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The Australian Multiple Sclerosis Nursing Manual was adapted from both the Canadian MS Nursing Care Plan and the United Kingdom Multiple Sclerosis Clinical Management Manual. Both these plans are recognised internationally as excellent educational resources in clinical practice and the nurses in Australia, who have contributed to this manual, are grateful to the Canadian and the United Kingdom groups who helped facilitate this adaptation.

The philosophy behind this Manual is to share evidence-based practice. Evidence-based practice should be the common denominator of multiple sclerosis (MS) nursing in the 21st Century. It is hoped that the content of this manual will help facilitate this.

The Manual is designed to help MS nurses in hospital or community settings. It may act as a reference point for experienced MS nurses, or as a structured teaching tool for less experienced nurses. Its application extends beyond the MS nursing team. It is envisaged that it will act as a useful resource to doctors, research fellows, and other members of the multidisciplinary team in a variety of care environments.

The Australian Multiple Sclerosis Nursing Manual will provide you with background information on MS, the nervous and immune systems, how the disease is diagnosed, as well as the various agents used in the treatment of MS. This Manual will also provide you with guidelines for the management of MS-related signs and symptoms, and lifestyle implications related to MS. In addition this Manual includes a module on the diverse roles of MS nursing and ends with a module on research.

This Manual is divided into nine modules; and modules one to seven are further divided into sections. Each section opens with a brief introduction and a list of learning objectives that highlight the topics to be covered. Where relevant, each module will end with a page of useful websites for further information and reading. This is the second edition of the Manual published in 2008, the first edition was published in 2004. The authors and reviewers are listed in the Acknowledgments, and their individual contributions are listed on the module title pages.

Note: At the end of this Manual there is a glossary and relevant appendices (modules eight and nine, respectively) containing resources and clinical tools that may assist you in your practice.
Multiple sclerosis (MS) is the most common serious chronic neurological disorder with an unpredictable course for which there is no cure.\(^1\) It is the most common cause of neurological disability in young adults; it usually begins between the ages of 20 and 40 and is nearly three times as common in women as in men.\(^1\) It is often diagnosed at a time when family and job responsibilities are most demanding.\(^2\)

MS can cause an unpredictable and diverse range of neurological impairments that are unique to each individual.\(^1,2\) Since damage can affect any part of the central nervous system, it can cause a variety of distressing symptoms including fatigue, visual disturbances, urinary and faecal incontinence, spasticity, tremor, pain, sexual dysfunction, depression, cognitive dysfunction and mobility problems.\(^1,2\)

Often people with MS experience many symptoms concurrently.\(^1,2\) \(90\%\) of people with MS experience relapses at the early stage of the disease and the majority will go on to develop progressive disability.\(^1,2\)

Relapses can be minor episodes that resolve spontaneously with no intervention, but may be severe profoundly disabling episodes, that require treatment.\(^1,2\)

Both people with MS and clinicians consider that it is important to reduce the number of relapses, or at least treat to reduce severity and duration.\(^1,2\)

The diverse and unpredictable nature of MS makes it one of the most difficult neurological diseases with which to cope.\(^1,2\) It is now recognised that people with MS need to adjust to changes whilst attempting to normalise their lives and social interactions.\(^1,2\) They require support, education and guidance in order to adapt effectively to the changes enforced by the disease.\(^1,2\)

The most dynamic changes in care have occurred at the diagnostic and minimal impairment stages.\(^1,4\) The arrival of disease-modifying drugs in the late 1990s changed the delivery of care to people with MS worldwide as they provided the first opportunity to directly influence the disease process. In addition, the introduction of diagnostic criteria may result in an increase in the number of patients diagnosed and linked into MS Services each year.\(^3,4\)

Although the delivery of disease-modifying drugs is a significant part of MS management, it is important to acknowledge that it is only one aspect of managing this chronic disease.\(^1\) Indeed, there are a number of key areas to MS management, each of which are distinct and important.

References

Without the following contributors, the review and development of this manual would not be possible. Serono Symposia International would like to thank all contributors for their expertise and input in sharing their knowledge in the management of people with MS in Australia. Individual contributions to both editions are listed on the title pages of each module. Serono Symposia International would especially like to thank and acknowledge the members of the Canadian MS Nurses’ Network and the United Kingdom Multiple Sclerosis Specialist Nurse Association for allowing the adaptation of The Canadian MS Nursing Care Plan and The United Kingdom MS Clinical Management Manual, respectively, for the development of the Australian Multiple Sclerosis Nursing Manual.

Second Edition

The second edition would not be possible without the contribution of the Editorial Committee. Their extra effort and time spent in sourcing contributors to update the first edition, adding their own contributions and peer reviewing others, are greatly acknowledged.

Serono Symposia International and the Editorial Committee gratefully acknowledges the input of Dr Julian Henwood from PharmaGuide. We would like to thank Julian for his commitment and expertise as Medical Writer and Editor of the manual. We would also like to thank Julian for his guidance through the revision and development of the second edition.

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In addition, the input of Janine Stovold from Serono Symposia International, as project coordinator for both the first and second editions, is gratefully acknowledged.
Sponsor’s Foreword

Merck Serono congratulates the Editorial Committee on the launch of the second edition of the Australian Multiple Sclerosis Nursing Manual.

Merck Serono has a long-term commitment to the development of innovative treatments to help manage MS. Merck Serono is proud to continue a tradition of support for MS nurses, such as an educational grant for the development of both editions of the Australian Multiple Sclerosis Nursing Manual. In providing on-going support for this, the second edition, Merck Serono acknowledges the essential contribution made by nurses to the MS community in Australia. We look forward to an on-going partnership with MS nurses with the aim of enhancing the quality of life of people with MS in Australia.
Supporting Organisations

The following organisations support the publication of this manual as a useful educational resource for nurses and allied health professionals caring for multiple sclerosis patients in hospital and community settings. On behalf of the Editorial Committee and contributing nurses, Serono Symposia International would like to thank each organisation for this support and acknowledge their names alphabetically as follows:

ANF (Australian Nursing Federation)
www.anf.org.au

Australasian Neuroscience Nurses’ Association
www.anna.asn.au

IOMSN (International Organisation of MS Nurses)
www.iomsn.org

MS Health Professional Network
www.mshpn.com.au

MS Nurses Australia Incorporated
www.msnainc.com.au
Multiple Sclerosis Australia (MS Australia)
www.msaustralia.org.au

Multiple Sclerosis Australia delivers services to people with MS via state based MS Societies:

- MS Australia ACT/NSW/VIC, www.mssociety.org.au
- MS Society of SA & NT, www.ms.asn.au
- MS Society of Western Australia, www.multiple-wa.asn.au

Neuroscience Trials Australia
www.neurotrialsaustralia.com

RCNA (Royal College of Nursing Australia)
www.rcna.org.au
1. Overview of MS

Introduction

Multiple sclerosis (MS) is thought to be an autoimmune-mediated and inflammatory disease of the central nervous system that usually presents with a history of an acute onset of neurological symptoms (attack, relapse or exacerbation), or with progressive neurological impairment. The cause of this disease is unknown although, in general, it is believed that viral infection – some specific viruses have been identified as potential causative agents – with other environmental factors, may trigger an autoimmune reaction in a genetically susceptible individual.

The disease affects people almost worldwide, although there is an established epidemiological variation indicating that a higher prevalence is associated with an increasing distance from the equator. It is now generally accepted that MS is an autoimmune disease and, as is characteristic of autoimmune disorders, it is more common in women than men at a ratio of approximately 3:1. 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. Although MS can occur at any age, it is most likely to be diagnosed in a young adult, aged 20-40, and is one of the most common causes of disability among adults of working age.

Common symptoms include difficulty walking, difficulties with bladder/bowel control and sexual function, numbness, pain and other abnormal sensations, temporary blindness or blurred vision, and extreme fatigue (see Module 4 for further discussion). Typically, when MS starts, there are distinct attacks – perhaps one or two a year – from which the patient may make a full recovery. As the disease progresses, recovery from attacks may not be complete and there is a gradual accumulation of disability.
1.1 MS Profile

1.1.1 Classification

In clinical practice, it is often impossible to put an individual into a particular disease category or classification. MS shows individual variability and patients rarely fit neatly into clinical categories. As a consequence, it is essential that due care is taken when discussing disease types and ensuring that the patients realise that their relapsing-remitting MS, for example, will not take on the same course as someone else’s. Not all people with MS will reach the same level of disability, and there can be wide variations in prognosis and functional difficulties between individuals.

Even as healthcare professionals, describing the clinical course of MS is often difficult and the terminology itself can cause difficulties. Lublin and Reingold recognised this and carried out an international survey of MS Neurologists with the aim of establishing an agreement pertaining to the various descriptive terms currently in use. Their survey supplied the following definitions of disease courses and types:

- Relapsing-remitting MS (RRMS)
- Secondary-progressive MS (SPMS)
- Primary-progressive MS (PPMS)
- Progressive-relapsing MS (PRMS)

Figure 1-1 illustrates the clinical course of disease at diagnosis and 11–15 years after diagnosis.

Figure 1-1. The clinical course of MS over time.

### LEARNING OBJECTIVES

After completing this section, the reader will be able to:

- Describe the common types of MS as well as benign MS, Malburg’s variant of MS, Neuromyelitis Optica and Clinically Isolated Syndrome
- Discuss the difficulties associated with disease classification
- Understand the prevalence and distribution of MS
- Discuss the importance of ‘twin studies’ in MS
- Discuss the risks involved if one family member develops MS
- Understand the economic implications of MS in Australia
Relapsing-Remitting Multiple Sclerosis (RRMS)

The majority of patients (85%) present with the relapsing-remitting form of the disease. A relapse is an acute episode of neurological symptoms that worsen for some days and then improve or completely subside over time. For clinical trials, a relapse lasts at least 24 hours in the context of a normal body temperature (a normal body temperature is essential as there is a syndrome called Uhthoff’s phenomenon, which can occur in MS and is associated with hyperthermia, resulting in a reduction of visual acuity). A period of 30 days should separate the onset of two events for them to be distinguished as separate attacks. The person may not experience a full recovery from their relapse, but relapses are clearly distinguishable from periods of remission and during remission there is characteristically a lack of disease progression (see Figure 1-2).

