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DISCLAIMER

The Multiple Sclerosis handbook has been developed based on the best available evidence with expert and peer review. The use of this handbook is intended as a resource/educational tool for non-specialist nurses and midwives working with people with Multiple Sclerosis.

As with all clinical policies, procedures, protocols and guidelines all components may not be appropriate for use in all circumstances. Decisions to adopt any particular section must be made by the nurse/midwife taking cognisance of:

- The patients/significant other(s) circumstances and wishes
- Available resources
- Local services, policies and protocols
- Available personnel and support services
- Clinical judgement and the experience of the nurse/midwife
- Knowledge of more recent research findings.
INTRODUCTION

This handbook has been developed in conjunction with the manual ‘Multiple Sclerosis Specialist Nursing in Ireland: A Guide to Best Practice’ which has been developed for Multiple Sclerosis Clinical Nurse Specialists. This handbook has been designed to provide non-specialist nurses and midwives with a brief overview of the essential aspects of caring for people with Multiple Sclerosis (MS). The aim is to provide evidence based, up to date information on nursing people with MS. The handbook provides an overview of the following:

- The condition (Multiple Sclerosis)
- The role of the multi-disciplinary team (MDT)
- Diagnosis
- Classifications
- Relapse
- Symptoms
- Treatments
- Complimentary therapies

Overview of MS

Multiple Sclerosis (MS) is a chronic, autoimmune, inflammatory disease of unknown origin that causes multi-focal demyelination, axonal damage and neuronal loss throughout the central nervous system. It can present with a variety of distressing neurological symptoms and is the most common disabling neurological disorder amongst young adults, affecting 2.5 million people worldwide. The prevalence of MS in Ireland is 120-180 per 100,000.

Diagnosis is typically between the ages of 20-50 years with a female predominance, females : males 3:1 ratio. There are over 7,000 people in Ireland diagnosed with MS although it is believed that this figure underestimates the true number of people diagnosed. The disease affects people almost worldwide with an incidence of ~0.1% although there is an established epidemiological variation indicating that a higher prevalence is associated with an increasing distance from the equator, most commonly in North-Western hemisphere. MS is diagnosed in Caucasians more often than in any other racial/ethnic group.
Although MS is not hereditary, it is accepted that there is a genetic link in that it develops in individuals who are born with a genetic predisposition to react to an environmental agent. One UK study examined the risks of developing MS in both first and second-degree relatives of a person with the diagnosis and reported the following figures; sister=4.4%, brother=3.2%, parent=2.1%, child=1.8%. Where both parents have MS, the risk to their children is obviously higher, approaching 20%. Although MS can occur at any age, it is most likely to be diagnosed in a young adult, aged 20-40.

Migration studies are particularly interesting when studying the cause of MS. These have suggested that the potential for developing MS may be established in early life and probably by the age of 15. Thus if a person is born in a high risk area (Northern Europe, Northern USA, Southern Canada, Southern Australia and New Zealand) but moves to a low risk area (Asia, Latin America, Middle East) before the age of 15, he will assume the low risk potential.
Environmental Factors

Climate is a well known risk factor. Temperate climates in the Northern hemisphere show an increasing frequency of MS. An Irish study carried out in 2010 stated the role of the environment is supported by the distinctive geographically distribution of MS with the greatest incidences recorded at high latitudes north and south of the equator. There is also some indication that lack of vitamin D may be implicated. This is supported by the fact that areas closer to the equator with sunnier climates and more exposure to vitamin D have a lower incidence of MS.

Symptoms

The symptoms associated with MS vary depending on the location of the lesions. Common symptoms include;

<table>
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<th>difficulty walking</th>
<th>pain and other abnormal sensations</th>
<th>depression</th>
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<td>difficulties with bladder/bowel control</td>
<td>temporary vision loss or blurred vision</td>
<td>cognitive impairment</td>
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<td>numbness</td>
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Typically, when MS starts, there are distinct attacks - perhaps one or two a year - from which the patient will usually make a full recovery. As the disease progresses, recovery from attacks may not be complete and there is a gradual accumulation of disability.
Section 2

Diagnosis
Demyelination

MS is a disease of the Central Nervous System; the (CNS) consists of the brain (i.e., brain stem, mid brain, cerebrum, cerebellum) and spinal cord. In MS, axons in the (CNS) lose their myelin sheath and, as a result, may break and disintegrate. Many of the typical symptoms of MS affect walking, balance, coordination, bladder function and bowel function. All of these functions depend on the cabling connecting the brain to the limbs, bladder and bowel via the spinal cord. Pain and other sensory disturbances can be explained by demyelination of sensory axons discharging spontaneously or short-circuiting. Loss of muscular control can also result from motor axon damage (i.e., breakage and degeneration).

MS is a chronic, inflammatory, demyelinating disease of the Central Nervous System with or without secondary axonal involvement. The inflammatory process is driven by a T-cell mediated immune reaction that leads an attack against both the myelin sheath and the cells that produce myelin, the oligodendrocytes.

Diagnostic Criteria

- The assessment and diagnosis of MS begins with a detailed medical and psychosocial history taken by the neurologist.

- Following the history, the neurologist will perform a neurological examination including an MRI.

- The key to diagnosing MS is clinical evidence as identified by the revised McDonald criteria (2010). The McDonald criteria lists the clinical presentation and additional data required to make a diagnosis of MS, such as number of neurological attacks experienced by the patient and evidence of lesions on an MRI.

- Lumbar puncture (LP) involves the examination of the cerebrospinal fluid which provides supportive information for the diagnosis of MS. It is not used as predictor of the clinical course of MS.
The sub-types of MS include:

- Relapsing-Remitting MS (RRMS)
- Progressive-Relapsing MS (PRMS)
- Secondary-Progressive MS (SPMS)
- Primary-Progressive MS (PPMS)
- Benign MS

**Relapsing-Remitting Multiple Sclerosis (RRMS)**

- The majority of patients (85%) who develop MS will present with the relapsing-remitting form of the disease.

- RRMS varies greatly in severity from individual to individual. The annual relapse rate initially averages about 2-2.5 and thereafter drops to approximately one per year. It is considered a poor prognostic sign if the person experiences frequent relapses, especially at the onset of the disease.

