the patient for safety
15. Keep the patient mentally stimulated (eg, puzzles, word finds, computer games)
16. Introduce change slowly, one step at a time

Figure 4: Strategies to help cope with cognitive deficits

Management of cognitive impairment is difficult and cognitive rehabilitation in MS is in its relative infancy⁷⁴, although nonpharmacological therapeutic procedures, particularly types of cognitive training, have been shown to be at least partially effective⁷⁵⁻⁷⁷.

5.5 Bladder Dysfunction

Poor bladder control is very disabling and many regard this as one of the worst aspects of their MS⁷⁸. Unpredictable urinary urgency, frequency and a danger of incontinence will make a person unwilling to venture out, and housebound, when access to toilets is uncertain.



Poor bladder control is very disabling and many regard this as one of the worst aspects of their MS.

The MS Nurse is likely to be in a position to initiate the process of identifying urological dysfunction. The evaluation can be started by reviewing symptoms recorded in the patient's medical records over time (table 5). Along with the use of a voiding diary and a check of the patient's post-void residual at the time of each visit, this can aid the MS nurse in recognising which urinary dysfunction could be affecting the patient⁷⁹.



The MS Nurse is likely to be in a position to initiate the process of identifying urological dysfunction.

Assessment of Bladder Dysfunction	
1.	Determine the nature of the bladder problem: <ul style="list-style-type: none"> Describe symptoms <ul style="list-style-type: none"> frequency urgency hesitancy burning and discomfort incontinence retention and nocturia Determine onset and duration of symptoms
2.	Categorise bladder dysfunction into one of the following categories according to the presenting symptoms: <ul style="list-style-type: none"> Failure to store Failure to empty Combination failure to store and failure to empty
3.	Identify possible contributing factors, such as: <ul style="list-style-type: none"> Concurrent medical conditions (eg urinary tract infection, other infections, constipation) Medications Reduced mobility Nutrition and fluid intake Lifestyle issues
4.	Assess the impact of the bladder dysfunction on the following aspects of daily living: <ul style="list-style-type: none"> Sexual activity Recreation/social activities Employment Quality of life
5.	Identify existing management strategies and coping behaviours

Table 5: Assessment of bladder dysfunction

Non pharmacological treatments involve the use of pelvic floor muscle training (Kegel exercises), stimulation, biofeedback, pessaries, bladder retraining, and sometimes intermittent catheterisation (table 6).

Non-Pharmacologic Interventions for Bladder Dysfunction	
1.	Rule out urinary tract infection through urinalysis and urine culture
2.	Instruct the patient to keep a 24-hour “urolog” (ie log of fluid intake-output)
3.	Perform a post-void residual (PVR) test <ul style="list-style-type: none"> • Ensure the patient consumes 2 litres of fluid the day prior to the test • Instruct the patient to drink two 240 ml glasses of fluid on the day of the test • Instruct the patient to void and measure urine volume prior to PVR • Measure PVR by intermittent urinary catheterisation or use a bladder scanner (ultrasound)
4.	Educate the patient on the role of medications and intermittent catheterisation in controlling symptoms
5.	Instruct the patient to perform clean, intermittent catheterisation (if the patient is willing and able and if PVR is greater than 100 ml)
6.	Assist the patient to develop a drinking and voiding schedule
7.	Educate the patient about factors that may influence symptoms, such as: <ul style="list-style-type: none"> • Caffeine • Aspartame • Alcohol • Infection • Constipation
8.	Refer patient to a urologist if symptoms remain unmanageable or if complications develop or are suspected

Table 6: Non pharmacologic approaches for managing bladder dysfunction

Intermittent catheterisation

Intermittent catheterisation is a technique for managing urinary problems related to insufficient emptying of the bladder. The aims of intermittent catheterisation are to prevent infections, avoid residual urine in the bladder, improve bladder elasticity, promote continence and protect kidneys⁷⁹. Catheterisation allows for complete emptying of the bladder at scheduled intervals, therefore frequency and nocturia can be significantly reduced. The nurse has the challenge of helping the patient accept intermittent catheterisation as a part of the rehabilitation process, as, if performed according to a prescribed schedule, it can promote improved bladder functioning.

Adequate information and through instruction by nurses help empower people to take control and master the treatment, which can potentially contribute to ongoing compliance and long-term urinary tract health. A major requirement for success with this technique is patient motivation. As a general rule, if patients are able to write and feed themselves they are likely to be able to perform the technique⁷⁹.

The UK consensus statement on the management of the bladder in MS⁸⁰ stated that successful management could be achieved based on a simple algorithm which includes testing for a urinary tract infection and measurement of the post micturition residual urine volume. Obtaining a detailed urinary history, often combined with the keeping of a micturition diary, can also be valuable in determining the source of MS-related bladder dysfunction. This is in contrast with guidelines from other countries that recommend cystometry.

The MS Nurse can also have an important role in teaching the person with MS behaviour strategies that aid in both evaluating and treating urinary dysfunction. The MS Nurse is often the primary instructor of techniques related to intermittent catheterisation procedures.

5.6 Bowel Dysfunction

Bowel dysfunction is common in people with MS. An online survey of 155 people with MS suggested that few strategies employed by patients resulted in successful bowel management and that there was a need for high-quality research on all aspects of managing bowel dysfunction in MS in order to improve patients' QoL⁸¹.

Although general recommendations for management of bowel dysfunction in MS include maintaining a high-fibre diet, high fluid intake, regular bowel routine and the use of enemas or laxatives, the evidence to support the efficacy of these recommendations is limited⁸² and reflected by poor patient satisfaction⁸¹. Biofeedback retraining has been shown to be effective treatment in some patients, particularly those with limited disability and a non-progressive disease course⁸² (table 7 and 8).

General interventions the nurse should try and implement	
1.	Educate the patient about the causes of bowel dysfunction
2.	Adjust medication regimens that may be contributing to the bowel dysfunction
3.	Instruct the patient to take advantage of the urge to defaecate (this ensures regular emptying of the bowels) <ul style="list-style-type: none"> Educate the patient about the gastrocolic reflex that occurs 20-30 minutes after a meal
4.	Establish a regular bowel routine individualised for the patient <ul style="list-style-type: none"> Assist the patient in determining a regular time for bowel defaecation
5.	Encourage dietary changes such as: <ul style="list-style-type: none"> High-fibre intake Adequate fluid intake: 1.5-2 litres/day Regular mealtimes
6.	Encourage regular physical activity
Interventions specific to constipation	
1.	Encourage regular and consistent mealtimes and increased fibre intake
2.	Instruct the patient on correct positioning for adequate defaecation <ul style="list-style-type: none"> Patient should bend forward and elevate knees so that they are higher than hips (a footstool may be required)
3.	Advise on the following sequential therapies: <ul style="list-style-type: none"> Bulk-forming agents Stool softeners Therapies that may be used alone or in combination with bulk-forming agents or stool softeners

Table 7: Interventions for constipation

Interventions specific to faecal incontinence / involuntary bowel movement	
1.	Ensure adequate evacuation of bowels on a regular basis
2.	Rule out bowel infection using stool cultures
3.	Avoid unnecessary use of antibiotics
4.	Educate patient to: <ul style="list-style-type: none"> • Avoid bowel irritants such as: <ul style="list-style-type: none"> Alcohol Caffeine spicy foods other identified dietary triggers • Use medication(s) for control of faecal incontinence/ involuntary bowel movement
5.	Recognise that anxiety and stress may play a role in this problem
6.	Provide ongoing evaluation of bowel dysfunction

Table 8: Interventions for faecal incontinence

It may take several weeks for nonpharmacologic interventions to be effective. The person with MS should understand that the goal of the bowel programme is to have predictable regular eliminations with a soft, formed stool, which decreases the problems of constipation or faecal incontinence. Another goal of an adequate bowel training programme is the long-term avoidance of the need for strong laxatives and enemas.

5.7 Speech and Swallowing

Dysarthria and dysphagia may or may not occur at the same time. The speech and language pathologist specialises in evaluating and treating speech, communication, cognitive, and swallowing problems. Dysphagia evaluation may include videofluoroscopic or barium swallow studies to track the movement of food during swallowing. Treatment is rehabilitative and educational. Changing the head or body position during eating may relieve the symptom. Eating smaller quantities at any one time may reduce fatigue and choking.

5.8 Spasticity / Mobility

The assessment and management of spasticity requires expertise, and the involvement of a multidisciplinary team. Treatment is primarily physical, and supplemented by pharmacological treatments, which can be systemic or focal. Management strategies should be goal directed, and targeted to the needs of the individual.



The assessment and management of spasticity requires expertise, and the involvement of a multidisciplinary team. Treatment is primarily physical, and supplemented by pharmacological treatments.

Two core principles of spasticity management are:

1. Optimising an individual's posture and movement through use of appropriate seating, stretching and exercise programmes⁸³.
2. Preventing or managing factors that may increase spasticity and spasms (see below). These procedures are paramount in the management of spasticity irrespective of other treatment options used⁸³.
 - **Optimising bladder and bowel management:** Any change, such as urinary retention or infection, constipation or diarrhoea, can trigger an increase in spasms. Resolving these issues is important before considering changing other aspects of spasticity management such as drug regimes.
 - **Maintaining skin integrity:** Preventing skin irritation, breakdown, infection and pressure sores minimises the risk of triggering spasticity.
 - **Maximising hygiene:** Good hygiene not only promotes healthy skin but also identifies other spasticity trigger factors such as ingrown toenails, deep vein thrombosis (DVT) or tight fitting clothes or orthoses⁸⁴.

Painful spasms can be managed with stretching, transcutaneous electrical nerve stimulation (TENS) and application of cold compresses⁸⁵; however, evidence to support cold applications for treatment of spasticity is unclear. **Skilled rehabilitation strategies are recommended for both focal and generalised spasticity.**

Skilled rehabilitation strategies are recommended for both focal and generalised spasticity.

Tightness and muscle shortening can be addressed with prolonged stretching, range-of-motion exercise, and posture and positioning changes. Range-of-motion exercise may also improve joint mobility and reduce the risk of joint contracture.