RRMS varies greatly in severity from individual to individual. The annual relapse rate initially averages about 2-2.5, and thereafter will gradually fall as the years progress. It is considered a poor prognostic sign if the person experiences frequent relapses, especially at the onset of the disease.

Secondary-Progressive Multiple Sclerosis (SPMS)

An initial relapsing-remitting nature tends to develop into a steadily progressive phase of the disease. 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 (see Figure 1-2). 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.

After 11-15 years, approximately 42% of people with RRMS will enter the secondary-progressive phase of the disease (see Figure 1-1). The Kurtzke Expanded Disability Status Scale (EDSS) can provide the Neurologist with an indicator of whether the patient is entering the secondary-progressive phase of the disease (EDSS; see Appendix A). Weinshenker et al state that patients at 4.0-5.5 on the EDSS scale are those most at risk of developing SPMS.
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 (see Figure 1-2). The unique clinical characteristics of this form make its diagnosis difficult. Typically, patients will be at a later age of onset, experiencing their first symptoms in their 40s 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 6.0 is approximately 6 years. Diagnostic criteria for definite PPMS include clinical progression for at least a year. The MRI of the brain can look normal as the plaques characteristically form in the spinal cord. Consequently, it is essential for a patient to have a spinal MRI in order to diagnose progressive MS.

Progressive-Relapsing Multiple Sclerosis (PRMS)

This form of MS follows a progressive course from onset, punctuated by relapses. There is significant recovery immediately following a relapse but between relapses there is a gradual worsening of symptoms. Identifying this type of MS has important implications for treatment.

1.1.2 ‘Other’ Forms of MS

Benign MS

There is increasing controversy regarding whether this particular category of MS truly exists. In benign MS, there is complete recovery from isolated attacks, with little or no accumulation of disability. The attacks may be separated by 10 or more years. Typically, patients with benign MS have a Kurtzke EDSS score of less than 3.0. A score of 3.0 indicates moderate disability in one functional system or mild disability in three or four functional systems though the patient is fully ambulatory.

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

Malignant MS (Marburg’s variant)

In addition to the five types above, there is a variant known as malignant MS. This is a rare and severe form characterised by multiple large lesions scattered throughout the CNS. The demyelination and loss of axons is much more extensive and result in a rapid accumulation of significant disability. It is such an atypical form that diagnosis is often very difficult. However, it will generally progress rapidly without any lasting remission and results in death within months of onset.

Neuromyelitis Optica (NMO/Devic’s Disease)

Neuromyelitis optica (NMO; also known as Devic’s syndrome or Devic’s disease) is an inflammatory disorder with a preference for the optic nerves and spinal cord. Acute transverse myelitis is often its initial manifestation. The principal features of NMO (optic neuritis and myelitis) and tendency to recurrence led to its classification as a subtype of MS, but it has several unique features. Devic’s syndrome consists of one or more clinical episodes of optic neuritis in combination with myelitis. These clinical events also occur commonly in typical MS, however, in NMO they are usually more acute (sometimes fulminant) and severe; these characteristics may raise initial diagnostic suspicion of NMO.

Neuromyelitis optica may follow either a monophasic or relapsing course. In monophasic NMO, patients experience either unilateral or bilateral optic neuritis (ON) and a single episode of myelitis, characteristically but not always, within a very short time of one another, but do not have further attacks. In contrast, patients with a relapsing course continue to have discrete exacerbations of ON and/or myelitis after they meet NMO diagnostic criteria (see also 4.7 Vision).
Clinically Isolated Syndrome (CIS)

A clinically isolated syndrome (CIS) is a neurological episode, lasting at least 24 hours, caused by inflammation/demyelination in one or more sites in the CNS. A person with CIS can have a single neurologic sign or symptom – for example, an attack of optic neuritis – caused by a single lesion (monofocal), or more than one sign or symptom – such as, an attack of optic neuritis accompanied by weakness on one side – caused by lesions in more than one place (multifocal).\(^{16}\)

Individuals who experience a clinically isolated syndrome **may or may not** go on to develop MS. It is important to note here that a person with CIS **does not** meet the diagnostic criteria for MS. However, studies have shown that when CIS is accompanied by MRI-detected brain lesions that are consistent with those seen in MS, there is a high risk of a second neurologic event, and therefore a diagnosis of (definite) MS, within several years. Individuals who experience CIS with no evidence of MRI-detected lesions are at a relatively low risk of developing MS over the same time period.\(^{16}\)

1.1.3 Prevalence

The distribution of MS varies throughout the world and appears to be related to geographical location and genetic background. Areas with high rates of MS include Australia, New Zealand, North America, and Northern Europe (see Figure 1-3).\(^{17}\) Worldwide, MS is more common in cooler climates and most MS in Australia occurs in Tasmania and Victoria. For example, MS is about 7 times more frequent in Hobart than in tropical Queensland.\(^{18}\) The prevalence of MS appears to be increasing, and a study in Newcastle from 1961 to 1996 has shown an increase, particularly in women, from 19.6 to 59.1 per 100,000 of population, and a significant increase in incidence from 1.2 to 2.4 per 100,000.\(^{19}\) Many factors have changed over the last 4 decades, such as more neurologists, increased awareness, greater propensity to seek medical help, more MRIs and greater diagnosis.

Figure 1-3. Worldwide prevalence of MS.\(^{17}\)
1.1.4 Distribution geography

Both environmental and genetic factors contribute to the aetiology of MS, and genetic factors contribute to MS susceptibility. MS is particularly prevalent in people from Northern Europe and their descendants, including those living in Australia, New Zealand and North America. It has been suggested that MS is more frequent in areas settled by Vikings and Goths and that migrants from these areas took this susceptibility throughout Europe, the New World, South Africa, Australia and New Zealand. MS is unevenly but non-randomly distributed throughout the world, and environmental factors play a significant role in the onset of MS.

Other prevalence rates are as follows:

- United Kingdom: 80-250 per 100,000
- Scandinavia: 32-93 per 100,000
- Northern United States (above 37°N): 69 per 100,000
- Asia, Africa, South America: 5 per 100,000
- Canada: 150-200 per 100,000

Within Caucasian populations, MS occurs more frequently in countries or regions of northern latitudes in the Northern Hemisphere and in those of southern latitudes in the Southern Hemisphere.

A study by Rothwell and Charlton suggests that the Orkney and Shetland Islands and South East Scotland have the highest prevalence rates in the world.

Race

MS affects Caucasians more than other races. It was virtually unknown among black Africans, although, of late, there are now increasing reports amongst these people. Migration studies are particularly interesting when studying the cause of MS. The potential for developing MS may be established in early life. 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 or she will assume the low risk potential.

Age

Although MS can occur at any age, the average age at diagnosis is approximately 30 years worldwide (see Figure 1-4). Childhood MS is rare (less than 4% of cases), and their presentation is generally one of relapses of sensory symptoms, with a relapsing-remitting course in most.

---

**Figure 1-4. Age-specific incidence of MS (women).**

Gender

Like the majority of other autoimmune diseases, MS predominately affects women. The ratio of women to men is approximately 3 women to 1 man. The only exception to this is PPMS in which the female preponderance is absent. The disease tends to be more severe in men and the male gender is typically associated with a poor prognosis.10

1.1.5 Genetics

Some specific gene markers have been identified as possible causative genes in MS, although their consistency across the MS population has yet to be established. Patients may ask for genetic counselling if they are planning to become pregnant, but because of the complexity of genetic control, any form of genetic screening or counselling is difficult.

The rate of MS among family members of an individual affected by the disease is higher than would be expected by chance, eg 20% of people with MS have a family history.21 However, this cannot be entirely attributed to genetics, as most family members share a similar environment and lifestyle.

One of the most common questions a newly diagnosed patient will ask, “Is MS inherited?” When counselling MS patients and their relatives it should be explained that the risk for first-degree relatives of people with MS is greater than the risk to second-degree relatives. Overall, siblings have the highest age adjusted risk followed by parents then children then uncles, aunts and cousins.26

One UK study27 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%.

Twins

In theory, if genes were solely responsible for determining the risk of the development of MS, then it would follow that if one monozygotic twin were diagnosed with MS, then there would be a 100% chance of the other twin also developing the disease. In fact this is not the case. In a Canadian study of twin pairs, Sadovnick et al28 followed up their study group for 7.5 years. They discovered the concordance rate is approximately 30% in monozygotic twins, which contrasts with the rate in dizygotic twins of approximately 4.7%. This is roughly the same risk as in non-twin siblings.

1.1.6 Economic impact

In 2005, MS Australia commissioned Access Economics to undertake an economic evaluation of the cost of MS in Australia.2 The report found that MS costs Australia nearly $2 billion a year in direct financial and other costs. The report confirms that the national financial cost of the disease is over $600 million every year. Nearly half (43%) is the cost of informal care. Lost productivity contributes $160 million. The lost value of healthy lives adds a further $1.3 billion.2

The report entitled Acting Positively: Strategic Implications of the Economic Costs of Multiple Sclerosis in Australia, revealed that Australians with MS are paying $160 million out of their own pockets to cover medication and tests, doctors’ fees, hospital stays, medical products and wheelchair modifications to home and car. When these personal costs are added to the community and government cost of $500 million for medical treatment, nursing home care, and sick leave from work and early retirement, the final figure is a growing concern.2

The report also highlights that MS is pushing young people into nursing homes and full time workers into part time or no work, and that some suitable pharmaceuticals are not PBS listed for the disease, for example new generation medications for bladder, fatigue and spasticity management.
A summary of key issues of greatest cost identifies:²

Loss of productive capacity

- During 2007, 3,200 people with MS will not be able to participate in the workforce.
- The annual lost production cost from reduced hours, early exit from the workforce and temporary absence is $160 million.
- The number of people with MS who work part-time is disproportionately high.

Growing informal care costs

- Informal carers provide an average 12.3 hours a week to people with MS.
- The cost of replacement care is $260 million (43% of the financial cost of MS).
- The disease’s increasing severity over time requires increased informal care.

Areas of greatest challenge:²

Work and family

- Using health management, employment policy and responsive welfare to keep people well, working and with their families for as long as possible.
- Providing policy and income support to people who have reduced earning capacity and higher costs because of their MS.

Support for informal carers is a priority

The replacement cost of informal carers is a quarter of a billion dollars. The cost of replacement residential care would be 60% higher.