- At 10 years after disease onset 50% of patients will enter the SPMS phase, by 20 years after disease onset this figure will rise to 80%.

**Progressive-Relapsing Multiple Sclerosis (PRMS)**

- Progressive-Relapsing MS can be identified as worsening Relapsing-Remitting MS.

- PRMS involves a progressive nature of disease with obvious relapses.

- It is important that this specific group are identified in the clinical setting, particularly in the context of addressing treatment options. Whether the patient with PRMS is already on disease modifying therapies or not, switching to other treatments such as, Tysabri or Mitoxantrone may be crucial in prevention of further disease activity and slowing down the evolution from PRMS to SPMS.
Secondary-Progressive Multiple Sclerosis (SPMS)

- SPMS is defined as progression of clinical disability (with or without relapses and minor fluctuations) after a relapsing-remitting onset.

- The patient does not recover from relapses/attacks and disability progresses even in between the relapses.

- When assessing patients, it can be difficult, at times, to establish when they are converting from RRMS to SPMS. This may only become apparent over a significant length of time.

Primary-Progressive Multiple Sclerosis (PPMS)

- PPMS is found in approximately 10% - 15% of the MS population and, as opposed to other forms of MS the female propensity is absent.

- The disease will be progressive from onset without any discernible relapses or remissions. The unique clinical characteristics of this form of MS make it difficult it diagnose.

- Typically, the patient will be at a later age of onset, experiencing their first symptoms in their 40’s onwards, but in rare cases it can occur at an earlier age.

- It typically presents with an increasing spastic gait that is already affecting their quality of walking. The prognosis is poorer; the time taking to reach EDSS of 6 is approximately 6 years.

Benign MS

- In Benign MS, there is complete recovery from isolated attacks, with little or no accumulation of disability.

- The attacks may be separated by 10 years or more.

- This type of MS often goes undiagnosed for several years and in many instances, benign MS is diagnosed post-mortem.
ASSESSMENT TOOLS/CLINICAL MEASURES

A variety of tools are available for the Neurologist, MS Clinical Nurse Specialist (CNSp) and medical team to adequately assess MS related symptoms such as fatigue, bladder and bowel problems, pain, spasticity, tremor and altered mobility.

Fatigue

Assessing the severity of the fatigue involves, administering a fatigue measurement scale such as the Modified Fatigue Impact Scale [MFIS] in The Multiple Sclerosis Quality of Life Inventory [MSQLI]; determining the effect of fatigue on the patient's daily activities; and asking the patient to complete a fatigue-management diary. Fatigue is an extremely common, but under-recognized, symptom in MS.

Pain

Pain can be assessed by several uni-dimensional and multi-dimensional measurement tools such as; the visual analogue scale, the descriptor differential scale, numerical rating scale, McGill pain questionnaire (long and short) and brief pain inventory. Patient’s self-report of pain should be included in the assessment due to the subjective nature of pain.

Spasticity

The severity of the spasticity may be assessed by use of the Modified Ashworth Scale which measures tone intensity. The Spasm frequency Scale is used to measure spasm frequency.

Tremor

The severity of the tremor may be assessed by use of the spiral test. The patient is asked to draw an Archimedes spiral. This spiral test is considered to be a valid and reliable index of essential tremor severity and takes less than a minute to record.
Altered Mobility

The most widely used assessment tool for measuring impairment and disability in MS is the Kurtzke Expanded Disability Status Scale (EDSS). It is a 20 step ordinal scale that ranges from 0 (normal status) to 10 (death due to MS). The assessment is made by a neurologist who carries out a neurological examination and then grades patients according to a set of 8 Functional System Scales and combining these with ambulatory function.

Depression

Tools for use in the assessment of depression include the Beck Depression Inventory (BDI), Hamilton Rating Scale and the Mental Health Inventory (MHI). The assessor must be competent in the use of these tools.

Cognitive impairment

An appropriately competent member of the MDT will assess cognitive deficits by use of the Mini-Mental Exam, Montreal cognitive assessment (MoCA), Paced auditory serial addition test (PASAT) and the Perceived Deficit Questionnaire from the MS quality of life inventory.
Section 3

Treatments and Complimentary Therapies
Relapses in MS are defined as new or worsening symptoms attributable to MS lasting greater than 24hrs in the absence of a temperature and period of 30 days should be observed between each event to differentiate separate attacks.

A period of 30 days should be observed between each event to differentiate separate attacks and eliminate “pseudoexacerbations” (episodes of deterioration in neurologic function precipitated by fever, infection and fatigue that is reversible within hours)

Relapses vary in severity and the degree of recovery is unpredictable.

Corticosteroids remain the most commonly accepted treatment for acute MS relapses. This usually comprises a course of glucocorticosteroids such as methylprednisolone.

Evidence concerning corticosteroid efficacy in relapse management is well established. They are effective in hastening recovery from the attack, but do not usually affect the eventual outcome in terms of degree of recovery or disease progression.

Over a short course and when given when there is evidence of a clinical relapse steroid therapy is well tolerated. Frequency of adverse events correlates with the dose, frequency, route of administration, duration of therapy and underlying disease state.

More common side effects can include:

1. Alterations to sleep patterns
2. Metallic taste in the mouth
3. Mood alterations
4. indigestion/gastro-intestinal symptoms
5. flushing
6. Osteoporosis
7. Increased appetite
8. Increased risk of infection/Raised white cell count
9. Hypertension
10. Altered blood glucose levels
**Less common side effects can include:**

1. On rare occasions, epileptic seizures.
2. Rapid infusions may trigger arrhythmias
1. Rarely urticarial hypersensitivity response requiring cessation of treatment
2. Transient ankle oedema
3. Transient weight gain

As nurses, it is important that we are aware of the short-term side effects that can occur as a result of steroids and that these are explained fully to patients. Patients need to know what to expect from a course of steroids so they are able to make informed choices. It is important that they are aware of the principle that whether they receive a course of steroids or not, their recovery from the relapse will ultimately be the same.
Nurses and midwives caring for people with MS need a good understanding of the medications prescribed for these patients and the methods of administration. Medication side effects and injection site reactions can sometimes make it difficult for people with MS to comply with therapy. Therefore a good understanding of this is important to ensure continuity of care in all health care settings.