Management of weakness includes strengthening exercises and, where necessary, use of braces, splints, orthotics, and mobility aids. Exercises should be done in a cool environment and with attention to avoiding muscle fatigue. Biofeedback may help relieve hypertonicity and concurrent contraction of agonist and antagonist muscles. Relaxation may help with hypertonicity, and balance/coordination activities and timing exercises may help with co-contractions.

These principles need to be regularly considered and reviewed over time and used in conjunction with medical treatments. Pivotal to their success is ongoing multidisciplinary teamwork across hospital and community settings working collaboratively with the person with spasticity to effectively manage their symptoms^{83,86}.

A spasticity management programme works if the person is able to successfully implement it. Individual habits and preferences, such as the person's ability or desire to stretch regularly, can make or break a programme. At the same time, factors related to MS such as cognitive changes (difficulties with attention, concentration, comprehension, and recall), limited mobility, fatigue, or depression can make it very difficult for even a highly motivated person to commit to a treatment programme⁸⁷.

MS Nurses have a significant role in educating a person on managing trigger factors and the available treatments to manage spasticity. They can provide on-going support and advice to a person and their family as they live with, and adjust to, managing spasticity and spasms over time. In the context of spasticity, MS nurses may have any of the following roles, which will be dependent on their working environment:

- Recognition when spasticity becomes problematic, and initiating referral to community-based therapists/neurorehabilitation team
- Education about spasticity triggers such as tight clothing
- Provision and reinforcement of advice in spasticity management to patients
- In some teams, the nurse may be able to prescribe systemic treatments
- Assisting in the prevention and management of the complications of spasticity as part of the multidisciplinary team



MS Nurses have a significant role in educating a person on managing trigger factors and about the available treatments to manage spasticity. They can provide ongoing support and advice to a person and their family as they live with, and adjust to, managing spasticity and spasms.

A person with MS who experiences reduced mobility must be assessed, y by a rehabilitation service. It is important to identify and treat any underlying impairment: especially weakness, fatigue, spasticity, ataxia, sensory loss and loss of confidence. Rehabilitation usually involves task-related, or goal focused, practice of activity or activities (for example, walking, transferring, using a wheelchair, climbing stairs). It may be possible to provide suitable equipment, including wheelchairs, driving equipment and adaptive technology (with training in its use). In addition, alterations to the environment may be possible, which will help maintain the individual's independence. It is also valuable to teach family carers how to safely assist with (or take over) tasks in support of everyday living⁸⁶.

5.9 Balance

Improving balance and gait involves many issues including ataxia, strength, vision, spasticity, tremors, and fatigue⁸⁸. A multidisciplinary approach is essential. Appropriate adaptive equipment can help maintain function as disability increases. However, people with MS may be reluctant to use assistive equipment and often need training and encouragement from the MS team, especially if safety is an issue. Using assistive devices can reduce fatigue and frustration, and patients will have the energy to accomplish more once they reach their destination.



Improving balance and gait involves many issues such as ataxia, strength, vision, spasticity, tremors, and fatigue. A multidisciplinary approach is important.

Improving fatigue and tremors and increasing endurance may help improve balance. Vestibular rehabilitation attempts to help patients adapt to balance problems and equipment has been designed to improve stability. Assistive devices, hand rails, and safety training can be considered to reduce the risk of falling.

Specific balance and gait interventions depend on the specific impairments that contribute to the problem. For example, maintaining postural control is an important outcome. Programmes such as Tai Chi, yoga, and aquatics may be helpful in maintaining gait and balance function.

5.10 Pain / Sensation

Pain is a complex, multidimensional phenomenon. It is an unpleasant experience, particularly when combined with the other symptoms of MS. It impacts upon many aspects of an individual's psychosocial and spiritual well-being and can be difficult for the individual to cope with.



Pain is an unpleasant experience, particularly when combined with the other symptoms of MS. It impacts upon many aspects of an individual's psychosocial and spiritual well-being and can be difficult for the individual to cope with.

Undiagnosed or sub therapeutically managed clinical depression, loss of sleep, mobility problems, financial insecurity, feelings of low self-esteem, all result in people finding it hard to manage their pain. This must be considered when developing pain management strategies for people with MS. Pain intensity has been shown to be related to levels of fatigue and depression and impacts patients' QoL, limiting both their daily activities and their working life⁸⁹. The importance of developing coping strategies is paramount and these can include relaxation, distraction, exercise regimes and the use of therapies that can be self-administered such as TENS and massage.

People with MS can experience pain due to problems other than MS, so other factors such as concurrent arthritis, rheumatism, previous injuries and surgery must be considered. Acknowledging that the pain is real is validating for some people with MS, particularly when many of them will have been told, sometimes by health professionals, that MS is not associated with pain.

When a person with MS presents with pain he/she should be assessed to identify the cause. This, along with impact on QOL and functioning, should be taken into consideration when devising a treatment plan (table 9 and 10). If pain remains unresolved it is advisable to refer them onto a specialist multidisciplinary pain team, if possible⁹⁰.

Pain Assessment	
1.	Acknowledge and validate the person's pain experience
2.	Inform the person that there is a range of strategies used to provide pain relief
3.	Identify the nature of pain and its intensity by using the following: <ul style="list-style-type: none">• Short-Form McGill Pain Questionnaire• Visual analogue scales• Faces pain scale
4.	Ensure that each site of pain is considered separately and try to establish the underlying cause.
5.	Obtain a pain history, discuss and review previous analgesic medication/interventions, and compliance.
6.	Identify possible contributing factors, such as: <ul style="list-style-type: none">• Relapse• Poor access to health care• Immobility• Concurrent illness (eg osteoporosis, disc herniation, migraine)

	<ul style="list-style-type: none"> • Goals/activity (eg gardening, sport, physical employment) • Psychosocial issues • Other MS-related symptoms
7.	Explore, assess and analyse emotional and/or spiritual contributory factors that could be related to pain.
8.	Determine the impact of pain on the following <ul style="list-style-type: none"> • Daily activities • Sexuality • Employment • Other MS-related symptoms • Psychological wellbeing (eg depression, anxiety, fear) • Psychosocial wellbeing

Table 9: Pain assessment

A thorough clinical and neurological examination is required and the use of a pain diary is recommended to document triggers, intensity, concomitant features, duration and pain-relief methods employed. Several studies have shown that visual analogue scales are the most appropriate method for recording pain severity (figure 5).⁹¹⁻⁹³

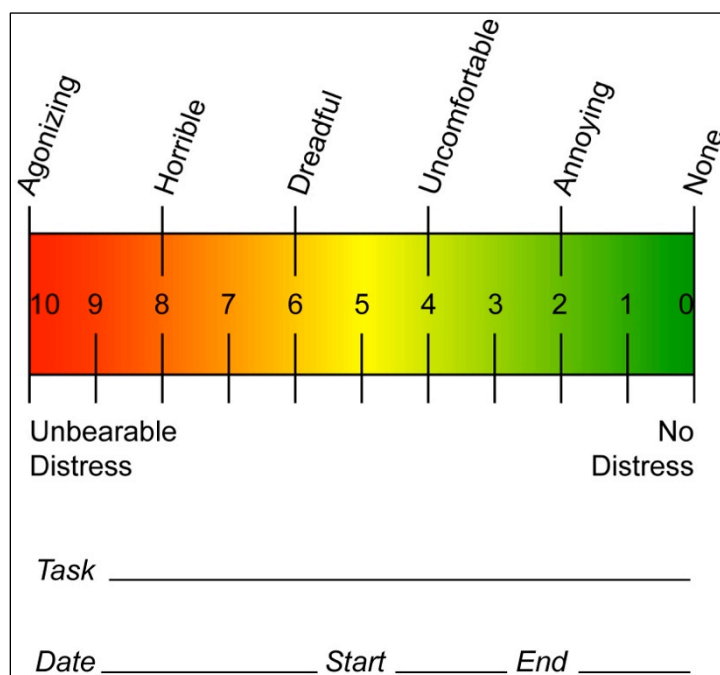


Figure 5: Example of a visual analogue scale to measure pain

To effectively manage MS pain a detailed evaluation is essential (table 9 and 10). Information required includes exploring previous pain experiences, the person's pain symptoms, onset, duration, frequency, location, the severity, its characteristics, relieving strategies and the impact on daily living activities. Anxiety, fear and depression do not necessarily increase the pain experience; however it does affect an individual's reaction to pain.

Pain Management	
1.	Explain and educate the person on the possibility of co-existing conditions contributing to chronic musculoskeletal pain: <ul style="list-style-type: none"> • Osteoporosis • Degenerative disc disease
2.	Refer patient to a physiotherapist and occupational therapist for assessment and rehabilitation interventions such as: <ul style="list-style-type: none"> • Assistive equipment • Seating, posture and gait training • Exercise
3.	Encourage the person to keep a pain diary to help identify pain variation periods throughout the day and night
4.	Explore pain management strategies <ul style="list-style-type: none"> • Resting for periods throughout the day • Restricting mobility • Regular medications • Support aids • Relaxation techniques • Hot packs/cold packs
5.	Acknowledge and discuss complementary therapies <ul style="list-style-type: none"> • Acupuncture • Reflexology • Yoga • Tai-chi • Massage • Relaxation • Visualisation • Aromatherapy • Reiki • Meditation

Table 10: Pain management

5.11 Pressure Sores

5.11.1 Introduction

Pressure sores, also referred to as pressure ulcers, bed sores, or decubitus ulcers, are areas of localised damage to the skin, which usually occur over bony prominences in any area of the body⁹⁴. Pressure sores may range from minor breaks to very large deep areas of dead tissues extending over many square centimetres; the skin can erode all the way down to the muscle, or even the bone. Once present they can be difficult to heal, and can cause general malaise and worsening of most impairments, and they carry a risk of generalised or localised infections.

5.11.2 Pathophysiology of Pressure Sores

When pressure of short duration is relieved, tissues demonstrate reactive hyperaemia, reflecting increased blood flow to the area. However, sustained high pressure leads to decreased capillary blood flow, occlusion of blood vessels and lymphatic vessels, and tissue ischaemia (see figure 6). These changes are ultimately responsible for necrosis of muscle, subcutaneous tissue, dermis and epidermis, and consequent formation of pressure ulcers⁹⁵.