Medical research

- Government spends less than the national health average on MS research.
- More MS research funds come from the USA than from governments in Australia.
- In 2006, the Prime Minister launched MS Research Australia, which requires $30 million over four years to deliver better treatments and products.

Health and long-term care

- There are too many young people with MS in nursing homes.
- People with MS use many parts of a health system that requires improved coordination of services.
- People need effective access to some pharmaceuticals currently not PBS-listed for MS, for example new generation medications for bladder, fatigue and spasticity management.
1.2 The Nervous System

Introduction

The CNS pathology of MS is characterised by the breakdown of the blood-brain barrier followed by inflammation and then neuronal damage. The myelin sheath and the axons are the primary target of the inflammation. Myelin is a fatty coating of the nerve axon and has an insulating effect, enabling electrical impulses to move faster from the brain to the rest of the body and back again. If the myelin is damaged there will be a disturbance of information as it travels along the axons. There is increasing evidence that without the myelin to protect them, the axons themselves will become damaged and can either break or disintegrate. Axonal loss leads to permanent disability.

1.2.1 CNS

MS is a disease of the CNS; the CNS consists of the brain (ie brain stem, mid brain, cerebrum, cerebellum) and spinal cord (see Figure 1-5). The peripheral nervous system consists of 12 pairs of cranial nerves that radiate from the brainstem and 31 pairs of spinal nerves that arise from the spinal cord. These nerves reach every part of the body.

The central and peripheral nervous systems consist of networks of neurons (nerve cells). The peripheral nervous system consists of sensory and motor neurons. Sensory neurons respond to stimuli (eg heat, pain, colour, etc) and send impulses to the CNS. Motor neurons transmit messages in the other direction, from the CNS to the peripheral organs and tissues. Therefore, in reality, peripheral nerves are actually bundles of both sensory and motor neurons.

LEARNING OBJECTIVES

After completing this section, the reader will be able to:

- List the components of the CNS
- Describe the function of sensory, motor, and association neurons
- Describe the structure of neurons
- Explain the function of myelin
- List and describe three important types of glial cells

Figure 1-5. The central nervous system.
Module 1 - Overview of MS

Association neurons
Most of the neurons in the CNS are association neurons that transmit impulses between other neurons.

The sensory neuron responds to a stimulus such as heat and sends an impulse to an association neuron in the CNS. The association neuron, in turn, activates the motor neuron, which causes particular muscles to contract (e.g., muscle contracts to withdraw hand from a hot plate). Figure 1–6 illustrates the relationship between sensory, association, and motor neurons.

Components of a neuron
Dendrites conduct impulses to the cell body; the axon conducts impulses from the cell body (see Figure 1–7). Most axons are covered by a layer of myelin. Myelin is a complex, fat-like substance that insulates the axon. Damage to the myelin sheath and the underlying axon causes the symptoms of MS.

The CNS is not made up entirely of neurons: 40% of the total volume consists of neuroglia or glial cells (glia is the Greek word for glue).

Figure 1–6. The relationship between sensory, motor and association neurons.

Figure 1–7. Structure of a typical neuron.
Neuroglia

Neuroglia consist of three important types of cells: oligodendrocytes, astrocytes and microglia (see Figure 1-8).

Oligodendrocytes synthesise myelin. Each oligodendrocyte has many processes or radiations that wrap themselves around short sections of nearby axons. A single oligodendrocyte usually encloses multiple axons in the central nervous system (CNS), whereas in the peripheral nervous system (PNS) each Schwann cell typically myelinates a single axon. While doing so, these radiations also produce layers of myelin. Therefore, the myelin sheath of an axon is not continuous, but rather is made up from the radiations of many oligodendrocytes, with short lengths of non-myelinated axon between them (see Figure 1-8). These unmyelinated regions are referred to as the nodes of Ranvier.

Astrocytes are star-shaped cells that provide the CNS with its physical structure. Some astrocytes have radiations that are in contact with the endothelial cells of cerebral blood vessels, helping to maintain tight junctions between them and thereby excluding large circulating cells. This is the main factor that constitutes the blood-brain barrier and normally prevents circulating cells from coming into contact with CNS neurons and neuroglia. In MS, this barrier is breached.

Microglia cells have the same precursors as circulating macrophages and fulfil similar functions – digestion of cellular debris and foreign matter. In MS, the function of microglia is corrupted, causing them to attack and destroy myelin.

Myelin

Nerve impulses are created by small amounts of electricity flowing along neurons. Myelin acts to insulate the neuron from this flow of electricity. When impulses flow along myelinated axons, the impulses jump over the myelinated areas from one node to the next. This makes the flow of impulses faster and more energy-efficient than in non-myelinated axons.

As well as helping the flow of nerve impulses, myelin and oligodendrocytes provide axons with physical support (literally holding them in place and helping preserve their structure) and functional support (by producing chemicals that keep the neurons functioning properly).
Grey and white matter

To the naked eye, some of the CNS looks grey, and some of it looks white – hence the terms “grey matter” and “white matter.” Grey matter is a mass of neuronal cell bodies and dendrites. White matter includes bundles of myelinated axons. The same neuron can have its cell body in grey matter and its axon in white matter.

The cerebrum consists of a thick outer layer of grey matter known as the cortex, which covers an inner core of white matter. An H-shaped core of grey matter runs through the middle of the spinal cord and is surrounded by white matter (see Figure 1-9).

Reflex arc

The white matter of the CNS consists of tracts. These tracts are comprised of bundles of myelinated axons that serve similar functions, just as a telephone cable is a bundle of individual telephone wires following the same route. In fact, the white matter is like the “long-distance cabling” of the CNS. There are sensory tracts, conducting impulses to the centre, and motor tracts, conducting impulses from the centre. Two examples of tracts include the pyramidal tract (a long motor tract that is involved in the voluntary, skilled movements of skeletal muscles such as writing, playing tennis, etc) and the extrapyramidal tract (regulates muscle tone, posture, and walking).

A reflex is a direct connection between stimulus and response that does not require conscious thought. They are simple automatic responses and involve either spinal or cranial nerves. A reflex arc is the simplest functional unit of the nervous system, involving the complete pathway of neurons from the receptor, which receives the stimulus, to the effector that produces the response (see Figure 1-9).

Further reading

Topics in Multiple Sclerosis (1)
An Immunological Perspective

Available online at:
www.mscolloquium.org/pdfs/An Immunological Perspective.pdf
References


Module 2  
Diagnosis

Second edition
Contributions by: Emma Christian, Jennifer Coleman and Melanie McMurtie
Reviewed by: Jennifer Coleman and Sue Shapland

First edition
Contributions by: Penny Martin, Surekha Mistry, Louise Rath and Suzanne Vanselow
2. Diagnosis

Introduction

Despite advances in technology, the most important requirement in determining a diagnosis of multiple sclerosis (MS) is the evaluation, ideally by an experienced neurologist, of a person’s history and clinical presentation. Diagnosis is heavily reliant on the skill of the neurologist in taking and interpreting the person’s medical history, conducting a neurological examination and interpreting magnetic resonance imaging (MRI) and other paraclinical evidence – including that obtained from lumbar puncture and evoked potentials.

A diagnosis of MS requires evidence of lesions that occur in more than one site in the central nervous system (ie they are disseminated in space) together with evidence that these lesions have emerged at different times (ie they are disseminated in time). This may be exhibited clinically or paraclinically. Differential diagnoses are systematically considered in order to fulfil the diagnostic criterion that a more likely diagnosis should not account for the findings.

It is appropriate to conceptualise a diagnostic phase as all the necessary evidence is accumulated and processed. A diagnosis of MS (or potential diagnosis) evokes an array of emotional responses, such as shock, fear and grief.

The role of the MS nurse is, effectively, to ease the person’s movement through this emotional roller coaster. With timely provision of advice, support, education and counselling, the MS nurse plays a crucial role throughout the diagnostic phase. The contents of this module will equip the MS nurse with knowledge to facilitate and enhance this role.
Introduction

The clinical presentation of MS can present a number of diagnostic challenges to the clinician. There is no single sign or symptom that is specific to MS and, to further complicate matters, there are a variety of presenting symptoms. In the early stages of the disease, MS signs and symptoms are frequently transitory and, therefore, may not be readily detectable by the clinician. Diagnosis of MS is dependent on the thorough evaluation, ideally by an experienced neurologist, of clinical, radiological and laboratory findings. Overall, the classical MS diagnostic criteria that are applicable are evidence that lesions in the central nervous system (CNS) are:

1. Disseminated in time
2. Disseminated in space
3. Attributable to no more likely diagnosis

2.1.1 History-taking and neurological examination

The assessment of a person for a diagnosis of MS begins by taking a detailed medical and psychosocial history. A neurological examination is then performed. These processes may identify characteristic signs and symptoms, which can be taken as evidence of lesions in specific functional systems of the CNS:

- Visual disturbances, such as unilateral loss or impaired sight and pain behind the eye are evidence of an optic-nerve lesion
- Muscle weakness and paralysis of one or more limbs are termed pyramidal symptoms, and are evidence of a pyramidal-tract lesion; abnormal reflexes may also indicate pyramidal-tract lesions
- Unsteadiness of gait or poor coordination (cerebellar symptoms) are evidence of a lesion in the cerebellum
- Involuntary eye movements (nystagmus), difficulties in articulating speech, and swallowing problems are evidence of a brain-stem lesion
- Spastic paraparesis is evidence of a spinal lesion
- Pain or altered perceptions of touch, or position, suggest impaired sensory functioning
- Bowel and bladder function disturbances suggest spinal lesions
- Mood and intellectual capacity reflect cerebral function and also refer the person for paraclinical investigations.