All nurses and midwives must adhere to An Bord Altranais guidelines in the management and administration of all medications. Please see Guidance to Nurses and Midwives on Medication Management July 2007, available online at:


**Interferons**

**Disease** modifying therapies commonly used for the treatment of MS include Avonex (Interferon beta 1a), Rebif (Interferon beta 1a), Betaferon (Interferon beta 1b) and Copaxone (Glatiramer acetate). The use of disease-modifying therapies is perhaps the most important therapeutic advancement in MS to date. These are the first line treatments for MS patients.

**Avonex** is indicated for the treatment of RRMS and clinical isolated syndrome (CIS). It is administered once per week by IM injection.

**Rebif** is indicated for the treatment of RRMS and CIS. It is administered by subcutaneous injection three times per week.

**Betaferon** is indicated for the treatment of RRMS, CIS and SPMS with relapses. It is administered alternate days by subcutaneous injection.

**Copaxone** (Glatiramer acetate) is indicated for the treatment of RRMS, where it reduces the frequency of relapses in ambulatory patients. It is also indicated for patients with a defined first clinical episode CIS. It is not for use in PPMS or SPMS. Glatiramer acetate is administered daily by subcutaneous injection.
Injection sites

Patient information leaflets pertaining to specific drug treatments provide specific information regarding the site and procedure for the administration of the injection. Nurses and Midwives should refer to the specific instructions in relation to the drug that they are administering. The following diagrams are examples of various sites that are used.

Appropriate depths for subcutaneous and intramuscular injections
Subcutaneous sites

- Encourage patients to inject in sites they prefer or that are most comfortable for them; however, always stress the importance of injection-site rotation.

- Other injection-site locations may include the abdomen above the waistline (maintaining a 2” circle of safety all around the umbilicus that should be avoided), the sides of the thigh and the lower back.
Intramuscular sites

Possible injection sites for disease-modifying therapies that are administered subcutaneously.*

- Note: Many patients find injection in the deltoid region awkward.
Side Effects

The most common side effects associated with Interferon beta (IFNβ) therapy are:

- **Injection-site reactions**
  The most common injection-site reactions include pain and cutaneous reactions. Injection-site necrosis is rare, but may occur.

- **Flu-like symptoms (i.e., myalgia, headache, chills, fever)**
  Approximately 60% of patients experience flu-like symptoms after the first dose of IFNβ.

- **Spasticity**
  Spasticity or worsening of spasticity may occur upon initiation of therapy, particularly in patients with pronounced spasticity prior to therapy. This drug-induced spasticity usually occurs 3-24 hours after IFNβ injection and may last for several hours or days.

- **Laboratory-test abnormalities**
  The most commonly observed laboratory abnormalities in patients receiving IFNβ therapies are leukopenia, lymphopenia, neutropenia, and raised liver aminotransferase values (e.g., serum glutamic oxaloacetic transaminase [SGOT] and serum glutamic pyruvic transaminase [SGPT]). These abnormalities, however, seldom result in serious complications.

- **Mood alterations**
  It is unclear whether IFNβ therapy itself causes depressive symptoms or whether these symptoms are due to poor adherence to therapy and/or an inability to cope with MS. Many clinicians prefer to start IFNβ therapy when the patient is, for the most part, emotionally stable or receiving effective treatment for depression.

- **Insomnia**
  Insomnia may occur upon initiation of therapy and may continue indefinitely.
IMMUNOMODULATORS

Immunomodulators are occasionally used in MS; however, few are licensed for use in MS. They are second line treatments for patients not responding to first line treatments. Immunomodulators commonly used in MS include Natalizumab, Mitoxantrone and Intravenous Immunoglobulin.

Natalizumab

Natalizumab (Tysabri), is a humanised, monoclonal a 4-integrin antagonist that inhibits the migration of leukocytes across the blood-brain barrier into the central nervous system. It is indicated for use in patients with highly active relapsing-remitting multiple sclerosis despite treatment with interferon beta or those with rapidly evolving severe relapsing-remitting multiple sclerosis. Treatment with natalizumab should be initiated and supervised by a specialist. Side effects of the Natalizumab infusion include dizziness, nausea, urticaria and rigors.

Patients who are treated with Natalizumab are at risk of developing PML.

PML is a demyelinating disease of the central nervous system that is caused by the human polyomavirus JC virus. PML is often fatal and cannot be treated. Patients who test positive for JCV antibodies and receive Tysabri treatment have a 1 in 2850 chance of developing PML in the first two years. After two years this risk increases to 1 in 357. For those who have previously received immunosuppressive drugs and are JCV positive the risk of developing PML is 1 in 833 cases in the first two years and this risk increases to 1 in 123 after two years of Tysabri treatment.

Mitoxantrone (Novantrone®)

Mitoxantrone is licensed for use in MS in the USA. This is chemotherapy agent. Trials have shown it to be a powerful immunoregulator and for this reason, it has been tested in a small number of patients with MS. Results are contradictory: some researchers have reported that mitoxantrone has positive effects on disease activity and/or measures of disease progression, whereas others have reported no effects.

The main disadvantage of mitoxantrone is its safety profile, in particular its cardiotoxicity. Echocardiograms are performed on the patient prior to receiving the drug, throughout the course of treatment and performed intermittently even when the drug has been stopped. Mitoxantrone use is also associated with nausea and vomiting, hair loss and ammenorhoea.
**Intravenous Immunoglobulin**

As with the immunoregulatory drugs, immunoglobulin (obtained from the blood of healthy human donors) is available, but not licensed, for use in MS. Although the mode of action of immunoglobulin in MS has not been established, it has been suggested that immunoglobulin may down-regulate antibody and cytokine production, and lymphocyte activity; block the constant-region antibody receptors on macrophages; and bind to activated complement components.