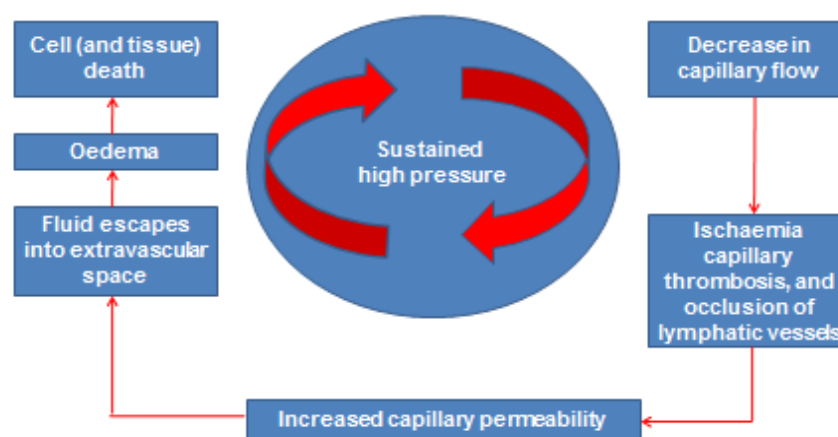


Figure 6: Pathophysiology of pressure ulceration

The European Pressure Ulcer Advisory Panel (EPUAP) classification system⁹⁶ for pressure ulcers highlights that damage can occur even before skin is broken

Grade	Evidence
1	Non-blanchable erythema of intact skin. Discolouration of the skin, warmth, oedema, induration or hardness may also be used as indicators, particularly on individuals with darker skin.
2	Partial thickness skin loss involving epidermis, dermis, or both. The ulcer is superficial and presents clinically as an abrasion or blister.
3	Full thickness skin loss involving damage to or necrosis of subcutaneous tissue that may extend down to, but not through, underlying fascia.
4	Extensive destruction, tissue necrosis, or damage to muscle, bone, or supporting structures with or without full thickness skin loss.

Table 11: European Pressure Ulcer Advisory Panel (EPUAP) guide to pressure ulcer classification

5.11.3 What Causes Pressure Sores?

Pressure sores are caused by a combination of factors both outside and inside the body. The three external factors which can cause pressure ulcers either on their own or in any combination are **pressure, shear and friction**.

Pressure, shear and friction

Pressure is the most important factor in pressure ulcer development. Shearing occurs when the body weight is sliding against a surface, for example when poorly seated or sliding down a bed away from a back rest. Friction is caused when two surfaces rub together, often skin against a bed or a chair surface. Any moisture present on the skin as a result of excessive sweating or incontinence will exacerbate the problem - the effects of friction are up to five times worse if moisture is present.

While immobility is a primary cause, other factors also increase the risk of pressure sores. These include paralysis or spasticity, which can decrease mobility; numbness and loss of sensation, which can result in the inability to feel the friction or irritation; advanced age, which is often accompanied by decreased mobility; poor nutrition, which hinders healing of the skin; and incontinence, because moist, wet or soiled skin can exacerbate the irritation.

Additional factors that are known to place people at even higher risk of acquiring pressure ulcers include:

- neurologically compromised
- obese or underweight
- poor posture
- using equipment, such as seating or beds, which does not provide appropriate pressure relief⁹⁷

5.11.4 Role of the MS Nurse in Managing Pressure Sores

Most pressure ulcers can be avoided by good anticipatory management. A systematic evaluation of risk factors will help to identify patients at risk of pressure ulceration. Those at risk must be assessed regularly, and risk assessment scales must be used as an adjunct to, not a substitute for, clinical judgment⁹⁸. Several risk assessment scales are currently used, including the Norton Scale, Waterlow scoring system and the Braden score, but vary in the risk factors assessed.

Patients and carers should be advised of warning signs that can increase the risk of developing a pressure ulcer. Questions the nurse should consider include:

- Are you eating or drinking less than usual?
- Is moving becoming more difficult?
- Is your skin regularly exposed to moisture?
- Is your skin prone to being very dry, sore or red?
- Have you been ill recently?
- Have you lost or gained a lot of weight recently?
- Has there been any change in your level of spasms?

Spasms can cause friction and shearing forces on the skin and a vicious cycle can be entered whereby the spasms cause the wound to worsen and the wound exacerbates the spasms. Every person with MS who uses a wheelchair should be assessed for their risk of developing a pressure ulcer⁹⁰. The individual should be informed of the risk, and offered appropriate advice. Whenever they are admitted to hospital (for whatever reason), their need for pressure-relieving devices and procedures should be assessed. The assessment should be clinical, specifically taking into account the risk features associated with MS, and not simply the recording of a pressure ulcer risk score; it should lead to the development and documentation of an action plan to minimise risk (table 12).

Reduce pressure	When possible alter position, even slightly, every 20 minutes during the day. If seated this could take the form of rolling slightly from cheek to cheek in the chair.
Appropriate equipment – cushions & mattresses	This includes: bed, armchair, wheelchair, car seat, office chairs, all equipment when on holiday, hospital or away from home for any reason. Seek advice from a nurse or occupational therapist. Avoid any form of ring cushion as this can occlude blood vessels and cause pressure damage itself.
Nutrition	Eat a well-balanced diet. Advice and diet sheets can be obtained from a dietician. Even a short period of not eating well increases the risk of skin damage, particularly if the patient is unwell with flu for example.
Hygiene and skin care	Skin should routinely be kept clean and fresh. Avoid allowing skin to be wet. Check for red areas on the skin once or twice a day. Reddened areas should fade within minutes when pressure is relieved.
Transferring	Obtain good instruction and support in transfer techniques and correct use of equipment. Avoid sliding and pushing when this may result in friction.
Positioning	Learn correct positioning for comfort and pressure relief, particularly when seated.

Table 12: Simple tips for the prevention of pressure ulcers



5.12 Summary

- Effective symptom management is an important component of therapy to maintain quality of life.
- Effective symptom management often requires a multidisciplinary team approach, including pharmacologic treatments as well as other more supportive approaches.
- It is important for MS Nurses to ask about and address symptoms of MS as part of the comprehensive management of the person with MS.



Reflective learning points:

What do you feel are the most important management strategies to teach people with MS suffering from symptoms of fatigue and spasticity?

Describe how important symptom management is in your day to day role as MS Nurse?

6 Health Screening in People with MS

6.1 Learning Objectives



Care of the whole person is an important area of emphasis for the MS Nurse. This section will look at primary care management for the person with MS and how the MS Nurse can assist. After review of this section, you will be better able to

- List primary care management steps for males and females that should occur in conjunction with MS treatment

6.2 Screening for Males & Females

Because MS care is highly specialised, people with MS may focus on managing the neurologic condition whilst neglecting many aspects of basic primary care, including recommended health screenings. Providers, as well as patients, may neglect basic maintenance care. During a neurologic follow-up visit, the focus is often on detecting signs of MS progression, determining whether the patient is administering disease-modifying therapy correctly, and managing any side effects. In the time remaining, there may be little opportunity to explore whether the patient has been keeping up with recommended gynaecologic or cancer screenings⁹⁹.



Because MS care is highly specialised, people with MS may focus on managing the neurologic condition while neglecting many aspects of basic primary care.

A more comprehensive array of screening steps is evolving as more is learned about MS, therapies used and its interactions with body systems¹⁰⁰⁻¹⁰². Vitamin D levels, herpes virus status, and thyroid function tests are moving to the forefront⁹⁹ (figure 7).

Recommended Screenings for MS Patients

- Mammogram/clinical breast exam
- Pap test and HPV test for cervical cancer
- PSA/clinical testicular and rectal exam
- Hemoccult stool test/colonoscopy
- Influenza vaccine (non-live vaccine recommended)
- Skin inspection for pressure ulcers, melanoma
- Bone densitometry (DEXA)
- Chest x-ray
- Electrocardiogram
- Comprehensive metabolic profile (glucose, liver enzymes, cholesterol)
- Complete blood count with differential
- Thyroid function tests
- Varicella zoster virus antibodies (when considering fingolimod)

Figure 7: Recommended screenings for people with MS

It is important that women with MS should be offered all relevant health screening, for example for cervical and breast cancer¹⁰³. Women should be asked if they are up to date with their screening programmes and are able to access the tests as women with chronic disabling conditions may face substantial barriers that limit health promoting activities critical to a healthy life.

6.3 Osteoporosis

Osteoporosis is a condition of impaired bone strength which leads to increased risk of fracture. People with MS are at a higher risk for osteoporosis than the general population¹⁰⁴. Reasons for this elevated risk include their impaired mobility, reduced levels of weight-bearing activity, low vitamin D levels, and the use of corticosteroids for MS treatment¹⁰⁵. Although osteoporosis risk is considerably higher among women regardless of comorbid diseases, the presence of MS heightens osteoporosis risk for men as well¹⁰⁶.



Osteoporosis is a condition of impaired bone strength which leads to increased risk of fracture. People with MS are at a higher risk for osteoporosis than the general population.

Because osteoporosis rates in MS are not in proportion to the person's age and ambulation level, there may be a pathological connection between MS and early bone loss¹⁰⁶. People with MS have a high risk for fractures due to falls, and osteoporosis significantly increases this risk.

Fractures

Marrie and colleagues used the NARCOMS database to examine rates of osteoporotic fractures among people with MS¹⁰⁴. Among a sample of 9,346 people with MS, 25% reported having osteopenia or osteoporosis, and approximately 16% reported a history of fracture. Of these, 35% were wrist fractures, 11% were vertebral fractures, 7% were hip fractures, and over 42% reported multiple fractures¹⁰⁵. In a nationwide sample of 20 years of hospital admissions in the USA, the prevalence of MS in the population with hip fracture was greater than twice that predicted, and MS patients suffered an acute fracture at an earlier age.¹⁰⁷

Bone density screening and supplementation with calcium and vitamin D have been shown to be substandard among people with MS and thus represent interventions that should be increased among those with MS¹⁰⁴.

Prevention is more effective than treatment of established osteoporosis. For all patients, nonpharmacological therapies should be considered for prevention of skeletal fragility, including adequate weight-bearing exercise, nutrition (protein, calcium, vitamin D), and lifestyle modifications. Disability is the most often cause of bone loss in patients with MS, and mechanical loading and exercise interventions can prevent osteocyte apoptosis and bone loss^{108,109}.