LEARNING OBJECTIVES

After completing this section, the reader will be able to:

- Understand what the neurologist is looking for when they meet a person suspected of having MS
- Describe some of the signs and symptoms of people with MS
- List some of the differential diagnoses
2.1.2 Differential diagnoses

Other more likely diagnoses must be excluded in reaching a diagnosis of MS. Neurological conditions that may mimic MS include migraine and neuropathies such as Chronic Inflammatory Demyelinating Polyneuropathy (CIDP). Differential diagnoses are not limited to the nervous system and encompass, for example, vascular diseases such as stroke and vasculitis, and other autoimmune diseases such as Sjogren’s syndrome and systemic lupus erythematosus (SLE).³

Evaluation, by the neurologist, of the person’s clinical presentation will determine the need for and type of paraclinical investigations which may be appropriate.
Module 2 - Diagnosis

2.2 Paraclinical Investigations

Introduction

It is possible for MS to be diagnosed solely from clinical findings. Paraclinical investigations, however, can be employed when added certainty is desired or when a diagnosis is unclear. Three categories of investigation are commonly employed to complement the clinical picture, these being radiological (magnetic resonance imaging) electro-physiological (evoked potentials) and immunological (cerebrospinal fluid).4

2.2.1 Magnetic resonance imaging (MRI)

MRI is used both for diagnosing and monitoring MS, and its use is increasing as MRI technology advances. MRI uses a strong magnetic field and radio waves to visualize internal body tissues such as the brain and spinal cord. Manipulation of the timing and reading of radio waves and signals produces the so-called T1- and T2-weighted images of the brain and spinal cord which aid MS diagnosis and monitoring.

T2-weighted images reveal pathological changes but do not show if these are due to inflammation, oedema or demyelination; nor do they distinguish between old and new lesions. T1-weighted images can reveal ‘black holes’ which are lesions resulting from extensive tissue destruction. On a T1-weighted scan, intravenously injected contrast medium, gadolinium (Gd), will cross a damaged blood-brain barrier and enhance acute inflammatory lesions. In this way recently formed lesions can be distinguished from pre-existing ones; thus providing evidence of dissemination in time.

MRI may predict the risk of developing MS. Longitudinal studies of people who presented with a single episode of optic neuritis have shown that initial MRI-lesion number and load correlate strongly with both the risk of developing MS and future disability.6,7

If there are brain lesions on MRI, a person has a greater than 50% chance of developing MS; a person with four or more lesions has a greater than 90% chance of developing MS within 5 years; and a person with a normal MRI scan has a less than 20% chance of developing MS.6 The brain stem and peri-ventricular areas are the most common sites of MS lesions in the brain.

It is known that normal brain MRI scans are found in 5% of people with MS. According to Palace,8 this is more likely in people with mild or early relapsing-remitting disease. In primary-progressive disease, there is a likelihood that the brain MRI may be normal as this type of MS predominately affects the spinal cord. It is not unusual therefore, for both brain and spinal MRI scans to be carried out during the diagnostic phase.1,9

Although there is some correlation between MS relapses and the appearance of new lesions on MRI,10 it is also accepted that MRI scans may detect many more lesions than are apparent through clinical examination.11

LEARNING OBJECTIVES

After completing this section, the reader will be able to:

• Explain the roles of MRI and MRS
• Discuss the role of evoked potentials
• Understand the rationale behind a cerebrospinal fluid test
This demonstrates that CNS lesions can form without causing detectable signs or symptoms, and highlights the capacity of MRI to provide a more sensitive marker for disease activity than the logging of relapses or new symptoms. However, the relationship between MS lesions and the accumulation of impairment and the development of disability is poor. This is particularly evident in people who have primary-progressive MS, where there are few lesions seen on MRI, yet there is a steady accumulation of disability.

### 2.2.2 Magnetic resonance spectroscopy (MRS)

MRS can be used to detect cell damage in brain tissue that appears normal in MRI images. It does so by detecting reduced levels of N-acetylaspartate (NAA) – a finding that indicates damage to nervous tissue. Loss of NAA is not confined to damage caused by MS, so the current role of MRS in MS tends to be as a research tool.

### 2.2.3 Evoked potentials

MS affects the speed of nerve transmission: demyelination slows the conduction of nervous impulses. Evoked-potential tests are used to detect this delayed conduction, thus demonstrating demyelination. The evoked potentials measured can be visual (using an alternating black and white checkerboard pattern as stimulus), auditory, or somato-sensory. The optic nerve is frequently affected in MS, either clinically (optic neuritis) or sub-clinically and, of the evoked potentials, visual evoked potentials (VEPs) contribute the most in the diagnosis of MS.

Abnormal VEPs can supplement information about a person who is suspected of having MS by demonstrating demyelination of the optic nerve. When lesions have been demonstrated in other parts of the CNS, abnormal VEPs may confirm the diagnosis. The role of evoked potentials in diagnosing MS is their capacity to provide objective evidence of dissemination of lesions in time and space.

### 2.2.4 Cerebrospinal fluid testing

Laboratory testing of cerebrospinal fluid (CSF) obtained through lumbar puncture will reveal evidence of abnormal immunoreactivity within the nervous system of at least 95% of people who have MS. CSF abnormalities include elevated immunoglobulin (IgG) levels, increased IgG synthesis rate, and oligoclonal bands. A person is considered positive for CSF oligoclonal bands when bands are present in the CSF that are not also present in the blood serum. It is important to note, however, that oligoclonal bands and elevated CSF IgG are not MS-specific and may be present in a number of other neurological conditions.

**Acknowledgment**

Allen Burton, Radiographer-Manager, Department of Radiology, Austin Health, Victoria is acknowledged for the advice and information he contributed to this section.
2.3 Diagnostic Criteria & Categories

Introduction

The lack of a single test or clinical feature that can be entirely attributed to MS means there has been a need to develop diagnostic criteria to assist the neurologist in making the diagnosis. Schumacher\(^{16}\) established the first formal criteria, which were later updated by Poser et al in 1983.\(^{17}\) The Poser criteria pre-dated comprehension of the value of MRI data in MS diagnosis and did not, therefore, mention MRI in any significant detail; nor did the criteria account for the diagnosis of primary-progressive MS (PPMS). Subsequent increase in knowledge of both the disease process involved in MS and of MRI scanning led McDonald et al\(^{1}\) to again revise the diagnostic criteria for MS and simplify earlier classifications. The McDonald criteria published in 2001 have been validated in further studies\(^{18}\) and revised\(^{9}\) to facilitate further diagnostic efficiencies.

2.3.1 Clinically definite MS

Clinically definite MS requires two attacks (at least 24 hours in duration, at least 1 month apart) and clinical evidence of lesions in two places. The evidence can be obtained from examination or history. Alternatively, one of the two lesions can be evidenced by paraclinical investigations (MRI or evoked potentials).\(^{17}\)
2.3.2 McDonald Criteria

McDonald Criteria\(^1\) use clinical, laboratory and MRI data to arrive at a diagnosis of MS (Tables 2-1 and 2-2). At the end of diagnostic work-up for MS, under these criteria, the patient will either have:

- MS
- Possible MS (MS has not been confirmed, nor has it been excluded. The diagnostic issue is still open, awaiting evidence of dissemination in time and space)
  
  or

- Not MS (the diagnostic work-up has ruled out MS)

### Table 2-1. The McDonald Diagnostic Criteria.\(^1\)

<table>
<thead>
<tr>
<th>Clinical presentation</th>
<th>Diagnostic criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Two or more attacks plus clinical evidence of two or more lesions.</td>
<td>The clinical presentation is sufficient to make a diagnosis of MS.</td>
</tr>
<tr>
<td>Two or more attacks plus clinical evidence of one lesion.</td>
<td>There must be evidence of a second lesion in the brain or spinal cord. This could come from an MRI, a combination of MRI and CSF analysis, or another clinical attack. One attack, objective clinical evidence of two or more lesions. The two lesions must be shown to have developed at least three months apart from each other, or there must be clear evidence of a second clinical attack.</td>
</tr>
<tr>
<td>One attack, objective clinical evidence of one lesion.</td>
<td>There must be evidence of at least two lesions, or a second attack to confirm diagnosis.</td>
</tr>
<tr>
<td>Insidious neurological progression suggestive of MS.</td>
<td>This is the most difficult presentation for diagnosis and a combination of tests carried out over time is required, these include MRI, CSF, and VEP.</td>
</tr>
</tbody>
</table>

### Table 2-2. Revisions to the McDonald Diagnostic Criteria (for other revisions see original reference).\(^9\)

<table>
<thead>
<tr>
<th>Clinical presentation</th>
<th>Diagnostic criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>When there are no clinical attacks and one objective lesion (i.e. progression from the outset).</td>
<td>There must be one year of disease progression plus two of the following: positive brain MRI, positive spinal cord MRI or positive CSF.</td>
</tr>
</tbody>
</table>
2.3.3 Clinically Isolated Syndrome (CIS)

Clinically Isolated Syndrome (CIS) is a single clinical event that can be attributed to demyelination. A CIS may be:

- **Monofocal** – referable to one single site in the CNS (dissemination in space or time not demonstrated).
- **Multifocal** – referable to a number of sites in the CNS (dissemination in time not demonstrated).

CIS remains suggestive of MS until dissemination in space and time can be demonstrated.

The most common CIS presentations are:

- **Optic neuritis**
- **Long tract symptoms and signs**
- **Brainstem syndromes**

2.3.4 Primary-Progressive MS

The diagnosis in patients presenting with progressive disease takes considerable time and should only be made after a variety of other causes are ruled out, in particular spinal cord compression. The very fact that a delay occurs in the diagnosis of this particular pattern of the disease generally results in a clear picture of progressive deterioration. The patient tends to be in the more mature age range (over 50) and will generally have signs and symptoms correlating to spinal disease.

Problems associated with establishing a diagnosis of primary-progressive MS (PPMS) have been given attention both in the original McDonald Criteria and in the 2005 revisions. PPMS diagnostic criteria of the former were derived from a research setting, whereas those of the latter have more relevance to the non-research clinical setting. Whereas positive CSF is considered preferable, this finding is no longer an essential component of a PPMS diagnosis.

The revised McDonald Criteria are now as follows:

- Continued progression for one year

  AND

- Two of the following:
  i) nine or more T2 lesions in the brain OR four or more T2 lesions with positive VEP
  ii) two or more focal T2 lesions in the spinal cord
  iii) positive CSF
2.4 Identifying MS Relapse

2.4.1 The MS relapse

The outward manifestation of MS disease activity is the MS relapse.\(^{19}\) People with relapsing-remitting and remitting-progressive MS can experience the onset of varying neurological signs and symptoms throughout the course of their disease. Such episodes, which last for 24 hours or longer, are referred to variously as relapses, attacks or exacerbations. The relapse may be a subjective observation from the person or an objective clinical assessment.\(^{1}\) Relapses are experienced by over 80% of people diagnosed with MS.\(^{20}\) Without disease-modifying treatment, the mean annual frequency of exacerbations in people with a relapsing form of MS is between 0.4 and 1.1 per person.\(^{19}\)

The McDonald Criteria state that there must be a period of a minimum of 30 days between the onset of the original symptoms and the development of new signs and symptoms for this to be considered a separate relapse.\(^{1}\)

2.4.2 Pseudo-attack

Signs and symptoms can also appear to be an exacerbation, and can be diverse.\(^{20}\) However, when the person is assessed by an expert clinician, the episode may be identified as a pseudo-attack. A pseudo-attack can be defined as the presence of neurological symptoms caused by a change in core body temperature or infection.\(^{1}\) It is essential to distinguish between an exacerbation and pseudo-attack. A pseudo-attack is not an exacerbation and tends to subside when the cause is addressed.\(^{21}\)

2.4.3 Features of an MS relapse

These are as follows:

- The appearance of a new clinical sign/symptom
- Or the clinical worsening of a previous sign/symptom that had been stable for at least the previous 30 days
- And which persisted for a minimum of 24 hours.