Side effects of IVIG range from moderate, headache, nausea, vomiting, chills, low-grade fevers, to more severe including aspetic meningitis, congestive heart failure, DVT, hypotension and anaphylaxis in those with IgA deficiency.

**Fingolimod (Gilenya)**

Fingolimod is indicated as single disease modifying therapy in highly active relapsing remitting MS. It is currently available on hi-tech prescription.

Side effects include bradyarrhythmia (all patients should be observed for a period of six hours post first dose), infections, blood pressure and respiratory effects.

Emerging treatments include Alemtuzumab and Fumerate. Less frequently used include Azathioprine, Methotrexate, Cyclophosphamide and Cyclosporine.
COMPLIMENTARY THERAPIES

Many MS patients use a variety of therapies to assist with the management of MS related symptoms however; these therapies are complementary to the medical treatments previously discussed above.

Some of the most commonly used physical, energy, and psychological complementary therapies in MS are acupuncture, chiropractic, massage therapy, meditation, reflexology, Tai Chi, and yoga. Although general evidence is inconclusive, complimentary therapies have been found to be beneficial in MS for example yoga, reflexology and acupuncture. Ai chi (water-based t’ai chi) has been shown to decrease fatigue, reflexology was found to produce benefits when used for MS related symptoms and the use of acupuncture was found to reduce MS related symptoms.
Section 4

The Role of the Multi-disciplinary Team and the Primary Care Team
In order to achieve holistic care of the MS patient a multi disciplinary team approach is required. Several authors agree that a multi disciplinary approach improves care for patient with MS.

THE ROLE OF THE MULTIDISCIPLINARY TEAM (MDT) AND PRIMARY CARE TEAM (PCT)
Nurse / Midwife

The ultimate goal of the nurse/midwife is to provide the highest quality of care to the person with MS and their families in order to promote the person’s independence and enhance their quality of life throughout the disease continuum. The nurse or midwife practicing in Ireland must practice within their scope of practice as defined by An Bord Altranais, while adhering to local policies and protocols. The role of the nurse/midwife in caring for people with MS, both in hospital and the community, involves assessing their needs, planning the care to address identified needs within an adequate timeframe, implementing care and evaluating the care provided, while involving the patient and their family in the process.

Clinical Nurse Specialist in MS

The MS clinical nurse specialist has a key role in aiding patients to adjust to their condition through expert assessment, guidance, support and education throughout the disease continuum. The MS Nurse Specialist is vital in providing an understanding of the condition and implementing a coordinated, inter-disciplinary and holistic approach. It involves recognizing, promoting and enhancing a person’s ability to meet their own needs and solve their own problems. MS Nurse Specialists in Ireland practice under the guidelines of An Bord Altranais. A competency framework was produced in 2011 by the Irish Network of MS nurses, designed for use by MS nurse specialists. The core concepts of this framework are based on those identified by the National Council for Professional Development of Nursing & Midwifery. These concepts guide the role of the MS nurse specialist and include the clinical practice role (direct and indirect patient contact), educational role (providing education for peers, junior colleagues, patients and families), patient advocate role (liaise between members of the MDT, coordinator of care between primary care and the community), audit/research role and consultancy role.

Neurologist

The Neurologist has an integral role in the diagnostic process, the recommendation and prescription of appropriate treatments, the monitoring of the patient throughout the disease process and the recognition of disease progression.

The Neurologist often refers the patient to the appropriate member of the multidisciplinary team for specialist assessment and therapies.
**Physiotherapist**

The physiotherapist assists the person with MS in improving or maintaining physical functioning through exercise. For example, gentle, sustained stretching exercises are beneficial in the management of spasticity. The physiotherapist is responsible for the assessment of many MS related symptoms such as spasticity and tremor, and assessment of patient safety when mobilising. Consideration needs to be given to the temperature of the environment in which the physiotherapy takes place, as a cooler environment will reduce the risk of elevating body temperature which leads to fatigue.

**Occupational Therapist**

The occupational therapist (OT) focuses more specifically on functioning with respect to activities of daily living. They also advise / provide aids and adaptations to enable the individual to maintain their maximum level of independence and health. For example, for an individual experiencing fatigue, the occupational therapist may assess how the person with MS plans daily activities and will provide recommendations on how to minimise fatigue and/or perform activities during times when energy levels are higher. The occupational therapist may also recommend weighted eating utensils and cups to decrease tremor during eating. The OT may assess the patient's home prior to discharge from hospital to ensure the environment is suitable, housing adaptations maybe recommended. The OT may assess and make splints for a patient if required.

**Social Worker**

The social worker assesses the individual and their family’s overall living situation and assists in such areas as financial arrangements and benefit entitlements, community resources and care packages, employment issues and alternative living situation. This service tends to be hospital based.

**Psychologist**

The psychologist can help the person with MS and their family psychologically prepare for active participation in rehabilitation. The psychologist may assess psychological status, coping styles, problem-solving skills, and cognitive function. Through counselling, the psychologist assists the individual in developing or strengthening the tools needed to cope during periods of extreme stress or turmoil. It is important to note that this is a very limited service and not readily available to all MS patients.
Continence Advisor

The continence advisor works with the person with MS who has bladder or bowel problems to assess, plan and implement a care plan designed to meet the individual’s needs.

Speech and Language Therapist

The speech therapist evaluates and treats individuals with speech and swallowing difficulties. Ideally, speech therapy is initiated when the symptoms first appear and focuses on teaching and training techniques that compensate for reduced neuromuscular function, such as an exaggeration in articulation. Concerns over subtle changes in speech or swallow should be reported to the Speech and language therapist. Nurses or family members may notice these small changes due to the time spent with the patient.

General Practitioner (GP)

The GP is the first line health care professional for MS patients in the community. The GP receives all up-to-date hospital based correspondence regarding the MS patient from the consultant neurologist, MS nurse specialist and relevant therapists involved in the patient care. The GP is responsible for renewing non-high tech prescriptions and monitoring the health of the MS patient in the community making referrals to the required members of the MDT when necessary.