Prevention is more effective than treatment of established osteoporosis.

There are currently no specific recommendations in people with MS regarding diagnosis of osteoporosis or therapeutic interventions; however, identification and treatment of any underlying cause should be the goal of therapeutic management. Optimally, individuals at higher risk of osteoporosis should be identified early, and preventive treatment initiated to avoid the bone loss and fractures¹¹⁰.



There are currently no specific recommendations in people with MS regarding diagnosis of osteoporosis or therapeutic interventions; however, identification and treatment of any underlying cause should be the goal of therapeutic management.

6.4 Role of the MS Nurse

The nurse's role in primary care of MS can involve the following¹⁸:

- Identifying and addressing the patient's primary care needs along a continuum of health and well-being
- Recognising and assessing (but not necessarily treating) the patient's symptoms and non-MS related conditions
- Referring the patient to appropriate providers
- Assessing outcomes, including adherence to recommendations, during subsequent visits
- Educating the patient and other healthcare providers about primary care needs within the context of MS

The nurse can help to advocate for the patient with primary care providers, identify providers and diagnostic facilities that can accommodate patients with neurologic disease (such as a facility that can manage mammography in a patient with physical impairments), or find resources within the neurology practice or MS centre to address health concerns beyond those directly related to the disease⁹⁹.



6.5 Summary

- Primary care management and general health screening is important for the person with MS and should not be overlooked because of the presence of MS.
- Recommended screenings include vitamin D levels, herpes virus status, and thyroid function.
- People with MS are at an increased risk for osteoporosis; those individuals should be identified early, and preventive treatment initiated to avoid bone loss and fractures.



Reflective learning point:

How do you go about ensuring that your patients are up-to-date with all their preventative health screening programmes and checks?

7 Women's Health

7.1 Learning Objectives



There is evidence indicating that gender affects the susceptibility and course of MS with a higher disease prevalence and overall better prognosis in women than men. This section will look at some of these gender issues in more detail, including pregnancy and menopause. After review of this section, you will be better able to

- Outline the current data on management issues in pregnant and breastfeeding women with MS
- Evaluate the impact of the menstrual cycle and menopause on females with MS

7.2 Pregnancy

The incidence of MS is highest in young women between the ages of 20 to 40 years. This coincides with childbearing years, such that women diagnosed with MS are frequently confronted with issues regarding the impact of MS on their capacity to bear children, and the potential effects of pregnancy on the course of their MS.



Women diagnosed with MS are frequently confronted with issues regarding the impact of MS on their capacity to bear children, and the potential effects of pregnancy on the course of their MS.

Women with MS who wish to become pregnant should not be discouraged. A recent study has shown that women who gave birth after the onset of MS took longer to progress to an EDSS score of 6 (a disability score that means that patients need some kind of assistance with walking; EDSS of 6 specifically refers to use of a cane)¹¹¹.

MS has no physiological effect on fertility¹¹². If one parent has MS, the statistical risk of having a child with MS is between 3 and 5% (compared with 0.02% in the general Caucasian population)¹¹². Although risk is increased 30-fold, the actual risk is, however, still low.

Some of the common MS symptoms such as fatigue, urinary frequency, constipation, and mood changes are similar to pregnancy-related symptoms¹¹³. Disease related (but not specific) issues such as fatigue and bladder and bowel problems may require specific consideration in MS; for example, a pregnant woman with MS might be more prone to develop urinary tract infections consequent to pressure from the foetus on a neurogenic bladder¹¹⁴.

Pregnancy tends to have a protective effect on MS; the disease process is generally less active and relapses less common, especially during the third trimester (figure 8). This protective effect is understood to be related to hormonal changes and normal suppression of the immune system during pregnancy. However, this protection does not seem to apply to women with progressive disease. Discussing this with patients can ease concerns over (temporarily) ceasing medications, if this is the selected approach.

In the first 3 months postpartum, there is an increased rate of relapse, although no overall increase in lifetime relapse rate^{115,116}. A two year follow up study determined that birth relapse risk is similar to that in the pre-pregnancy year¹¹⁷.

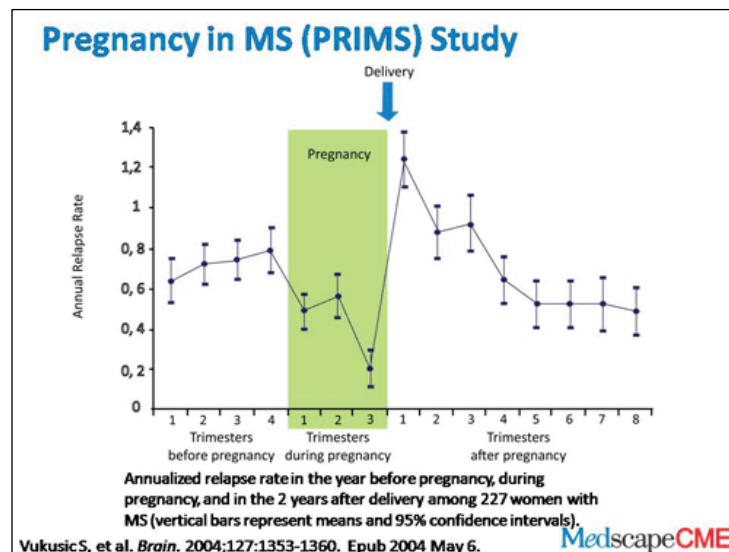


Figure 8: Pregnancy in MS (PRIMS) study

For women with MS who are taking disease modifying treatments, adequate contraception should be used whilst on treatment, as many of the drugs used in the treatment of MS are inadvisable during pregnancy and breastfeeding. Steroids may be used with relative safety in pregnancy¹¹⁸. All forms of immunomodulatory therapy should ideally be stopped 1-6 months prior to conception (see individual product information for recommendations); however, information on specific DMTs in pregnancy is available from the manufacturers. As in all pregnancies, all potentially teratogenic drugs should be avoided; for example, baclofen should be avoided particularly in the first trimester.

There is little information regarding effects of MS disease modifying treatments on human male fertility or pregnancy outcomes in fathers receiving treatment. A recent prospective, collaborative study carried out by the MS Study Group of the Italian Neurological Society assessed outcomes of pregnancies fathered by MS patients undergoing DMD. They found no association between paternal DMD exposure at time of conception and risk of spontaneous abortion, adverse fetal outcomes and congenital malformations.¹¹⁹

MS has little or no effect on the course of pregnancy or delivery. Although some studies indicate that women with MS have a slightly increased risk for having small-for-gestational-age newborns¹¹³, there is no increased risk of miscarriage, foetal malformations, stillbirths, birth defects or infant mortality when the mother has MS.

Decisions regarding management of labour should reflect obstetric issues alone¹¹⁴. There is no evidence that either breast feeding or epidural analgesia has any effect on relapse rate or disability¹¹⁷. Consideration of breastfeeding should include the physiological and psychological needs of both mother and infant. There is some evidence that breastfeeding might extend the period of relative protection from MS disease activity conferred by the hormonal changes associated with pregnancy¹¹⁵. A recent German study reported significantly reduced postpartum relapse rate during the first 3 months after birth in exclusively breastfeeding mothers compared with nonexclusively breastfeeding or nonbreastfeeding women with MS ($p < 0.0001$).¹²⁰ The

decision on when to recommence (or commence) immunomodulatory therapy will depend on whether or not a woman is breastfeeding, and her level of disease activity in the postpartum period.



A review of recent studies found that:

1. The relapse rate is reduced during the second and third trimester
2. The relapse rate increases during the first 3 months following delivery
3. Overall there is no net change in relapse rates over the entire pregnancy year (9 months gestation + 3 months postpartum)
4. Exclusive breastfeeding has been recently reported to dramatically reduce the postpartum exacerbation risk
5. Limited data on the longer-term effects of pregnancy on MS indicate a beneficial effect¹²¹

Something that should be considered is the level of disability of the mother and the availability of help with the care of the baby, should this be necessary. It is important that the woman considers making a birthing plan; a list of family and friends that can be called on should be drawn up, as well as the help available from her health visitor, local service provision for mothers and support groups locally. Levels of fatigue should also be taken into account, bearing in mind that this common symptom can be exacerbated by the pregnancy itself and by subsequent disturbed nights.



MS is unpredictable and therefore decisions about having children can be difficult to make. The best that can be done is to support and encourage exploration of all the issues, many of which will be uncomfortable, with as much knowledge as possible.

Management of MS and decision making surrounding pregnancy are complex subjects. For some time, pregnancy was believed to have a negative effect on MS, and while this has not been supported by evidence, women with MS can experience negative attitudes about pregnancy and MS from their healthcare providers. Results from a small recent study suggest that healthcare providers do not discourage pregnancy for women with MS, recommend that women not use DMTs while pregnant, and have a positive view of breastfeeding. The results of this study do highlight a need for evidence-based recommendations related to the effect of DMT on pregnancy and breastfeeding, as well as the need for better guidelines on MS management related to family planning, pregnancy, and breastfeeding.¹²²

7.3 Impact of Menstrual Cycle and Menopause on Relapse / MS Symptoms

Many women have reported cyclical changes in MS symptoms and feel that their symptoms deteriorate two to three days prior to the onset of their period and improve once bleeding has started. A few small studies have confirmed this anecdotal evidence¹²³⁻¹²⁵. In another small

study, it was found that 78% of women had premenstrual worsening of their MS symptoms in one or more of the menstrual cycles analysed¹²⁶.



Many women have reported cyclical changes in MS symptoms and feel that their symptoms deteriorate two to three days prior to the onset of their period and improve once bleeding has started.

Symptoms that may increase premenstrually are arm and leg weakness, pain and nocturia. A greater understanding of this 'menstrual cycle effect' would help to reduce anxiety associated with an unexpected increase of symptoms. Current data suggest that premenstrual symptoms alone cannot account for the change in MS symptoms and hormonally related factors may be important.