LEARNING OBJECTIVES

After completing this section, the reader will be able to:

- Understand the MS relapse
- Differentiate between a pseudo-attack and an exacerbation
- Describe the features of a relapse
2.5 Quantitative Clinical Measures

2.5.1 The Expanded Disability Status Scale (EDSS)

The EDSS\textsuperscript{22} is the most widely used assessment tool for measuring impairment and disability in MS. Scores in this 20-step scale range from 0.0 (normal status) to 10.0 (death due to MS). The scale is not linear, but ordinal, hence score increases reflect progressive accumulation of impairment and disability, and progress of 1 point is not equivalent across the scale. Scores of 0.0 to 3.5 mainly rely on the functional systems, scores of 4.0 to 7.5 rely on ambulation, scores of 8.0 to 8.5 will indicate upper arm function, and scores of 9.0 to 9.5 indicate bulbar involvement.\textsuperscript{22} With scores higher than 3.5 primarily reflecting mobility, criticisms of the scale include its insensitivity to sensory symptoms and to major impairment such as blindness or dementia.\textsuperscript{23}

Inter-rater and intra-person reliability, particularly at lower ends of the scale, have also been a cause for concern.\textsuperscript{24} In spite of these shortcomings the EDSS is considered to have sufficient sensitivity and clinical relevance\textsuperscript{23} to warrant its widespread use in MS assessment. EDSS scoring is included in Appendix A.

2.5.2 The Multiple Sclerosis Functional Composite Score

The MSFC is a scoring system commonly used in MS clinical trials. It seeks to address some of the shortcomings of the EDSS by reducing reliance on lower limb function and by incorporating measures of cognitive and upper limb function. The composite score is arrived at by averaging the results of three separate components:

- **Leg function** (timed ambulation over 25 feet).
- **Arm function** (9-Hole Peg Test – the time taken, with each hand sequentially, to insert and then remove 9 pegs into a pegboard).
- **Cognitive function** (Paced Auditory Serial Addition Test or PASAT which assesses calculation ability as well as speed and flexibility of auditory information processing).

Although designed as a composite score and research tool, there is a capacity for individual components of the MSFC to be applied in the clinical setting.

2.5.3 Other scales

Other scales and scoring systems used in the diagnosis of MS include:

- **Guy’s Neurological Disability Scale\textsuperscript{26}**
- **Multiple Sclerosis Composite Score\textsuperscript{25}**
- **Multiple Sclerosis Impact Scale (MSIS-29)\textsuperscript{27}**
- **Scripps Neurological Rating Scale\textsuperscript{28}**
- **Ambulation Index\textsuperscript{29}**
- **Functional Independence Measure\textsuperscript{30}**
2.6 Paediatrics

2.6.1 Early onset multiple sclerosis

MS is accepted to be largely a disease of young adults aged between 20 to 40 years of age (see Module 1. Overview of MS). However with increasing awareness of the disease and advancing diagnostic technology this notion has been challenged; many adults diagnosed with adult onset MS often report that their first symptom episode was in childhood. Thus, the literature refers to early onset MS (EOMS) as a distinct group of people with definite MS diagnosed during their childhood, that is, before 18 years of age.\(^{31-35}\)

The incidence of EOMS is approximately 2 to 5% of people with MS experiencing their first clinical symptoms before age 16;\(^{36-38}\) the age of onset is <1% below 10 years and <4% between 10 and 18 years of age. The earliest onset has been reported as young as 10 months, and the highest risk appears at 12 years of age, and affecting girls more than boys (ratio 3:1).\(^{39,40}\)

Children may be under diagnosed due to the following:
- Acute disseminated encephalomyelitis is more common than EOMS
- A multitude of CNS diseases mimic MS
- Delay in diagnosis until adulthood.

2.6.2 Clinical subtypes

Similar to adult onset MS (AOMS)
1. Most common: Relapsing-remitting MS\(^ {37,41}\)
2. Moderately common:
   Secondary-progressive MS
3. Relatively infrequent: Primary-progressive MS\(^ {37}\)
4. Rare: Benign MS
2.6.3 Natural history

Children often exhibit systemic symptoms, such as malaise, irritability, and/or low-grade fever, which are similar to symptoms of encephalomyelitis or metabolic encephalopathy.

In retrospective paediatric MS studies, a consistent finding is lower disability scores compared to adult MS, taking into account disease duration. Median time to reach EDSS of 4.0 was approximately 20 years for paediatric MS, and 10 years for adult MS.22 Although the clinical course may be favourable initially, EOMS people can be more disabled at an earlier age.32,38

2.6.4 Presenting symptoms at onset

Frequent symptoms (most to least):

- Hemisensory disturbances – numbness, paraesthesia, Lhermitte’s sign
- Motor deficits – limb weakness, tremor
- Optic neuritis – blurred vision, diplopia, decreased visual acuity
- Brainstem/cerebellar – vertigo, dysarthria, ataxia
- Seizures
- Bladder dysfunction
- Cognitive changes

2.6.5 Potential ongoing symptoms

- Cognitive deficits – decline in school performance
- Fatigue
- Heat intolerance
- Headache
- Tremor
- Spasticity
- Seizures

2.6.6 Symptoms of exacerbation or relapses

- Seizures
- Sensory and/or motor deficits
- Heat intolerance
- Fatigue
- Changes in bladder and bowel pattern

2.6.7 Diagnosis

1. Typical clinical history and examination, CNS lesions disseminated in time and place
   - Two separate episodes of symptoms
   - Optic neuritis, sensory or autonomic disturbance
   - Transverse myelitis
   - Lhermitte phenomenon, Uhthoff’s phenomenon
   - Triggers (exacerbation and increase in symptoms): rise in body temperature, stress, infections

2. MRI findings in symptomatic and asymptomatic people
   - Bright colour lesions on T2-weighted and perfusion diffuse images
   - T1 Gadolinium enhancing lesions
   - T1 “Black holes”
   - Brain areas mostly affected: periventricular white matter, adjacent to the lateral ventricles, corpus callosum, subcortical white matter36
   - Lesions can also occur in spinal cord and brainstem36
   - Cortical atrophy may be present or seen over time
   - Cautions: mimics of MS (eg post-infection or drugs)

3. Laboratory findings that support the diagnosis
   - CSF oligoclonal bands
   - VEP testing
2.6.8 Impact of diagnosis

The following could be explored:

- Label – a very disabling disease
- Growth and development – cognitive, physical
- Parents/family – education and support
- Nursing role – EOMS Clinic

2.6.9 Therapeutic aims

1. Shorten the duration of a relapse:
   - Rest
   - Steroids
   - Intravenous gammaglobulin
2. Modify disease course (modulate the inflammatory process, thereby reduce axonal injury):
   - Interferons (Betaferon, Rebif, Avonex)
   - Glatiramer acetate (Copaxone)
   - Immunosuppressive (methotrexate, cyclophosphamide, mitoxantrone)
   - Humanised monoclonal antibody (Tysabri)

Efficacy and tolerability data for the immunotherapies is extremely limited in the paediatric age group, and are not indicated for use in children with MS. There is some reported experience in literature using these therapies in children.42

3. Considerations
   - Dosage, physiological derangement, side effect management
   - Initiating therapy
   - Education
   - Addressing adherence
   - Support for parents and children
4. Management of secondary effects of the disease
   - Symptom management
   - Treat infections
   - Nutrition

2.6.10 Management considerations34,43

- Promptness of diagnosis and treatment
- Parents required to make informed decisions regarding treatment and care
- Children may lack maturity to understand, decide and accept treatment options
- Lack of clinical trials that provide evidence to support the efficacy of disease-modifying therapies in the paediatric cohort
- Growing CNS and immature immune system
  - affects dosing of disease-modifying therapies
  - steroids may cause growth retardation with prolonged use42
- Care approaches need to change at different stages of growth and development
- School issues and behaviour problems44
- Potential cognitive impact during this period of ongoing myelinogenesis (unknown consequences)44,45
- Include paediatric health professionals in providing comprehensive multidisciplinary care to meet inherent needs

2.6.11 Psychological impact on the child, adolescent and parents

Challenges exist for both children and parents related to dealing with the unpredictable nature of MS, behavioural changes and the potential for major disability.44 Shock and dismay are common feelings that parents and caregivers experience when having to face the diagnosis of MS in a child or adolescent.41

The most common age group to be affected by paediatric MS is adolescence. Sensitivity is essential when dealing with teenagers as they may be particularly vulnerable psychologically. The paucity of research available on the topic and its management can make assisting with psychosocial issues more difficult.44

As with other chronic medical diseases, a sense of isolation, dependence on long-term treatment and the need for self-management may result in this group being at a greater risk of behavioural problems.
In MS, severe fatigue, motor impairments, visual loss and bladder dysfunction can be particularly problematic symptoms. MS-specific factors affecting behavioural problems in MS may be physical disabilities, living with a rare disease and its unpredictable nature. Negative effects on a child’s self-perception may result from all these factors.44

Social functioning and school impact:44
- Frequent sick days
- Unpredictable symptoms resulting in misinterpretation (teachers need to adapt to changeable symptoms)
- Gait impairments may interfere with getting to class
- Fatigue may limit a child’s ability to attend school
- Visual disturbances may interfere with note taking and exams
- Uncharacteristic behaviour in the classroom
- Questioning of future career goals

Effects on the individual:44
- Behaviour changes including risk-taking behaviours that raises health and safety concerns
- Depression, social withdrawal

Family:44
- Parents frequently report feeling lost
- Rarely meet other parents in similar situation
- Mourn the loss of a healthy child

Coping with chronic diseases are better dealt with when good communication, a supportive and expressive family atmosphere, and external support from friends and health care providers is achieved.