Dietician

The dietician provides a therapeutic and nutritional advisory service to improve a person’s health. The dietician works as part of a multi-disciplinary team in the care of those with MS in the hospital or people with MS may be referred as Outpatients.
Public Health Nurse and Community Registered General Nurse

The Public Health Nurse (PHN) and Community Registered General Nurse (CRGN) are members of the primary care team (PCT) and are involved in the holistic care of the patient. They are committed to best practice in providing services to patient / client with MS and their family in the community setting. The PHN/CRGN has an advocacy role and liaises with GPs, Practice Nurses and all Multi-disciplinary Primary Care Team members, Hospitals, and other health service providers (both statutory and voluntary) to ensure that the needs of the patient / client with MS and their family are met by the overall health service. The PHN/CRGN is involved in health promotion, assessment of needs and has responsibility for coordinating care of the patient with MS and implementing their care plan. She/he assists the patient to adapt to problems associated with daily living as a result of their MS. This may involve the provision of a home help/health care assistant or a package of care where appropriate. The PHN/CRGN has a key role in identifying carer’s needs and referring to support agencies such as the Carers Association.

The Multiple Sclerosis Society of Ireland (MS Ireland)

The MS regional community workers work for the MS society of Ireland. Services provided include support, information, advice and counselling for patients and families regarding issues such as finance, benefits & entitlements, access to services, housing and transport. Activities provided include information days, stress management programmes, physiotherapy & exercise, and support groups sessions. The MS regional community workers are located throughout Ireland.

MS Ireland funds the MS Care Centre in Rathgar, Dublin. This facility provides respite care for people with MS. Services available include physiotherapy, occupational therapy and nursing care.
Section 5

Nursing care of specific problems associated with Multiple Sclerosis
NURSING CARE

The nurse must undertake a complete holistic assessment of the patient incorporating a full physical, psychological and social assessment, and then use this assessment to appropriately plan care. The assessment and care plan should be based on a recognised theoretical framework and incorporate a plan for the evaluation of patient care.

Along with a good understanding of what the condition is, how it is diagnosed and classified, and a thorough understanding of symptoms, medical management and the contribution of members of the MDT, there is much that nurses/midwives can do to relieve symptoms when a patient with MS is being care for. The role of the nurse/midwife is now discussed under the most commonly encountered symptoms in clinical practice.

Please see the Assessment Tools/Clinical Measures section for some examples of the tools used to assess MS symptoms.

The complaints and symptoms most commonly associated with multiple sclerosis (MS) are:

- Fatigue
- Bladder and bowel dysfunctions
- Pain
- Spasticity
- Tremor and alterations in mobility
- Speech and swallowing difficulties
- Visual disturbances
- Depression
- Cognitive impairment
Fatigue

- Fatigue is recognised as the most common symptom of MS.
- 75-95% of individuals experience fatigue, and 50-60% report fatigue as their most disabling symptom.
- Fatigue not only exacerbates impairment and disability, it is also directly related to the individual’s sense of control over the illness and overall mental health. It is suggested that fatigue is one of the major reasons for unemployment among people with MS.

Nursing care

Assessment:
The nurse, in conjunction with the patient will identify possible contributing factors, such as relapse, medications, sleep disturbances, concurrent illness (e.g. infection), level of activity (e.g. deconditioning), heat, lifestyle patterns, diet, exercise, psychosocial issues, pain, depression and spasticity.

Plan:
Set agreed and achievable goals to allow the person with MS and nurse to plan to take action on the issues of fatigue raised during the assessment process.

Intervention:
The nursing care for MS patients experiencing fatigue involves encouraging appropriate lifestyle modifications such as frequent rest breaks and prioritising activities.

Evaluation:
The nurse’s role, regarding fatigue must include ongoing evaluation of the patient’s fatigue management strategies, to ensure they are effective and if not, investigate the reasons in conjunction with the patient and revise the plan of care.
**Bladder Dysfunction**

- 75–95% of patients with MS experience some type of bladder dysfunction during the course of their disease.

- 1 in 10 MS patients may experience bladder symptoms at disease onset but these symptoms usually occur as MS progresses, appearing at approximately year 6.

- The types of bladder dysfunction most commonly associated with MS are:
  - Failure to store
  - Failure to empty
  - Combination failure to store and failure to empty

**Nursing care**

**Assessment:**
The nursing care for bladder dysfunction will include a detailed assessment of the problem and referral where appropriate to the continence advisor for specialist intervention i.e. bladder ultrasound, catheter care and patient and family education.

If appropriately qualified and competent the nurse may perform a bladder ultrasound. This will allow the obtainment of a post void residual. The significance of results depend on local hospital policy, please refer to local hospital policy in your area.

**Plan:**
Set agreed and achievable goals to allow the person with MS and nurse to plan to take action on the issues of bladder dysfunction raised during the assessment process.

**Intervention:**
Patient and family education regarding catheter care is a key aspect in preventing complications associated with indwelling catheters. The nurse may provide information and support to the patient and family/carers on drainage and emptying, risk of infection and risk of blockage.

**Evaluation:**
The nurse’s role, regarding bladder dysfunction must include ongoing evaluation of the patient’s management strategies, to ensure they are effective and if not, investigate the reasons in conjunction with the patient and revise the plan of care.
**Bowel dysfunction**

- Bowel dysfunction is common among MS patients.
- Bowel problems are under reported and neglected in MS patients.
- Bowel dysfunction does not appear to be associated with the degree of disability. However, it is associated with the duration of MS.
- The two main types of bowel dysfunction in MS are constipation (more common associated with reduced mobility) and bowel urgency.

**Nursing care**

**Assessment:**
The nurse must adequately assess the patient’s baseline bowel function and in-conjunction with the patient identify the problematic bowel issues.

**Plan:**
Set agreed and achievable goals to allow the person with MS and nurse to plan to take action on the issues of bowel dysfunction raised during the assessment process.

**Intervention:**
The nurse will assist the patient to develop a regular bowel routine based on their usual daily activities and plan a regular timeframe for defecation.

Instructing the patient to take advantage of the urge to defecate to ensure regular emptying of the bowels. Making use, for example, of the gastro-colic reflex which occurs 20mins approx after a meal. The nurse may refer the patient to members of the multidisciplinary team for appropriate assistance, for example;

The dietician for appropriate advice regarding high fibre diet and adequate fluid intake which both have impact on healthy bowel function.