Menopause does not appear to have any positive or negative¹²⁷ effect on MS. Whether hormonal fluctuations in menstrual cycles or menopause are associated with exacerbations of MS symptoms has been difficult to address^{123,125,128,129}. Although about one half of patients reported worsening of MS symptoms at menopause, there are no definitive conclusions possible due to the low number of patients involved and the difficulty to differentiate between the subjective worsening as a consequence of hormonal changes and the natural progression of the disease which often occurs at that age (relapsing-remitting MS converting into a more progressive pathology). Moreover, serial magnetic resonance imaging (MRI)-based examinations were unable to show differences in brain lesion activity during ovarian cycle¹³⁰.

There is anecdotal evidence, as well as a few small studies, which indicate that any symptoms which worsen during menopause may be responsive to hormone replacement therapy (HRT) and that the majority of women with MS who have used this therapy report improvement rather than deterioration in their condition. Given that loss of bone density may be a problem for women with MS, the beneficial effect of HRT in reducing the risk of osteoporosis – particularly if they are prone to falling – should be taken into account.



7.4 Summary

- Pregnancy is safe in most women with MS and does not negatively influence the overall MS disease course.
- Use of disease-modifying treatments around conception should be considered on a case-by-case basis, weighing risks of drug exposure against risks of relapses.
- There is no reason why a woman with MS should be deterred from becoming pregnant if she wishes, although she should be advised that the risk of relapse decreases during pregnancy, and increases temporarily post-partum.
- When giving birth, women with MS should have the analgesia that seems most appropriate and acceptable to them, without fear of it affecting their MS.
- Menopause does not appear to have any effect on MS either positive or negative.



Reflective learning point:

How will understanding gender-specific issues help improve the way that you manage your patients?

8 Sexuality and Sexual Function

8.1 Learning Objectives



Sexual problems cause distress to the person with MS and may affect the family bond. This section will outline some of the issues surrounding this area and will evaluate the role the nurse can have in assisting patients to address problems they might have. After review of this section, you will be better able to

:

- Discuss the sexual health issues in males and females with MS
- Describe and apply strategies for the assessment of sexuality

Please refer to Module 2 for a detailed discussion of the different types of sexual dysfunction that might be seen in a patient with MS

8.2 Introduction



The impact of MS on a person's sexual functioning must not be underestimated. Symptoms such as spasticity, urinary incontinence, and fatigue interfere with sexual health and well-being. Medications such as anticholinergics, used to manage MS symptoms, together with medications used to treat other common health problems, will affect sexual functioning¹³¹. Alterations in body image will negatively impact a patient's perception of himself or herself as a sexual being.

A recent study found that moderate-to-severe pelvic floor symptoms are extremely common among MS patients, with 41% reporting bladder, 30% reporting bowel, and 42% reporting sexual dysfunction. Most respondents had been asked about bladder (61%) or bowel (50%) issues by their health-care providers, but only 20% had been queried about sexual dysfunction. Most respondents were moderately to very satisfied with the management of their bladder and bowel disorders but significantly less satisfied with that of sexual dysfunction.¹³²

In patients with MS, sexual dysfunction has a much larger detrimental impact on the mental health aspects of HrQoL than severity of physical disability.¹³³ Therefore this reinforces the need for physicians and nurses to ask patients with MS about their sexual concerns.



The impact of MS on a person's sexual functioning should not be underestimated. Symptoms interfere with this aspect of a person's life. In addition, medications used to manage MS symptoms, as well as medications used to treat other common health problems, can affect sexual functioning.

The nature of sexual problems make discussion difficult for both people with MS and healthcare professionals. Individuals may not be aware that MS can affect sexual functioning and assessment of these needs is important. MS nurses need to be aware of the complexity of sexual dysfunction, ensuring that problems are detected and fully assessed so that appropriate

treatment can be recommended when necessary, while also ensuring that treatments are not given inappropriately¹.

8.3 Assessment

Assessment and treatment of sexual problems should combine medical and psychosexual approaches and begin early. Intervention may be by recognising sexual needs, educating and providing information, by letting patients express their difficulties and referral to specialists and other information resources. People should be offered information about locally available counselling and supportive services. If all else fails psychosexual counselling may be considered¹³⁴.

Sexual expression is relevant to everyone. Often, there concerns about sexual functioning with a new partner, or about finding a partner in the face of mobility problems, continence difficulties and so on, need the opportunity to be voiced.



Sexual expression is no less of an issue for those not in a relationship. Often there is a greater degree of reticence about asking for help.

A commonly used model in facilitating discussion of sexual dysfunction is known as the **P-LI-SSIT model**. This is a hierarchical model that can be applied by any healthcare professional to the point at which they feel able to operate¹³⁵. The components of the acronym are pyramidal; many people will benefit from the first intervention but few from the fourth. All healthcare professionals can undertake the first step in the PLISSIT model providing they are prepared to listen. This alone can be of immense therapeutic benefit.

P-LI-SSIT model

P – giving people permission to discuss sex and relationship worries. Professionals should be able to pick up cues or ask specifically about sex and relationship issues. “MS can have quite an effect on the more intimate side of life. Has that caused you any concern?”

LI – providing limited information about any areas of concern. This can be done by whoever the person with MS has confided in. If they feel unable to provide information, then having listened to the problem they can make a referral to another agency such as a sexual dysfunction clinic, counselling or Relate. Acknowledgement of the problem and empowerment to look further for help is very important.

SS – providing specific suggestions, for example about how to manage continence problems to allow sexual intimacy, managing fatigue, positioning to avoid spasm or pain. Many of these suggestions are made most appropriately by a professional with knowledge of neurological problems rather than just skill in treating sexual dysfunction.

IT – intensive therapy. Specialised psychosexual therapy. The majority of problems can be dealt with earlier in this model.

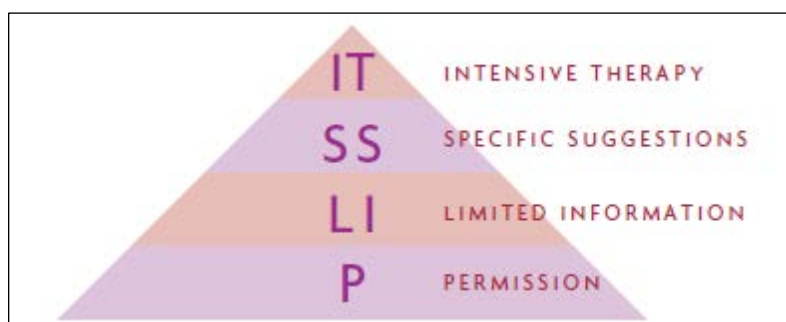


Figure 9: PLISSIT model

8.4 Role of the MS Nurse

The MS Nurse is typically not an expert in this area; some nurses may wish to gain additional expertise in this area but for most it is something that will be managed by the primary care provider or another expert from the multidisciplinary team. The nurse will almost certainly identify that there is an issue and then reassure the patient he/she will make an appropriate referral if desired.



The MS Nurse is typically not an expert in this area; the nurse will almost certainly identify that there is an issue and then reassure the patient he/she will make an appropriate referral if desired.

The MS Nurse should try and develop an organised method for evaluating sexual functioning and people's concerns. Numerous conceptual frameworks are available to assist the nurse in collecting health information pertinent to sexual assessment. Questions should be direct and open-ended, assess sexual functioning and satisfaction, and incorporate sensitivity to cultural belief systems. Most importantly, careful discernment is crucial when determining the timing and context in which to assess sexual functioning, and the patient's partner should be present whenever possible. Recommended questions for MS Nurses to ask when assessing sexual function in people with MS are provided in table 13.

<ul style="list-style-type: none">• How has your diagnosis with MS affected the way you see yourself as a wife / husband / partner? How has this affected your sexuality?
<ul style="list-style-type: none">• How important is sexual intimacy to you?
<ul style="list-style-type: none">• How often do you engage in sexual activities? Is this normal / unusual for you? Are you satisfied with this?
<ul style="list-style-type: none">• How easy is it for you to feel subjective pleasure with sexual stimulation?
<ul style="list-style-type: none">• Are you satisfied with your sexual response (erection, orgasm, lubrication, etc.)?
<ul style="list-style-type: none">• Have you been experiencing a change in your MS-related symptoms (fatigue, spasticity, bladder / bowel function)? Have you had any changes in medication?
<ul style="list-style-type: none">• What information, interventions, or resources can I provide to help you fulfil your sexual functioning?

Table 13: Recommended questions for assessing sexual function

Anticipating patient concerns and potential obstacles enable the nurse to intervene with helpful suggestions that increase patient understanding and long-term success in treatment outcomes as prescribed by the physician (table 14). In collaboration with the physician—and together with appropriate community resources—the nurse should continually engage in the patient's long-term care plan. MS Nurses may see patients at office visits, but they also help on the phone when patients forget instructions, need positive reinforcement, and/or have questions related to

sexual dysfunction. As resources are provided by the healthcare team, nurses should reinforce the importance of these resources and intervene with nursing guidance if necessary.



As resources are provided by the healthcare team, nurses should reinforce the importance of these resources and intervene with nursing guidance if necessary.

Problem or concern	Specific Suggestions
Muscle spasm from MS	Experiment with different sexual positions
Hemiplegia impeding sexual activity	Lie on affected back or side
Discomfort or pain	Use lubricant and consider other sexual activities
Catheter in situ	Spigot the catheter (men fold the catheter along the penis and use a condom; women tape the catheter to the tummy and alter position if excessive clitoral stimulation)
Altered perception of sexuality	Discuss what this means to them and identify what enhances these feelings

Adapted from Taylor and Davis 2006

Table 14: Suggested solutions for some common sexual problems¹³⁶



8.5 Summary

- Every person (or couple) with MS should be asked sensitively about, or given the opportunity to remark upon, any difficulties they may be having in establishing and/or maintaining sexual and personal relationships



Reflective learning point:

Thinking about the competencies that make up your role as MS Nurse, how do you go about assessing a person with MS for any sexual issues they might have?