Health care:44
- May refuse treatment regimen adherence, particularly when not experiencing relapses and seem healthy

Interventions may include:44
- Medication management and empowerment in decision-making
- Counselling with a chronic illness focus
- Support network

A multidisciplinary approach to assessment and interventions for any problems is recommended, addressing the child’s functioning at home, school and among peers. Consequences for the overall family unit are also important to address.

2.6.12 Resources for persons with MS and families

The National MS Society (US) and the MS Society of Canada have established a support network called Young Persons with MS: A Network for Families with a Child or Teen with MS. It targets both children 18 years and younger with MS and parents of a child or teen with MS. An online handbook has been developed, written by Paediatric Specialists. It is called Kids Get MS Too: a Guide for Parents Whose Child or Teen has MS and is available to download from the Canadian MS Society’s website:
www.mssociety.ca/en/pdf/PediatricMSQAEN.pdf

Mighty Special Kids is an activity book for kids with MS aged from 5-12 years old. It aims to help families talk about MS. An interactive version of the book can be accessed through the National MS Society website or directly at:
http://main.nationalmssociety.org/MSkids/index.html

Talkin’ Teens is a chat room available for teens with MS. Open to ages 13-18. Details are available on the National MS Society website www.nationalmssociety.org/ under the ‘Teen InsideMS’ link. Teens must register with MS World at www.msworld.org/
Teen magazines can be downloaded from this site.

Other Paediatric MS resources for children, teens and parents are provided at:
National MS Society website www.nationalmssociety.org/
Canadian MS Society www.mssociety.ca/ or
Multiple Sclerosis Resource Centre www.msrg.co.uk

Acknowledgment

In addition to the cited references, Dr Andrew Kornberg, Consultant Neurologist, Department of Neurology, Royal Children Hospital, Melbourne is acknowledged for the clinical information initially provided for the Paediatrics section.
Introduction

Nurses play a critical role in the education and support of newly diagnosed people with MS and their families. This role demands that nurses have a comprehensive understanding of the disease process and the effects of MS on overall personal health and life status.

A diagnosis of MS evokes an array of emotional responses that can range from shock, grief, anger, and fear, to profound relief in the knowledge that the reason for the symptoms has finally been discovered. Therefore, nurses should develop care plans that effectively ease the person’s movement through this emotional roller coaster and assist in the development of an effective nurse-person relationship. Nurses should also be able to communicate this knowledge effectively to people and/or their families.46

In this section, a care plan for people newly diagnosed with MS is presented (see Table 2-3). Perceptions formed at this time can have lasting effects on coping and on relationships with members of the health care team.46
<table>
<thead>
<tr>
<th>Nursing diagnosis</th>
<th>Intervention</th>
<th>Rationale</th>
<th>Desired patient outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety relating to:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Knowledge deficit of disease process</strong></td>
<td>Review patient’s present knowledge and understanding of MS</td>
<td>Basic knowledge may already be present</td>
<td>Understands disease process</td>
</tr>
<tr>
<td></td>
<td>Expand patient’s present knowledge base</td>
<td>Patient may have misconceptions about the disease</td>
<td></td>
</tr>
<tr>
<td><strong>Uncertainty about future physical and social capabilities</strong></td>
<td>Provide positive information</td>
<td>Positive information allows the patient to remain hopeful throughout the disease process</td>
<td>Confident about the future</td>
</tr>
<tr>
<td></td>
<td>Expand patient’s present knowledge base</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Worries regarding parenting</strong></td>
<td>Provide relevant information about pregnancy and parenting issues in relation to MS</td>
<td>Given all relevant information, parenting should be an individual decision</td>
<td>Understands issues related to MS and parenting</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Inability to recognise the symptoms of an attack</strong></td>
<td>Provide information about what constitutes a true attack</td>
<td>Knowledge of symptoms of true and pseudo attacks reduces anxiety</td>
<td>Distinguishes between the symptoms of a true MS attack and those of a pseudo attack</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nonadherence relating to:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Denial of diagnosis</strong></td>
<td>Review diagnostic criteria and classification</td>
<td>Patient may be confused about the certainty of the diagnosis</td>
<td>Accepts diagnosis</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Powerless relating to:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Unpredictable nature of disease</strong></td>
<td>Review patient’s comprehension of his/her prognosis</td>
<td>Patient may have preconceived ideas and misconceptions about future abilities</td>
<td>Possesses realistic expectations of disease process and future abilities</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grief relating to:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Loss of former self</strong></td>
<td>Reinforce that grieving is acceptable</td>
<td>Grieving allows the patient to move forward</td>
<td>Accepts disease</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Confusion relating to:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Difficulty in distinguishing which symptoms are related to MS and which are related to other conditions</strong></td>
<td>Educate the patient on the disease process and on other conditions that may coexist with MS</td>
<td>Wellness and an understanding of the disease process promote a healthy outlook on life</td>
<td>Recognises that other conditions may be responsible for symptoms</td>
</tr>
<tr>
<td></td>
<td>Promote patient wellness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information-seeking relating to:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Need to confirm present knowledge</strong></td>
<td>Direct patient to appropriate information resources (eg library, literature packages supplied by clinics, MS Society of Australia, reputable websites; see Module 6.3 for a list of such websites)</td>
<td>Empowerment is gained through knowledge</td>
<td>Possesses correct knowledge of disease</td>
</tr>
<tr>
<td><strong>Need to make informed decisions about available treatment options, resources, and supports</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Need for control</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*The plan for educational sessions for people newly diagnosed with MS should include discussions on how the diagnosis is made and the definitiveness of diagnosis. The patient should be encouraged to guide the course of the session. In order to promote patient understanding, the function and purpose of paraclinical tests should be reinforced.*
References


3. Disease-Modifying Therapies

MODULE OVERVIEW

This module contains three sections:

**Section 1:** Overview of Disease-Modifying Therapies

**Section 2:** Management of Side Effects

**Section 3:** Patient Education & Promoting Adherence to Therapy

Introduction

Prior to the advent of the disease-modifying therapies for multiple sclerosis (MS), pharmacotherapeutic management of MS was largely directed towards the treatment of acute exacerbations and the management of MS-related symptoms.

The disease-modifying therapies, otherwise known as immunomodulating drugs, include the interferon beta-1a therapies (Avonex®, Rebif®), the interferon beta-1b (Betaferon®), glatiramer acetate (Copaxone®), and the monoclonal antibody natalizumab (Tysabri®). These agents have a direct influence on the course of MS, and represent an important step forward in the care of individuals with MS.

In this module, the disease-modifying therapies are discussed as well as protocols for managing side effects associated with their use. It should be noted that discussion about therapies couldn’t take place without emphasising that the roles of the neurologist and the nurse are integral in ensuring adherence to therapies. The neurologist works with the person with MS to identify treatment needs and initiates the treatment while the nurse has the most frequent contact with the person with MS and/or their family/carers. The nurse is in the best position to identify the patient’s needs and provide information about MS. Methods for educating and promoting adherence to these therapies to people with MS are also outlined.
3.1 Overview of Disease-Modifying Therapies

3.1.1 PBS Guidelines

As discussed earlier, there are currently five disease-modifying therapies available in Australia that alter the course of MS. All these therapies are approved on the Pharmaceutical Benefits Scheme (PBS) as authority required prescriptions as follows:

For interferons and glatiramer acetate:

*Initial treatment of clinically definite relapsing-remitting MS in ambulatory (without assistance or support) patients who have experienced at least 2 documented attacks of neurological dysfunction, believed to be due to MS, in the preceding 2 years. The diagnosis must be confirmed by MRI of the brain and or spinal cord and the date of the scan included in the authority application, unless the authority application is accompanied by written certification provided by a radiologist that an MRI scan is contraindicated because of risk of physical (not psychological) injury to the patient. The authority will be limited to the maximum quantity and number of repeats indicated in the schedule;*

*Continuing treatment of clinically definite relapsing-remitting multiple sclerosis in patients previously issued with an authority prescription for this drug who do not show continuing progression of disability while on treatment with this drug and who have demonstrated compliance with, and an ability to tolerate, this therapy. Authorities will be limited to the maximum quantity and number of repeats indicated in the schedule.*

(Source: www.pbs.gov.au/)

For natalizumab:

*Initial treatment, as monotherapy, by neurologists, of clinically definite relapsing-remitting multiple sclerosis in an ambulatory (without assistance or support) patient 18 years of age or older, who has experienced at least 2 documented attacks of neurological dysfunction, believed to be due to multiple sclerosis, in the preceding 2 years.*

*The diagnosis must be confirmed by magnetic resonance imaging of the brain and/or spinal cord and the date of the scan included in the authority application, unless the authority application is accompanied by written certification provided by the radiologist that an MRI scan is contraindicated because of the risk of physical (not psychological) injury to the patient.*

*A maximum quantity of 6 infusions will be issued with the initial authority. Private hospital authority required.*

*Continuing treatment, as monotherapy, of clinically definite relapsing-remitting multiple sclerosis in a patient previously issued with an authority prescription for this drug who does not show continuing progression of disability while on the treatment with this drug, and who has demonstrated compliance with, and ability to tolerate, this therapy.*

18 years of age or older, who has experience at least 2 documented attacks of neurological dysfunction, believed to be due to multiple sclerosis, in the preceding 2 years.

The diagnosis must be confirmed by magnetic resonance imaging of the brain and/or spinal cord and the date of the scan included in the authority application, unless the authority application is accompanied by written certification provided by the radiologist that an MRI scan is contraindicated because of the risk of physical (not psychological) injury to the patient.

A maximum quantity of 6 infusions will be issued with the initial authority.

Private hospital authority required.