The physiotherapist for an activity plan to include regular physical activity to promote bowel function. It may be appropriate for the nurse to liaise with the GP regarding the patient’s bowel care plan.
Evaluation:
The nurse’s role, regarding bowel dysfunction must include recognition of any stress and anxiety that may be exacerbating the issue. It also involves the ongoing evaluation of the patient’s management strategies in order to determine their effectiveness, and in conjunction with the patient determine why some strategies may no longer be effective. The nurse and patient must then work together to identify other solutions and interventions.
**Pain**

- Pain is common in people with MS.
- Pain is defined as an unpleasant sensory and emotional response to a condition caused by actual or potential tissue damage.
- Estimates of the prevalence of pain in MS vary from 10% to 80% depending on the type of pain experienced.
- Most patients with MS experience chronic pain; acute pain syndromes occur in approximately 10% of patients.
- Acute pain is often characterised by paroxysmal attacks that are brief in duration (i.e., lasting seconds) and occur repeatedly.
- Subacute pain may last days or even weeks. It is caused by demyelination (optic neuritis is the most common) or a secondary source, such as painful bladder spasms associated with a neurogenic bladder and infection or vertebral compression fractures resulting from frequent corticosteroid treatment or prolonged immobility.
- Chronic neuropathic or dysesthetic pain occurs in about one-third of patients with MS; it is believed to be directly related to the demyelination of sensory pathways. Chronic musculoskeletal pain, such as backaches and painful leg spasms, usually results from MS-related symptoms rather than the disease itself.

**Nursing care**

**Assessment:**
Please see the Assessment Tools/Clinical Measures section for a list of appropriate tools for the adequate assessment of pain. Assess the severity of pain using an appropriate assessment tool, taking into account the patient's description of the pain. Referral to a pain specialist may required.

**Plan:**
Set agreed and achievable goals to allow the person with MS and nurse to plan to take action on the issues of pain raised during the assessment process.
**Intervention:**
The nurse should administer the appropriate prescribed analgesia. Non-pharmacological methods of relieving and coping with pain such as massage, meditation and reflexology (not a limited list) may be appropriate for use by the patient.

**Evaluation:**
The nurse must acknowledge and validate the patient’s pain experience and provide ongoing evaluation of analgesia and pain management strategies for the specific pain category.
**Spasticity**

- Spasticity is a common MS-related symptom.
- Spasticity or muscle hypertonia occurs as a result of abnormal spinal and brain stem reflexes.
- Defined as disordered sensorimotor control, resulting from an upper motor neurone lesion, presenting as intermittent or sustained involuntary activation of muscles.
- Spasticity can be both phasic (spasms) and tonic (constant stiffness). The muscle groups that are most likely to develop spasticity are the quadriceps, hamstrings, and gastrocnemius muscles.
- Mild spasticity is generally treated through passive stretching of the affected joint.
- Severe spasticity, which is most often noted in individuals with restricted mobility, can lead to skin breakdown, seating problems, contractures, and pain.

**Nursing care**

**Assessment:**
The nurse will, in conjunction with the patient, identify possible contributing factors to spasticity such as relapse, infection, stress, anxiety, constipation, bladder dysfunction, altered skin integrity and medications.

**Plan:**
Set agreed and achievable goals to allow the person with MS and nurse to plan to take action on the issues of spasticity raised during the assessment process.

**Intervention:**
The nurse may assist the physiotherapist and/or occupational therapist with exercise programmes, assistive devices and seating modification to aid with the management of spasticity.

**Evaluation:**
The nurse's role, regarding spasticity must include ongoing evaluation of the patient's management strategies, to ensure they are effective and if not, investigate the reasons in conjunction with the patient and revise the plan of care.
Tremor

• Tremor is a complex movement disorder characterised by involuntary uncontrolled movements.

• Tremor in MS can affect the limbs, trunk, or speech. It is often the most disabling symptom because it is frustrating for patients and difficult to treat. Even a mild tremor can make simple tasks difficult to perform.

• Tremor is generally classified as either postural, intention, or rest tremor.

Nursing care

Assessment:
The nurse will determine the nature of the tremor in terms of onset, location, duration, degree of motion (gross or fine), and velocity (fast or slow). Describe the symptom characteristics i.e. is the tremor at rest, with position, or with voluntary movement. The severity of the tremor may be assessed by use of the spiral test.

Plan:
Set agreed and achievable goals to allow the person with MS and nurse to plan to take action on the issues of tremor raised during the assessment process.

Intervention:
The nurse may assist the physiotherapist and / or occupational therapist with instruction on activities to help manage tremor such as patterning (i.e., tracing and repeating basic movement patterns until they become automatic), weighting, robotic aids, e.g., Handy 1 Robotic Aid.

The nurse may need to approach the issue of possible loss of the adult role. Patients with tremor may no longer be able to perform normal adult activities such as feeding or grooming themselves. In fact, patients often rate the inability to feed themselves as the worst consequence of tremor (women also rate the inability to groom themselves as one of the worst consequences).

Evaluation:
The nurse’s role, regarding tremor must include ongoing evaluation of the patient’s management strategies, to ensure they are effective and if not, investigate the reasons in conjunction with the patient and revise the plan of care.
Altered mobility

- Mobility is defined as the ability to change and control body position.
- Symptoms that contribute to altered mobility in MS include spasticity, tremor, ataxia, weakness, loss of balance, pain, fatigue, dizziness, and vertigo.
- Within 10 to 15 years of disease onset, 80 percent of persons with MS experience gait problems due to muscle weakness or spasticity, fatigue, and balance impairments.

Nursing care

Assessment:
The nurse will determine the nature of the mobility alteration in terms of onset, duration and describe the symptom characteristics of altered mobility such as loss of balance, tripping, falling, inability to transfer, inability to walk. Acute mobility may be the indication of a relapse. Chronic mobility may be long term and secondary to disease progression.