9 Lifestyle Management

9.1 Learning Objectives



MS can affect a person's life in many different ways, and may impact upon their work, social and family environment. This section will discuss some of ways that the MS Nurse can help the person with MS manage their lifestyle following a diagnosis of MS. After review of this section, you will be better able to:

- Assess the economic, social and emotional impact of living with MS
- Outline factors that promote and hinder employment of people with MS
- Describe the impact that a diagnosis of MS can have on the family unit
- Discuss strategies to improve lifestyle of people with MS

9.2 Living a Healthier Life

Health promotion activities encompass a number of self-initiated health behaviours and emphasise the need to enhance each person's responsibility and commitment to a healthy lifestyle. A variety of health promoting behaviours such as physical activity, stress management, healthy eating, and building supportive interpersonal relationships can contribute significantly to the person's perceived health, functional status, and quality of life¹⁰³ and are reflected in the list of leading health indicators proposed in Healthy People 2010¹³⁷. A growing body of literature also provides supportive evidence of the positive impact of health promotion/wellness interventions for persons with chronic and disabling conditions¹³⁸.



Health promotion activities encompass a number of self-initiated health behaviours and emphasise the need to enhance each person's responsibility and commitment to a healthy lifestyle. There is supportive evidence of the positive impact of health promotion interventions for persons with chronic and disabling conditions.

9.2.1 Nutrition

Good nutritional planning is important in maintaining health in people with MS. However, no dietary supplement or elimination of certain foods has been proven to have an effect on the disease course, despite some claims to the contrary. Poor nutrition can make a patient prone to infection or complications, and fibre and fluid intake can have an impact on constipation, which is a common complaint in MS. Weight control is important in managing both MS and the person's overall health¹³⁷. Fatty fish intake might decrease the risk for MS. A hypothetical explanation is that intake of fatty fish may compensate for vitamin D deficiency that is associated with increased MS risk.¹³⁹

Results from 2 recent case-control studies suggest that drinking alcohol appears to have a protective effect on the risk of developing MS.¹⁴⁰ A dose-dependent inverse association was found between alcohol consumption and risk of developing MS that was statistically significant in both sexes. These findings give no support to advising patients with MS to completely refrain from alcohol consumption. The protective effect of alcohol was greater in smokers.

9.2.2 Exercise

Exercise is also an important component in MS wellness and is thought to help people control pain, stiffness, balance, weakness, depression, anxiety, insomnia and fatigue when done appropriately. Some activities such as yoga, T'ai chi, walking, and swimming are thought to be especially beneficial¹⁴¹. A systematic review found exercise training was not associated with an increased risk of relapse, and risk of adverse events was not higher than in healthy populations. This evidence should alleviate uncertainty regarding the safety of exercise training in MS.¹⁴²

9.2.3 Smoking

Although it is well known that smoking is detrimental to everyone's health, it has also been associated with an increased risk of MS¹⁴³. In a study of 22,312 people between the ages of 40 and 47, the risk for developing MS was nearly twice as high in people who currently smoked or had ever smoked as in non-smokers. When men and women were evaluated separately, the risk for developing MS was nearly three times greater for men and one and a half times greater for women who smoked than in non-smokers. A recent meta-analysis concluded that smoking is a significant risk factor for subsequent development of MS¹⁴⁴. Smoking has been found to increase the risk of MS in a dose response manner and affects MS risk regardless of age at exposure.¹⁴⁵ Further studies suggest that smoking may be a risk factor for transforming a relapsing-remitting clinical course into a secondary progressive course¹⁴⁶⁻¹⁴⁸.

In addition, children exposed to parental smoking at home have been found to have a higher risk of childhood-onset MS¹⁴⁹. Further studies are needed to investigate the effects of smoking and MS. In addition, reverse causality should be considered, as MS onset or MS symptoms might influence smoking habits¹⁵⁰.

9.2.4 Vitamin D

Vitamin D has several important roles in the body including regulating immune responses. Its possible role in MS remains the focus of much debate and research. There is some evidence that links risk of disease development and disease course to the serum level of 25-hydroxyvitamin D which is the biologically inactive storage form of vitamin D. Increased sun exposure during childhood has been consistently shown to decrease the risk of MS¹⁵¹. Several epidemiological studies have also provided a direct correlation between vitamin D intake and vitamin D serum levels with both the risk for new disease development and the course of already established MS^{152,153}.

Vitamin D supplementation in healthy individuals is emerging as an approach to MS prevention; however evidence supporting a therapeutic effect of vitamin D in modifying the course of MS is less compelling¹⁵⁴. Studies are currently underway, or in the planning stages, to look at the prevalence of vitamin D deficiency in people with MS, to establish the safety of high doses (up to 40,000 IU/day) of vitamin D in MS, and to assess the effects of supplementation on the immune system and on the skeleton. Results from a recent 5-year prospective study demonstrated that people with low levels of vitamin D and early signs of MS get worse faster than people with higher vitamin D levels.¹⁵⁵ MS patients with high blood levels of vitamin D had a 57% lower rate of new brain lesions, a 57% lower relapse rate, and a 25% lower yearly increase in lesion volume compared to those with the lowest levels of vitamin D. However, it is not clear if insufficient vitamin D itself causes a more aggressive disease course or if low levels of vitamin D are only a biomarker, not the cause.

9.3 Financial / Vocational

Financial planning is important at any stage of life and under any circumstances; however, with a chronic illness it becomes the highest priority if optimal quality of life is to be the aim¹⁵⁶. MS often strikes working people at the height of their careers; therefore people with MS may be devastated by the prospect and eventual reality of unemployment, with subsequent loss of income. Family or friend caregivers may also face employment reduction as demands of caregiving increase. In both patients and caregivers, productivity is lost due to absenteeism or sick days¹⁵⁷.

Reference WHO and World bank Report 2011 re discrimination in workplace??



MS often strikes working people at the height of their careers; therefore people with MS may be devastated by the prospect and eventual reality of unemployment, with subsequent loss of income.

People with MS may face a restricted range of job opportunities, transportation and architectural barriers, financial disincentives, and limited vocational rehabilitation services. Employer perceptions and self-evaluation of work capacity influence the vocational decisions of people with MS, often negatively, because of inadequate or wrong information.

The **loss of employment** brings detrimental consequences to patients and families with respect to short-term and long-term economic, psychosocial and healthcare utilisation¹⁵⁸. Of those diagnosed with MS for less than 5 years, 67% change job status and 45% switch to a different field¹⁵⁹. As disability increases, finding a new job becomes more difficult. Approximately 21% of people with MS for less than 5 years are unemployed, versus 92% of those with MS for at least 30 years^{159,160}.

Loss of employment

The UK Work Foundation recently published a report looking at employment of people with MS¹⁶¹:

- On average, 37% of people with mild MS are employed, however, many have to change or quit their jobs due to fluctuating functional capability;
- More than 75% of people with MS report that the condition has impacted their employment and career opportunities;
- Up to 80% of people with MS stop working within 15 years of the onset of the condition;
- At the same time 30% of individuals with a significant level of disability remain in employment;
- Up to 44% of people with MS retire early due to their condition – compared to the European average of 35%;
- People with MS lose an average of 18 working years, assuming a retirement age of 60.

Patients are less likely to be employed when they exhibit global markers of disease severity including physician disability ratings¹⁶². In addition, unemployment has been associated with decreased ambulation and mobility in relation to changes in work status^{163,164}, longer disease duration, and a progressive disease course. Specific symptoms such as fatigue, perceived levels of cognitive dysfunction, and poorer performance on neuropsychological tests have also been associated with employment problems in MS. A recent study found that work capacity and HRQoL among individuals diagnosed with MS are highly influenced by fatigue, and also by heat-sensitivity, cognitive difficulties and emotional distress. Significant predictive factors besides fatigue were physical disability (EDSS), age, sex, and level of education. Remaining at work also gives a better HRQoL.¹⁶⁵

It is important to try to minimise the impact of an MS diagnosis on work/employment if possible. Being in employment has many health benefits and, among other, enables an individual to retain self-esteem, social contacts, financial independence and a valued place in society¹.

Factors that contribute to an individual's ability to remain working are shown in figure 10.

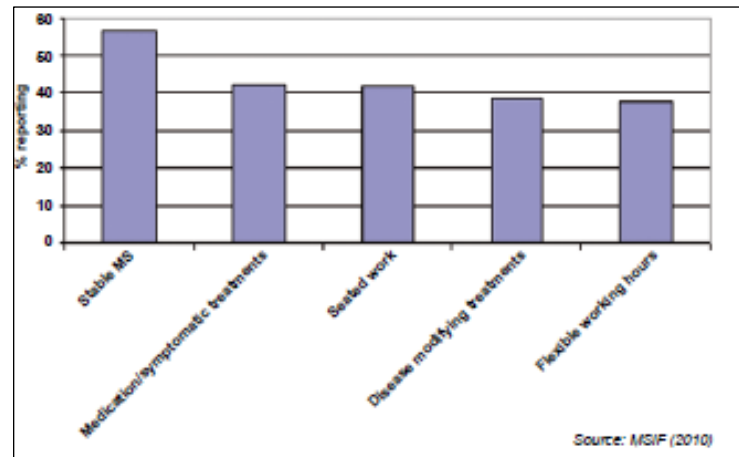


Figure 10: Top 5 factors that enable employment for people with MS (n=3,792)¹⁶⁶

Within the work environment reasonable adjustments may prevent a premature decision to leave a job during a difficult time. Flexible working hours, scheduled work breaks with a place to rest, improved awareness of MS amongst colleagues and increased support from employers and colleagues may all assist individuals with MS to remain in work.

The MS Nurse should usually ask any person with MS specifically if they have problems with motor skills, fatigue or cognition which might impact their ability to work. Where possible, such difficulties should be assessed by a specialist vocational rehabilitation service which will be able to advise the individual on strategies, equipment, adaptations and services available to assist with these difficulties. The employer may also benefit from information or advice, with permission from the person with MS. In some cases where an individual cannot stay in or find alternative employment, they may find voluntary work worthwhile alternative and providing information on such options may be useful¹.



How do you go about identifying the factors that might be affecting someone's ability to work – what do you look out for?

Statistics show that many MS patients are prematurely retired from work, with two of the most important contributing factors being fatigue and cognitive problems. If a problem is identified, it is important to work with the person with MS and their employer to try and find a solution to enable the person to remain in employment. Some of these solutions might include shorter working hours with flexi time; air conditioning to help keep the person cool; allowing the person to work from a seated position in a suitable chair to avoid fatigue; modification of duties.