Continuing treatment, as monotherapy, of clinically definite relapsing-remitting multiple sclerosis in a patient previously issued with an authority prescription for this drug who does not show continuing progression of disability while on the treatment with this drug, and who has demonstrated compliance with, and ability to tolerate, this therapy.
The disease-modifying therapies may reduce one or more of the following, please check the latest product information sheets, including that for natalizumab:\(^1\)

- Rate of relapse
- Likelihood of hospitalisation
- Severity and duration of relapse
- Steroid use
- Number of brain lesions
- Progression of disability

### 3.1.2 Interferons

The interferons are a group of proteins that are normally produced by cells in response to viral infection and other stimuli. There are three main types of interferon.\(^2\)

Interferons beta (\(\beta\)) and alpha (\(\alpha\)) are produced mainly by white blood cells and certain connective tissue cells called fibroblasts.\(^2\)

Interferon gamma (\(\gamma\)) is produced primarily by activated T cells, and is a naturally-occurring substance in the body that promotes inflammation; it is thought to be involved in MS exacerbations.

---

Table 3-1. Provides an overview of the PBS approved disease-modifying therapies in relapsing-remitting MS.\(^3\)

Adapted from approved product information

<table>
<thead>
<tr>
<th>Manufacturer</th>
<th>Avonex®</th>
<th>Betaferon®</th>
<th>Copaxone®</th>
<th>Rebif®</th>
<th>Tysabri®</th>
</tr>
</thead>
<tbody>
<tr>
<td>Description</td>
<td>Interferon beta-1A 166 amino acid glycoprotein</td>
<td>Interferon beta-1B 165 amino acid lyophilised protein</td>
<td>Glatiramer acetate. Synthetic mixture of four amino acids</td>
<td>Interferon beta-1A 166 amino acid glycoprotein</td>
<td>Recombinant IgG4 monoclonal antibody</td>
</tr>
<tr>
<td>PBS indication (authority required). For TGA approved indication see approved product information</td>
<td>Relapsing-remitting MS</td>
<td>Relapsing-remitting MS</td>
<td>Relapsing-remitting MS</td>
<td>Relapsing-remitting MS</td>
<td>Relapsing-remitting MS</td>
</tr>
<tr>
<td>Administration</td>
<td>Intramuscular injection</td>
<td>Subcutaneous injection</td>
<td>Subcutaneous injection</td>
<td>Subcutaneous injection</td>
<td>Intravenous infusion</td>
</tr>
<tr>
<td>Dosing</td>
<td>30(\mu)g once a week</td>
<td>0.25mg every other day</td>
<td>20mg once daily</td>
<td>44(\mu)g 3 times a week</td>
<td>300mg every 4 weeks</td>
</tr>
<tr>
<td>Disability progression*</td>
<td>Significantly delayed</td>
<td>No significant change in progression (trend only) but delays progression in secondary progressive disease</td>
<td>No significant change in progression</td>
<td>Significantly delayed</td>
<td>Significantly delayed</td>
</tr>
<tr>
<td>Magnetic resonance imaging (MRI) activity</td>
<td>Lesion load significantly reduced versus placebo</td>
<td>Lesion load significantly reduced versus placebo</td>
<td>Lesion load significantly reduced versus placebo</td>
<td>Lesion load significantly reduced versus placebo</td>
<td>Lesion load significantly reduced versus placebo</td>
</tr>
</tbody>
</table>

*In the Betaferon®, Copaxone®, Rebif® and Tysabri® trials, progression was defined as an increase of at least 1 point on the Kurtze Extended Disability Status Scale (EDSS) that persisted for a minimum of 3 consecutive months. In the Avonex® trial, progression was defined as an increase of at least 1 point on the EDSS that persisted for a minimum of 6 consecutive months.

In this module each of the disease-modifying therapies are described in detail.
Once tried as a treatment for MS, it was found to make
the disease worse. Interferon beta works to counteract
the effects of interferon gamma.2

3.1.3 Interferon beta (IFN-β)

IFN-β has multiple effects on the immune system,
including increasing suppressor lymphocyte activity and
inhibiting stimulation of other immune cells. It also can
regulate production of interferon gamma. The actions
of interferon beta have the net effect of reducing the
immune response that is directed against central
nervous system myelin in people with MS.

Myelin is the fatty sheath that surrounds and protects
nerve fibres. Its destruction, known as demyelination,
causes nerve impulses to be slowed or halted and
produces the symptoms of MS. Damage to the myelin
sheath is also associated with destruction of the nerve
fibres themselves.

3.1.4 Glatiramer acetate

Glatiramer acetate is a synthetic polypeptide of four
amino acids (L-glutamic acid, L-alanine, L-tyrosine
and L-lysine – the building blocks of proteins) that are
found in myelin. It reduces the number and severity of
exacerbations (also called attacks, relapses, or flares) in
people with MS. This may be achieved by diverting the
patient’s immune system from attacking myelin.

3.1.5 Natalizumab

Natalizumab is a monotherapy treatment for patients
with relapsing remitting multiple sclerosis to delay
the progression of physical disability and to reduce
the frequency of relapse. The safety and efficacy of
natalizumab beyond two years are unknown. The
specific mechanisms for how natalizumab works have
yet to be fully defined. It is a recombinant humanised
IgG4 monoclonal antibody produced in mouse cells
that binds to 4-integrin which prevents the adhesion of
leucocytes and transmigration across the endothelium
into inflamed parenchymal tissue.

Following administration there is an increase in the
number of circulating leucocytes (eg lymphocytes,
monocytes, basophils, and eosinophils.)

Natalizumab is a disease-modifying treatment and not a
cure for MS. The recommended dose for natalizumab is
300mg administered every 4 weeks as a 1 hour infusion
(300mg/15ml concentrate diluted in 100ml 0.9%
sodium chloride for injection followed by
1 hour of observation).

3.1.6 Other therapies

Immunosuppressive treatments

An immunosuppressive drug would be expected
to slow down or stop the demyelinating process
without, however, being able to reverse damage or
improve symptoms. Since the myelin damage in MS
may be caused by an autoimmune response, some
immunosuppressive or cytotoxic drugs are used to help
shorten attacks or slow the progression of MS. Other
drugs, like steroids, are used to treat the inflammation
that accompanies demyelination.

The following have been used overseas for MS:
azathioprine, methotrexate, cyclophosphamide,
cyclosporin, cladribine, mitozantrone, total lymphoid
radiation, monoclonal antibodies, corticosteroids,
intravenous gammaglobulin, plasma exchange and
bone marrow transplants. These are not approved in
Australia specifically for the treatment of MS, although
some of them are used for this condition.

Some agents (eg glucocorticoids, azathioprine) have
been studied extensively and have demonstrated
benefit. Other approaches (eg total lymphoid radiation
or bone marrow transplants) may carry either large
or unknown short-term risks for patients. Some of the
cytotoxic agents (eg cyclosporin, cyclophosphamide)
are both acutely toxic and, if used for prolonged
periods, carry uncertain long-term risks to health. As
a result of such difficulties, in addition to the lack of
unequivocal evidence for efficacy, the clinical use of
these agents has remained limited and, indeed, many
of the currently available agents should be considered
only in very carefully selected circumstances.
Corticosteroids

For some time corticosteroids have been the selected treatment for relapses. It is suggested that corticosteroids reduce inflammation which may lead to a decrease in oedema, alter the blood-brain barrier, suppress the autoimmune response and perhaps assist with regeneration of myelin. Even though corticosteroids hasten the recovery process during an exacerbation, they are not thought to affect the disease process in the long-term.

Intravenous methyprednisolone is a commonly prescribed steroid for exacerbations. The effect is rapid and the course of administration is over a short period, usually between 3 to 5 days. Side effects can include gastric disturbance, fluid retention, weight gain, hypokalaemia, insomnia, psychological effects and acne. IV dexamethasone, IM adrenocorticotropic hormone and oral steroids have also been used for exacerbations however there is no recommendation for the use of these agents.

Azathioprine

Azathioprine is a mercaptopurine derivative which has cytotoxic and immunosuppressive effects. It is commonly used in chemotherapeutic regimens for cancer patients and to treat rheumatoid arthritis, it has also been evaluated as a treatment for MS to stabilise the patient’s clinical course. Azathioprine (eg Imuran®) is a relatively mild immunosuppressant that has been used primarily in secondary-progressive MS. A Cochrane review has concluded that azathioprine is an appropriate maintenance treatment for patients with multiple sclerosis who frequently relapse and require steroids, and is a fair alternative to IFN-β therapy. It is generally administered at a total daily dose of 2-3 mg/kg with the therapeutic goal of lowering the white blood cell count to between 3,500 and 4,000 cells/ml. Cumulative doses of 600g should not be exceeded in relation to a possible increased risk of malignancy. This treatment is also generally well tolerated although some patients will experience abdominal pain or nausea.

Mitozantrone

Mitozantrone hydrochloride (eg Novantrone®), also known as mitoantrone, is a disease-modifying therapy. It is a cytotoxic agent commonly used to treat different types of cancers and severe immune system disorders. Mitozantrone is an immunosuppressant with immunomodulatory abilities. It works by exerting effects on the lymphocyte cell undergoing proliferation in response to newly presented antigens. Mitozantrone profoundly inhibits B cell activity and antibody secretion, suppresses humoral immunity, and diminishes T cell production.

It is not approved in Australia for the treatment of MS, although it is approved for this use in some overseas countries. Mitozantrone is most effective in people with MS who have experienced relatively rapid progression of disease (progression of disability) or who are suffering from frequent relapses. The medication has been used for worsening relapsing-remitting MS, secondary-progressive MS, and progressive-relapsing MS. Mitozantrone is not currently recommended for patients with primary-progressive MS.

There are several treatment courses that a neurologist can use for mitoantrone. Some examples are as follows:

- Monthly for three months followed by once every three months for two years
- Monthly for six months
- Every three months for two years.

Mitozantrone is given at monthly or 3-monthly intervals, as the medication has an accumulative effect it can result in permanent heart damage.

Blood tests and investigations to evaluate heart function are necessary before mitoantrone treatment can be ordered, and are recommended during and after the treatment period.

Other treatments for MS are under investigation, such as fingolimod (FTY72) a new oral immunomodulating agent for relapsing MS, and cladribine, a lymphocyte depleting agent with immunosuppressive properties, currently used for treating various leukaemias. In addition, there are several monoclonal antibodies used in other indications and are under investigation for use in MS (eg alemtuzumab, rituximab and daclizumab).
3.2 Management of Side Effects

Introduction
The most common side effects associated with IFN-β therapy are:1

• Injection-site reactions
• Systemic reactions
• Flu-like symptoms (ie myalgia, headache, chills, fever)

The less common side effects associated with IFN-β therapy are:

• Spasticity
• Laboratory-test abnormalities
• Mood alterations
• Insomnia
• Other side effects

The most common side effects noted with glatiramer acetate use are injection-site (ie pain, cutaneous reactions, lipoatrophy) and systemic reactions referred to in the literature as the ‘post injection syndrome’ (ie chest pain, palpitations, and anxiety).