The nurse will identify specific needs in relation to personal care, undertake pressure ulcer risk assessment and organise appropriate nursing aids/assistance e.g assistance with personal care, hospital bed, pressure relief appliances, hoist, showering/bathing aids as identified by need.

Plan:
Set agreed and achievable goals to allow the person with MS and nurse to plan to take action on the issues of altered mobility raised during the assessment process.
**Intervention:**
Patient education is a key intervention with regard to altered mobility. The nurse will inform the patient regarding the causes of altered mobility such as spasticity, weakness, loss of balance, sensory changes. The potential risks associated with altered mobility include falls, fractures, and reduced capacity for self care and safe driving. The potential complications of altered mobility include contractures, skin breakdown (pressure ulcer formation), compression neuropathies and pain.

It may be appropriate for the nurse to refer the patient to the physiotherapist and/or occupational therapist for assistance in the management of altered mobility including gait retraining, mobility aids, stretching and strengthening programmes, balance training, energy conservation training and environmental accessibility and adaptive equipment.

**Evaluation:**
The nurse’s role, regarding altered mobility must include ongoing evaluation of the patient’s management strategies, to ensure they are effective and if not, investigate the reasons in conjunction with the patient and revise the plan of care.
Speech and Swallow difficulties

- Speech and voice disturbances are usually present as spastic-ataxic dysarthrias that involve disorders of voice intensity, voice quality, articulation, and intonation
- Dysarthria affects 40% of MS patients.
- Dysphagia affects 30% of MS patients and up to 60% of advanced MS.
- Depending on the location and extent of demyelination, swallowing disorders can relapse and remit along with MS exacerbations.

Nursing care

Assessment:
Assessment involves determining the nature of speech and swallow difficulties, identifying possible contributing factors, determining how other activities are impacted upon, identifying the patient’s management strategies and in collaboration with the patient suggesting strategies that can improve the symptoms.

Plan:
Set agreed and achievable goals to allow the person with MS and nurse to plan to take action on the issues of speech and swallow difficulties raised during the assessment process.
**Intervention:**
The nurse should refer the patient to a Speech and Language therapist for detailed assessment which may include videofluoroscopy (for swallow assessment).

Interventions for the management of speech problems can then be planned such as oral motor exercises, appropriate timing and rate of speech, new strategies to help patient communicate, signing, hand and facial gestures, use of assistive devices such as computers and/or letterboards.

Interventions for swallow problems include correct positioning, dietary modifications such as changes in texture and consistency of foods, alertness at mealtimes, supervision at meals, management of secretions.

The nurse may undertake a nutritional assessment using the MUST (Malnutrition Universal Screening Tool) and refer to a dietician for guidance on appropriate nutrition and maintenance of body mass index (BMI).

**Evaluation:**
The nurse and speech & language therapist must include ongoing evaluation of the patient’s management strategies, to ensure they are effective and if not, investigate the reasons in conjunction with the patient and revise the plan of care.
Visual disturbances

- In many cases visual problems are the first symptom that people present with prior to a diagnosis of MS.

- Visual problems in MS include optic neuritis and eye movement problems such as diplopia (double vision) and nystagmus (uncontrolled eye movements).

- Visual problems can impact on activities of daily living.

Nursing care

Assessment:
Nursing assessment of visual problems involves obtaining a patient history of visual problems. Description of when the symptom started and the features of the visual problem including characteristics e.g. blurred, double, pain, loss of vision.

Plan:
Set agreed and achievable goals to allow the person with MS and nurse to plan to take action on the issues of visual disturbances raised during the assessment process.

Intervention:
Education is a key role for the nurse regarding many MS related symptoms. The nurse may inform the patient about possible causes of visual problems in MS. Educate patient on treatments including IV Steroids. Provide information on resources in the community to assist the person with visual problems. Refer to Multiple Disciplinary Team (MDT) including Neuro-Ophthalmologist and Occupational Therapist. Assist patient in implementing strategies to manage visual problems as recommended by MDT.

Evaluation:
Evaluate the impact of visual problems on the person with MS including safety (e.g. risks of falls, bumping into furniture), changes in lifestyle and communication. Provide ongoing support as needed.
Psychological care

- Depression is very common among individuals with MS.
- The lifetime prevalence for major depression in MS is over 50%.
- MS patients at greater risk of depression are those with shorter disease duration (newly diagnosed), greater disease severity and less social support.
- The MS patient is most vulnerable to developing depression in the first two years after diagnosis and at times of disease progression.

Nursing care

Assessment:
The nurse will adequately assess the patient’s psychological function and report any changes to the medical team. Please see section on clinical measures for some assessment tools used.

Plan:
Set agreed and achievable goals to allow the person with MS and nurse to plan to take action on the issues of depression raised during the assessment process.

Intervention:
Administer prescribed medication and evaluate effectiveness. The nurse may assist members of the multi-disciplinary team and the patient and family with non-pharmacological programs for depression. The nurse will help to reduce worries through advocating on behalf of the patient, will refer to social worker and MS support group. If appropriate the nurse will coordinate a package of care.

Evaluate:
The nurse in conjunction with the medical team and/or psychologist must include ongoing evaluation of the patient’s management strategies, to ensure they are effective and if not, investigate the reasons in conjunction with the patient and revise the plan of care.
Cognitive impairment

• Cognitive changes are common in MS; they occur in approximately 40–70% of individuals with MS.

• These include short term memory, reduced attention span, altered concentration, reduced speed of information processing, alteration in visuospatial perception and construction, and in the ability to perform calculations.

• The cognitive functions most commonly affected by MS are short term memory, attention span, concentration, speed of information processing, executive functions, visuospatial perception and construction, and the ability to perform calculations.

• In many instances, cognitive difficulties are incorrectly attributed to depression or other emotional disturbances. However, proper identification of cognitive problems is necessary for the development of appropriate management and treatment strategies.

Nursing care

Assessment:
The nurse should educate the individual about any assessment tests (if necessary), reassure the patient that there is no pass or fail and that these results will assist the neurologist and / or psychologist to determine the cognitive areas the patient may need assistance with. Please see the clinical measures section for some of the assessment tools used.