It is very important to ensure the employer is educated about the condition and the nurse can often assist with this process by providing the employer with the necessary information and materials. It is essential that this is done with the patient's consent - sometimes MS patients

hide their diagnosis for a number of different reasons. According to my experience, the employers are usually very positive, as long as they are informed. The types of information they might need include basic information about MS including symptoms, some idea of how the MS might progress, and the treatment (medical and other). It is important to describe the nature of MS and how the status and symptoms can change from day to day, and even throughout the same day (e.g. fatigue).



The MS Nurse should usually ask any person with MS specifically if they have problems with motor skills, fatigue or cognition which might impact their ability to work. Where possible, such difficulties should be assessed by the MDT, especially OT services.

9.4 Household / Activities of Daily Living

Activities of daily living include those needed around the house to maintain life and safety and a reasonable standard of cleanliness. They include cooking, washing up, all aspects of managing clothing (e.g. washing, ironing) and keeping the house clean. They may also include for some people other activities such as caring for children, and responding to financial and other demands such as paying bills. In contrast to personal activities, domestic activities often make more demands on cognitive skills, and consequently may be affected more by cognitive deficits.

An individual's ability to conduct every day activities has a huge influence on their ability to be independent. A significant proportion of people with MS may eventually experience limitations on their ability to undertake activities such as shopping, housework and undertaking personal care. Occupational or rehabilitation therapists are usually the professional group with most expertise who lead the rehabilitation of activities of daily living.



An individual's ability to conduct every day activities has a huge influence on their ability to be independent. A significant proportion of people with MS may eventually experience limitations.

When assessing a person with MS for their ability in daily activities it is important to determine the person's previous and current functioning, to understand their goals, and support caregivers aspirations and priorities as well as their actual potential. It is also worth considering both their current needs and those in the future. Following this assessment, a programme of interventions should be developed for the person with MS, with the aim of increasing and maintaining independence wherever possible, which is fully agreed by the individual. The interventions should be goal-directed, and designed to meet the individual's priorities, interests and potential¹. There should be regular monitoring to check how effective the interventions are, with a view to changing them if necessary¹.

The occupational therapist and/or the rehabilitation nurse can help patients improve their activities of daily living as well as their mobility. Practical techniques and assistive devices ease the burdens of dressing, bathing, eating, household chores, and daily care.



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9.5 Leisure / Social

Leisure gives a healthy balance to life, as well as giving opportunities for social interaction. The impairments and disabilities that may affect work will usually also affect leisure, but the person with MS can have more control over their leisure pursuits. Loss of independent social activity is very common in people with MS; one survey in the USA found that 62% of people with MS were either socially inactive or depended upon the initiative of others¹.

When a person with MS whose participation in or enjoyment of a leisure or social activity becomes limited, they should be referred to a specialist neurological rehabilitation service. However, if this is not possible, the MS Nurse can try to identify whether previous activities are still achievable and, if not, help the person consider new activities. A rehabilitation service can assess for, and then teach, the skills and techniques that could help achieve the desired activities.

9.6 Family / Relationships / Parenting and MS

From the time of diagnosis, MS can affect the life cycle of the entire family, compounding and confusing the normal transitions and stresses of everyday living. Patients may be confronted with considerable alterations in their social environments due to MS. In some cases, unmarried patients are forced to return to their family homes, and both patients and their parents and siblings must adapt to this frequently stressful situation.



MS can affect the life cycle of the entire family, compounding and confusing the normal transitions and stresses of everyday living.

Having a parent with MS may have negative psychosocial effects, and long-term impacts on subsequent life chances and health, on children and adolescents of the parent, but there is a lack of consensus (positive aspects have also been found).¹⁶⁷

Family members (including any children) living in the same house as a person with MS, and family members delivering substantial help (even if living elsewhere), can be supported through some simple measures. Firstly, asking about their physical and emotional health and well-being, especially in the case of children aged 16 years or less, and offering advice and referring on for additional support if necessary. It can also be helpful to provide general factual information about MS, but it is important to obtain permission from the person with MS before providing information on issues related specifically to that person. The MS Nurse should confirm that the carer is able to provide support for personal activities of daily living (such as dressing and toileting), and that they are safe and competent at such tasks, and that the person with MS is happy for them to provide such assistance. Where applicable, carers should be informed about services and benefits that might be available to them¹.

Cumulative disability can interfere with the performance of a person's roles within the family. For example, a primary earner may need to give up working; a parent may need help with childcare activities; a homemaker may be unable to manage household tasks. As with every other loss brought about by MS, these major life changes need to be mourned before the individual and family can begin to make constructive adaptations. It is important to assess and treat families as a dynamic unit in order to assure comprehensive intervention plans.¹⁶⁸

The turmoil of emotions which may occur in response to the onset of disability, impacts upon the partner and may alter their need for autonomy and intimacy. A change in roles within a relationship from an equal partnership to one of 'carer' and 'cared for' substantially alters the dynamics of the relationship. In addition the effects of cognitive changes on the relationship may need to be addressed. Some couples may adjust and adapt to a new type of relationship but others may experience difficulty. Identified risk factors within relationships are the presence of a progressive condition, marriages begun before the onset of disability and the presence of a sexual dysfunction¹⁶⁹⁻¹⁷². The importance of intimacy and communication within couples is vital as people often have difficulty talking about problems with each other.

For those people with MS who care for their children at home, the stress, guilt, and fatigue these people experience while keeping up with the physical and emotional demands of a young child or children can be particularly difficult to endure. Developing support systems and backup plans for when these patients may need extra rest or childcare assistance can help them manage their child-related responsibilities¹⁷³.



What might be the needs of the family and others when someone is diagnosed or living with MS and what might you do to support and inform them?

The family has similar needs to the person with MS and typically requires information about the condition. A child may have a fear of a parent dying, or be worried that they might catch MS. Adolescents can be fearful that their parent is going to be an embarrassment to them. All these fears and questions need to be addressed and appropriate support given to family members. The family needs assurance that it is normal to feel angry or frightened or unsure of how they are reacting to the diagnosis; MS is a family affair. The family can benefit from special family adaptation courses; these usually take place over a weekend or are evening based, e.g. 3-4 evenings.

Family issues are often overlooked during the nursing assessment as patients may find it difficult to discuss these issues. Many patients do not feel comfortable sharing the concerns they may have about the impact of MS on their social and personal lives. The impact of MS on emotional status and family relationships therefore often goes unrecognised and untreated.



Family issues are often overlooked during the nursing assessment as patients may find it difficult to discuss these issues.

The MS Nurse plays a significant role in ensuring both patients and their families remain positive throughout the lifestyle accommodations and adjustments that may be needed throughout the disease process. They can help facilitate individual and family adjustment to the illness.



The MS Nurse plays a significant role in ensuring both patients and their families remain positive throughout the lifestyle adjustments that may be needed.

9.7 Cultural & Ethnic Considerations

The patient population is not homogeneous and MS Nurses will see people from a wide variety of settings and cultural backgrounds. People from different countries/ethnic background will have a different understanding of MS and/or may be frightened by it. It may be difficult to deal with cultural diversity and varying health literacy, especially with those who are not using their first language to communicate with their nurse.

Try to involve others in their family network, work network, or, religious network. It is important that two “sets of ears” listen to what is being said. Ask the patient and significant others to relay back what has just been said, to make sure they understand the terms that have been used and the procedures they have been asked to do—and to make sure it is all acceptable to their culture. Even with patients whose families have been here for generations, it is important to be careful about cultural norms.

Culture is defined as learned beliefs, values, behaviours, attitudes and customs, shared by a group. Cultural competence is defined as understanding biological variations and effects of medications and disease processes in different ethnic groups. Purnell developed the Purnell model for cultural competence with the following precepts¹⁷⁴:

- All cultures share similarities
- One culture is not better; they are just different
- Cultures change slowly over time
- Difference exists within, between and among cultures
- Culture has a powerful influence on patients’ reactions to illness and interactions with the healthcare system

Easterling has described a model that recognises cultural diversity in MS that has been described as the transcultural assessment model. Principles implicit in this model include that the MS Nurse:

- Recognises every individual as unique
- Identifies literacy level and those “at risk”
- Identifies cultural health practices and beliefs
- Plans culturally based learning experiences
- Uses materials using different languages when appropriate
- Uses visual aids
- Uses concrete rather than abstract words
- Invites questions

- Avoids the use of complex medical terminology when possible

Nursing strategies include that the nurse must validate brief information in writing and use humour cautiously. The MS Nurse should avoid the use of slang words. It is important to include the family, when possible, in planning and learning sessions¹⁷⁵.

Successful individualised treatment of different cultural groups in MS calls for the MS Nurse to have ongoing self-awareness, knowledge, and sensitivity about differences, accepting and respecting those differences, resisting judgmental attitudes and being open and comfortable with cultural encounters¹⁷⁶.

9.8 End of Life

MS is a complex and often fluctuating condition. It is impossible to predict how a person with MS will be affected over time and each person will have their own experience of living with MS. The majority of people diagnosed with MS can look forward to many years of near normal activity but it is important that people with MS are given the opportunity to discuss their wishes relating to their care needs early on in the course of the condition. “Will I die from MS?” is not an unusual question from one faced with this diagnosis.



The majority of people diagnosed with MS can look forward to many years of near normal activity but it is important that people with MS are given the opportunity to discuss their wishes relating to their care needs early on in the course of the condition. “Will I die from MS?” is not an unusual question from one faced with this diagnosis.

What are my own feelings about end of life? How do they influence my behaviour when caring for people with MS?

End of life care is less about the very end of life and more about the specific needs along the whole care pathway. The supportive and palliative care needs that it entails will be required in the last year or two of life for some, but for others these needs may come and go throughout the whole pathway.

Advance care planning can be used to set out a person's preferences and wishes in relation to their future care. This may encompass any wishes relating to end of life care. Lasting powers of attorney can also be granted so that a relative or friend can make decisions relating to property, financial affairs and personal welfare on a person's behalf should they lose the capacity to do so themselves. A new approach to caring for dying people based on the needs and wishes of the person and those close to them has recently been launched in the UK. It takes the form of five new Priorities for Care. This new approach focusses on giving compassionate care and is a move away from previous processes and protocols. It recognises that in many cases, enabling the individual to plan for death should start well before a person reaches the end of their life and should be an integral part of personalised and proactive care.