The nurse will identify possible contributing factors by discussion of same with the patient. Factors may include fatigue, pain, stress and other MS related symptoms.

Plan:
Set agreed and achievable goals to allow the person with MS and nurse to plan to take action on the issues of cognitive impairment raised during the assessment process.
**Intervention:**
Assist in the implementation of practical tools which may aid the person with MS in carrying out daily activities which may have been affected by changes in cognition, for example reminders in familiar locations around the house. An occupational therapist may be able to assist in this case.

**Evaluate:**
The nurse in conjunction with the medical team and/or psychologist must include ongoing evaluation of the patient’s management strategies, to ensure they are effective and if not, investigate the reasons in conjunction with the patient and revise the plan of care.
Section 6

Other supports available
Benefits & Entitlements for people with MS in Ireland

People with MS may be entitled to some of the following benefits. However, many of these are means tested. Please refer to the following webpage from The MS society of Ireland, where each of the available benefits are explained with links to specific websites;

http://www.ms-society.ie/pages/benefits-and-entitlements-

- Disability Benefit
- Disability Allowance
- Working and Claiming a Disability Payment
- Disablement Benefit and unemployed Supplement
- Motorised Transport grant - fully explained at the following link: http://www.hse.ie/eng/services/Find_a_Service/lho/CavanMonaghan/Disability_Services/
- Mobility Allowance fully explained at the following link: http://www.hse.ie/eng/services/Find_a_Service/lho/CavanMonaghan/Disability_Services/
- Exemptions / refunds for Disabled Drivers / Passengers
- Disabled Person’s Parking Card
- East / West Link Toll Charges
- Reorganisation of Services for People with Disabilities
- Primary Medical Certificate – for severely disabled people, fully explained at the following link: http://www.hse.ie/eng/services/Find_a_Service/lho/CavanMonaghan/Disability_Services/

Carers

- Carers Allowance
- Respite Care Grant
- Free Travel
- Companion Pass
Benefits under EU Regulations and bilateral Social Security Agreements

- EU Regulations
- Transferring UK Disability Benefits to Ireland
- Bilateral Social Security Agreements

Health Services

- MedicalCard: [http://www.hse.ie/eng/services/Find_a_Service/entitlements/Medical_Cards/](http://www.hse.ie/eng/services/Find_a_Service/entitlements/Medical_Cards/)
- Drug Payment Scheme: [http://www.hse.ie/eng/services/Find_a_Service/entitlements/Drugs_Payment_Scheme/](http://www.hse.ie/eng/services/Find_a_Service/entitlements/Drugs_Payment_Scheme/)
- Medical Card Income Guidelines
- VHI: [https://www.vhi.ie/](https://www.vhi.ie/)
- Free Travel to health services
- Prescribed Drugs and Medicines
- Dental, Optical and Aural Services
- Aids and appliances
- Disability Resource Centre
- Long-stay nursing home
- Nursing Home Subvention
Community Care Services

- MS Society: http://www.ms-society.ie/
- Irish Wheelchair Association: http://www.iwa.ie/
- Centre for independent living (CIL)
- Public Health Nurse / Community registered general nurse
- Home Help / Health care assistants
- Social workers
- Occupational Therapies
- Physiotherapist
- Dietician
- Speech and language therapist
- Other community services
- Respite Care
- Personal Assistant Services

Citizens Information Centre (CIC)

Citizens information centre provides free, confidential and impartial information on any subject to anyone who asks. There are over 80 Centres around the country. Information is supplied on topics such as income tax, health services, redundancy, housing etc. http://www.citizensinformation.ie/en/

Suggested Reading

Section 7

Suggested additional reading
SUGGESTED ADDITIONAL READING

The information in this handbook was elicited from a variety of both national and international sources including textbooks, articles, websites and guidelines, all of which are found in ‘Multiple Sclerosis Specialist Nursing in Ireland: A guide to best practice 2nd edition, 2012’.


MS Trust (2011) Multiple Sclerosis Information for health and Social Care Professionals, 4th ed. Hertfordshire


The United Kingdom MS Clinical Management Manual, 2006

The MS Society of Ireland (2000) Diagnosed with multiple Sclerosis, 2nd ed. Dublin, Ireland

For information on medications for MS:

http://www.medicines.ie/

http://www.imb.ie/

http://www.medicinescomplete.com/mc/bnf/current/
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Glossary of terms
GLOSSARY OF TERMS

ABA  An Bord Altranais
BMI  Body mass index
BDI  Beck Depression Inventory
CIS  Clinically isolated syndrome
CNS  Central nervous system
CNSp  Clinical nurse specialist
CRGN  Community registered general nurse
CSF  Cerebrospinal fluid
DMT  Disease modifying therapy
EDSS  Expanded disability status scale
GP  General Practitioner
IPHA  Irish Pharmaceutical Healthcare Association
IFNb  Interferon beta
IVIG  Intravenous immunoglobulin
IV  Intravenous
LFT  Liver function test
LP  Lumbar puncture
MDT  Multidisciplinary team
MFIS  Modified fatigue Impact scale
MHI  Mental Health Inventory
MoCa  Montreal cognitive assessment
MRI  Magnetic resonance imaging
MS  Multiple Sclerosis
MSQoLi  Multiple Sclerosis quality of life inventory
MUST  Malnutrition universal screening tool
OCBs  Oligoclonal bands
OT  Occupational therapist
PASAT  Paced auditory serial addition test
PCT  Primary care team
PHN  Public Health Nurse
PML  Progressive multifocal leukoencephalopathy
PPMS  Primary progressive multiple sclerosis
PRMS  Progressive relapsing multiple sclerosis
RIS  Radiological isolated syndrome
RRMS  Relapsing remitting multiple sclerosis
SGOT  Serum glutamic-oxaloacetic transaminase
SGPT  Serum glutamic-pyruvic transaminase
SPMS  Secondary progressive multiple sclerosis
VEPs  Visual evoked potentials
Useful websites

MS society of Ireland - http://www.ms-society.ie/

UK MS society - http://www.mstrust.org.uk/

http://besthealth.bmj.com/x/topic/392732/essentials.html

Canadian MS society - http://mssociety.ca/en/