The MS Nurse should support increased openness and discussion about care preferences and end of life care issues, so that people with MS are made aware of the range of support and services that are available to them. This is a particularly important issue to consider given the

cognition and communication problems that may present in the later stages of the disease trajectory for people with MS. An honest discussion about progression and end of life choices, along with timely referrals to and collaboration with comprehensive palliative care or hospice services, can return to the patient a sense of hope for whatever amount of time is remaining, be it months or many more years.



9.9 Summary

- It is important for the person with MS to make the most of their physical and emotional wellbeing to enable them to live life to the fullest.
- Eating healthily and exercising regularly can help maintain a healthy weight, preserve muscle strength and flexibility, minimise fatigue and improve mood.
- People with MS may face a restricted range of job opportunities, which can bring detrimental consequences to patients and families.
- MS can affect the life cycle of the entire family, compounding and confusing the normal transitions and stresses of everyday living.



Reflective learning points:

How do you try and help your patients maintain a healthy, fulfilling lifestyle?

How does understanding the impact that MS has on the family unit help you in fulfilling your role as MS Nurse?

Describe some of the economic and social issues that a person with MS might encounter? How can you, as MS Nurse, help in these situations?

10 The Role of the MS Nurse

10.1 Learning Objectives



Over the past twenty years, MS Nurses have played an increasingly active role in MS care, helping people with MS and their families to implement treatment strategies, attend to their own and each other's health and wellness, and partner effectively with their healthcare providers. This section will look at the role of the MS Nurse and how it is evolving. After review of this section, you will be better able to:

- Outline the competencies that make up the role of the MS Nurse
- Indicate the value of the MS Nurse in optimising patient support

10.2 Introduction



Rapid advances in technology and medications used for MS, and an increased emphasis on home care and patient self-care, challenge nurses to face increasingly diverse responsibilities in caring for patients with MS. Nurses not only must help meet the healthcare requirements of these patients but often must also serve as the hub of communication, education, advocacy, and counselling for patients, their families or care partners, and other healthcare professionals.

As the health professional with most frequent contact with patients, the MS Nurse often serves as the management hub — identifying medical, psychological, and social issues, making referrals, acting as patient advocate and/ or care manager, and fostering communication among the clinicians involved, and between the clinicians and the patient and family. Therefore the Nurse has a crucial role to play throughout the disease course.



The MS nurse is:

a registered nurse who is educated and skilled to deliver high-quality care and support to people with MS and their families.

The MS nurse will:

establish a therapeutic relationship of trust with empathy, compassion and understanding.

The MS nurse role is:

dynamic, able to respond to the ever-changing needs of the MS population and can promote self-determination and successful self-care.

10.3 The Role of the MS Nurse within the Multidisciplinary Team

The MS Nurse has emerged as a pivotal member of a multidisciplinary team who provides education, skills development, and healthcare delivery for patients with MS and their families. MS Nurses now treat patients in primary, acute, specialised, and rehabilitative settings. MS Nurses are educators and advocates. Some have prescription privileges, and most work closely with the patient in monitoring and assessing treatment outcomes. MS Nurses often initiate, coordinate, or contribute to clinical research.

In many respects, the nurse functions as the eyes and ears of the team, providing information and feedback to team members about the person's physical, emotional, and cognitive state, and ability to be an active participant in his or her own care. Having identified the person's needs, the nurse acts to coordinate the necessary interventions, thus helping to ensure that the identified needs are adequately addressed²⁷. They often must act as liaisons between patients and other members of the multidisciplinary team involved in the care of patients with MS (ie neurologist, family physician, pharmacist, physiotherapist, etc). Therefore, in order to maintain patient trust in the healthcare team's competence and commitment to the course of treatment, nurses should ensure that all team members provide patients with consistent reliable information.

10.4 Competencies of the MS Nurse

The MS Nurse is a competent expert who collaborates with those affected by MS and shares knowledge, strength, and hope. The experienced MS nurse will use extended skills in making a differential diagnosis, screening for concomitant disease, developing preventative care management programmes and referring or discharging patients.

MS Nurses can enhance adaptive and coping skills, facilitate empowerment and a sense of control, and give hope and positive attitudes among people with MS and their family members or care partners. Key elements of the role are:

- Direct patient care
- Symptom management
- Health promotion and living well with MS
- Monitoring and surveillance of disease-modifying therapies
- Psychosocial and family support.

MS nursing practice elements in Europe consist of the following:

10.4.1 *Direct Patient Care:*

- Assess individuals holistically, using a range of different assessment methods, and consider the whole person when addressing any co-morbidities;
- Identify silent and subtle changes through their understanding of the pathology and presentation of MS;
- Work in partnership with the patient and other health and social care professionals;
- Deliver direct care to people with MS throughout the disease trajectory, ensuring ongoing monitoring of the patient;
- Consider health promotion and prevention, anticipating and assessing patients for risk factors to their health and then acting accordingly;
- Help preserve patients' sense of wellbeing and maintain realistic hope;
- Provide telephone and/or email access offering support and information to patients, their families, and other health and social care professionals;
- Draw upon an appropriate range of multi-agency and inter-professional resources in their practice; and
- Appropriately define the boundaries of their role

10.4.2 Education:

- Educate patients on specific drug regimens and other therapies, and provide specialist advice and guidance on risk assessment to reduce or prevent complications;
- Teach patients how to self-administer injections;
- Educate and support patients in the management of side effects from their medication;
- Provide educational opportunities for patients and other members of the MDT; and
- Provide education at a level that the patient understands.

10.4.3 Improving Quality and Developing Practice:

- Create a service that is accessible and responsive to the needs of people with MS and their families;
- Evaluate and audit their care, actively seeking feedback from patients;
- Continually assess and monitor risk in their own and others' practice;
- Critically appraise and synthesise the outcomes of relevant research, evaluations and audits, and apply the information when seeking to improve practice; and
- Alert treating physicians to gaps in evidence or practice knowledge and, in collaboration with others, support research that is likely to enhance practice.

10.4.4 Developing Self and Others:

- Ensure that their education and training remain up to date;
- Provide and participate in structured educational programmes on MS;
- Develop the knowledge-base of patients and their carers in a manner appropriate to their preferred approach to learning motivation and developmental stage;
- Disseminate and share information, experience and research findings within the MDT;
- Facilitate patient empowerment by promoting advocacy, facilitation and networking among people with MS;
- Actively seek and participate in peer review of their own practice;
 - Work in collaboration with the MDT to plan and deliver interventions to meet their learning and development needs;
 - Have high-level communication skills and contribute to the wider development of those working in their area of practice by publicising and disseminating their work through presentations at conferences and articles in the professional press; and
 - Network with other MS Specialists and participate in professional-interest groups and bodies.

The role of the MS Nurse has changed

- MS Nurse practice has evolved in all areas; education, clinical practice, support, patient advocacy and researcher
- Work in partnership with the neurologist and GP
- Collaborate with many other health providers to provide multidisciplinary care
- Up to date knowledge and expertise in MS, symptom management and all treatments
- Develop networks with MS Societies, regional hospitals, community organisations, and health care providers
- Work to provide patient and nurse support materials, participating in advisory boards, etc.

Figure 11: The role of the MS Nurse



10.5 Summary

- The role of the MS Nurse is critical to successful long-term management and outcomes in MS.
- The MS Nurse can deliver positive outcomes to all affected by a diagnosis of MS, using elements of care and support that differ from the other health and social care professionals who may be involved in care.



Reflective learning points:

How does your role as MS Nurse compare to the competencies described in this section?

How do you think your role might evolve in the future?



Summary of Module

- Good communication provides a foundation that promotes empowerment and encourages positive attitudes.
- This contributes to the establishment of a strong, trusting relationship between MS Nurses and their patients.
- The MS Nurse-patient relationship can last for many years and confidence and trust between the patient and MS Nurse often evolves through the ups and downs of the person's journey with MS.
- The MS Nurse has an important role to play in ensuring the person with MS is well informed and well educated.
- There are a number of different strategies the MS Nurse can employ to achieve effective education.
- Care plans are an important tool to enable care to be tailored to meet the individual needs of the person with MS.
- Treating a person with MS often encompasses a multidisciplinary team approach which has been shown to be the most effective way of treating patients.
- Most people with MS will require some kind of emotional support at different stages during the course of their condition.

- Anxiety and depression are frequently present in people with MS but are often under recognised and under treated.
- Effective symptom management is an important component of therapy to maintain quality of life.
- Effective symptom management often requires a multidisciplinary team approach, including pharmacologic treatments as well as other more supportive approaches.
- It is important for MS Nurses to ask about and address symptoms of MS as part of the comprehensive management of the person with MS.
- Primary care management and general health screening is important for the person with MS and should not be overlooked because of the presence of MS.
- Recommended screenings include vitamin D levels, herpes virus status, and thyroid function.
- People with MS are at an increased risk for osteoporosis; those individuals should be identified early, and preventive treatment initiated to avoid bone loss and fractures.
- Pregnancy is safe in most women with MS and does not negatively influence the overall MS disease course.
- Use of disease-modifying treatments around conception should be considered on a case-by-case basis, weighing risks of drug exposure against risks of relapses.
- There is no reason why a woman with MS should be deterred from becoming pregnant if she wishes, although she should be advised that the risk of relapse decreases during pregnancy, and increases temporarily post-partum.
- When giving birth, women with MS should have the analgesia that seems most appropriate and acceptable to them, without fear of it affecting their MS.
- Menopause does not appear to have any effect on MS either positive or negative.
- Every person (or couple) with MS should be asked sensitively about, or given the opportunity to remark upon, any difficulties they may be having in establishing and/or maintaining sexual and personal relationships.
- It is important for the person with MS to make the most of their physical and emotional wellbeing to enable them to live life to the fullest.
- Eating healthily and exercising regularly can help maintain a healthy weight, preserve muscle strength and flexibility, minimise fatigue and improve mood.
- People with MS may face a restricted range of job opportunities, which can bring detrimental consequences to patients and families.
- MS can affect the life cycle of the entire family, compounding and confusing the normal transitions and stresses of everyday living.
- The role of the MS Nurse is critical to successful long-term management and outcomes in MS.
- The MS Nurse can deliver positive outcomes to all affected by a diagnosis of MS, using elements of care and support that differ from the other health and social care professionals who may be involved in care.