Table 3-2 provides a brief summary of the adverse effects experienced with these disease-modifying therapies, as tabulated in each product information.1

3.2.1 Injection-site reactions

Description of problem
The most common injection-site reactions include pain and cutaneous reactions. Injection-site necrosis and lipoatrophy are rare but may occur with the interferons.17,18 Lipoatrophy is common with glatiramer acetate.

Pain
Pain can occur immediately upon injection (eg stinging) and/or develop 24-48 hours post injection, and is often described as “tenderness to touch”, that may be red or bruised mottled purple in colour that lasts anywhere from a few days to a few weeks.

For the majority of individuals this pain is transient and self-limiting and rarely results in termination of treatment.

A common side effect with subcutaneous injections is a local injection site reaction. The common symptoms are skin redness, itching and inflammation. Most of these local symptoms are mild, do not interfere with daily activities and usually diminish with time.
Injection-site necrosis

The mechanism by which IFN-β induces skin necrosis is unknown. However, possible aetiological factors include thrombosis and necrosis of the dermal vessels.\textsuperscript{19,20}

Possible risk factors for necrosis include:\textsuperscript{21}

- Incorrect injection technique
- Insufficient needle length
- Administration of cold IFN-β solution
- Repeated use of the same injection site
- Excessive exposure of injection sites to sunlight or ultraviolet rays

Interventions

- Use interventions for the management of injection-site reactions
- Educate and prepare patient for the advent of possible pain and injection-site problems
- Advise patient to:
  - Rotate injection sites
  - Select injection sites properly (see Figure 3-1)
  - Allow solution to come to room temperature before administration
  - Follow injection and reconstitution (in the case of reconstituted preparations) procedure as per instructions
  - If on subcutaneous injections to use the automatic injectors supplied free of charge and obtained from the manufacturer, MS Society or MS Clinic. The automatic injectors may assist with both needle phobia and injection site reactions.
In some instances SLOW manual injection may need to be learned.
  i) Use vial adapters ie magni-guide, mixject (in the case of reconstituted preparations)
  ii) Inject only into normal healthy tissue
  iii) Apply ice/heat pack pre- and post-injection for up to 5 minutes or PRN (wrap pack in paper towel etc to avoid burns and discomfort)

iv) Massage site (following IFN-β injections only) but do not rub

v) Instruct patient on regular self skin examination and how to identify the first signs of lipoatrophy

vi) Advise patient to discuss use of paracetamol and/or ibuprofen with their doctor

• Treat necrosis if patient experiences injection-site necrosis, in consultation with the physician

The attending physician must then decide whether or not to continue the IFN-β therapy that is causing the necrosis. If IFN-β therapy is discontinued, the physician may or may not decide to use an alternative disease-modifying treatment during the healing process. The patient must also be assessed for the signs and symptoms of infection at the injection sites.

A course of antibiotics may be needed if infection is noted.

A complete blood count (CBC) must be performed to determine whether the white blood cell (WBC) count is high enough to allow autolysis. Finally, appropriate topical treatment is initiated based on the WBC, the stage of the wound, and the presence or absence of infection.

• Evaluate/assess injection sites at each follow-up visit and review injection technique PRN

Desired patient outcomes

• Demonstrates appropriate site selection
• Follows procedures for minimising injection-site reactions (eg rotation of injection site, application of cold/heat pre- and post-injection, etc)
• Regularly self examines and reports on condition of the injection sites

NOTE: If injection-site reactions continue to be a problem despite the implementation of commonly accepted interventions, careful consideration should be given to switching agents. This consideration should be made with the MS nurse specialist, neurologist and patient.
3.2.2 Systemic reactions

Description of problem

In the approved product information, approximately 26% of patients with MS who received glatiramer acetate reported transient chest pain.1 Other systemic reactions that may occur immediately following subcutaneous injection are:

• Flushing
• Palpitations
• Anxiety
• Dyspnoea
• Constriction of the throat
• Urticaria

However, these symptoms were invariably transient and did not require specific treatment.

Table 3-2. Provides an overview of the side effect profile of disease-modifying therapies.1
Adapted from approved product information.

<table>
<thead>
<tr>
<th></th>
<th>Avonex® (IFNβ-1a)</th>
<th>Betaferon® (IFNβ-1b)</th>
<th>Copaxone® (glatiramer acetate)</th>
<th>Rebif® (IgG4 (IFNβ-1a))</th>
<th>Tysabri® (IgG4 monoclonal antibody)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flu-like symptoms</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Hypersensitivity</td>
</tr>
<tr>
<td>Injection/infusion</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>site reactions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Palpitations</td>
<td>Rare</td>
<td>Yes</td>
<td>Yes</td>
<td>Not stated</td>
<td>No</td>
</tr>
<tr>
<td>Vasodilatation</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Not stated</td>
<td>No</td>
</tr>
<tr>
<td>Chest pain</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Not stated</td>
<td>Yes</td>
</tr>
<tr>
<td>Asthenia</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Infection</td>
<td>Rare</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Pain</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Nausea</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Muscle ache/pain</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Dyspnoea</td>
<td>Rare</td>
<td>Yes</td>
<td>Yes</td>
<td>Not stated</td>
<td>Yes</td>
</tr>
<tr>
<td>Arthralgia</td>
<td>Yes</td>
<td>Not stated</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Intermenstrual</td>
<td>Not stated</td>
<td>Yes</td>
<td>Yes</td>
<td>Not stated</td>
<td>Yes</td>
</tr>
<tr>
<td>spotting</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>Rare</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Anaemia</td>
<td>Yes</td>
<td>Not stated</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>White cells decrease</td>
<td>Yes</td>
<td>Yes</td>
<td>Rare</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Hypertonia</td>
<td>Rare</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>ALT/AST increase</td>
<td>Rare</td>
<td>Yes</td>
<td>Rare</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Please note that this is an approximate guide only with data taken from different placebo-controlled studies, hence this is not to be used for comparative purposes. Please review latest approved product information for any subsequent update.
Module 3 - Disease-Modifying Therapies

Interventions

- Inform patient receiving glatiramer acetate of the possibility of immediate post-injection reactions
- Advise patient to contact their doctor if they are concerned about any of the above mentioned symptoms

Desired patient outcomes

- The patient is aware of the possibility of immediate post-injection reactions (if receiving glatiramer acetate) and does not panic if these reactions occur
- Recognises symptoms and understands management strategies of post-injection reactions

3.2.3 Flu-like symptoms

Description of problem

Approximately 60% of patients experience flu-like symptoms after the first dose of IFN-β. These symptoms usually begin 2-6 hours after injection and may include:22,23

- Myalgia
- Headache
- Nausea
- Chills
- Fatigue
- Fever complex

Flu-like symptoms usually resolve within 24 hours of injection but may persist for 3 months following the initiation of therapy. Anecdotally, these flu-like symptoms may persist for as long as 6 months.

Interventions

- Prepare patient for the advent of flu-like side effects through educational sessions
- Titration schedule should be used when initiating disease-modifying treatment*
- Advise patient to discuss use of paracetamol pre- and post-injecting with their doctor

If flu-like symptoms continue, consider the following:

- Changing time of dose of paracetamol so that peak analgesic effects of paracetamol occur at peak times of side effects
- Changing time of dose of disease-modifying therapy so that peak times of side effects occur during sleep
- Administering non-steroidal anti-inflammatory drugs (NSAIDs) with or without paracetamol†

Figure 3-1. Possible injection sites for subcutaneous disease-modifying therapies.
The titration schedule most commonly used in Australia depends on the treatments; the nurse or doctor should consult individual product information sheets for the specific titration schedules of each of the IFN-β therapies or contact the state MS society or MS Clinic for information on the titration schedule they are using.

†NSAID and/or paracetamol schedules may vary from centre to centre.

For the occasional patient who is refractory to either paracetamol or NSAID prophylaxis, the patient should be referred to their doctor for consideration of further options which may include:

- Decreasing IFN-β dose to 25-50% of usual dose for 3-4 weeks to minimise side effects, then gradually increasing dose (as tolerated) to the recommended level
- Administering ibuprofen 400mg twice daily plus paracetamol for the first 6 months of treatment
- Administering 5–10mg of oral prednisone on the day of injection, for the first 1–2 months of therapy

**Desired patient outcomes**

- Experiences minimal flu-like symptoms
- Identifies need for analgesics and determines the dosage needed
- Times medication appropriately to minimise symptoms
- Describes side effects associated with drug treatment and can intervene appropriately
- Follow dosage schedules developed to minimise symptoms
- Understands that flu-like symptoms may last from 3–6 months after the initiation of therapy

### 3.2.4 Laboratory-test abnormalities

**Description of problem**

The most commonly observed laboratory abnormalities in patients receiving interferons and glatiramer acetate are shifts in white blood cell count (eg leucopenia, lymphopenia, neutropenia) and raised liver aminotransferase values (eg ALT, AST). These abnormalities, however, seldom result in serious complications.23,25

**Interventions may include:**

- Obtaining laboratory-test values, including a CBC and liver function test (LFT) values, before initiation of therapy. Check patient is aware of this recommendation and to check with their GP or neurologist for a pathology referral.
- Monitoring laboratory-test values at regular intervals after initiation of therapy and PRN*
- Consideration of adjusting dosage or interrupting treatment if patient exhibits abnormal blood count and/or LFT values (see Table 3-3 for tolerable laboratory-test values)
- Although most laboratory-test abnormalities do not necessitate modification of therapy, continued monitoring of laboratory-test values is recommended since long-term consequences of therapy are unknown
- Monitoring of patient for signs of pathology (eg increased infection rate)

*Some clinics perform laboratory tests on day 1 of therapy, 1 month following the initiation of therapy and every 3 months thereafter.

**Desired patient outcomes**

- Follows up with required blood testing
- Adheres to follow-up schedule
- Maintains an accurate diary of treatment events (eg symptoms experienced following injection, rotation of injection sites, etc)
### 3.2.5 Mood alterations

#### Description of problem

The following symptoms of depression are frequent in patients with MS:23

- Changes in sleep patterns and/or diet
- Lack of interest in personal affairs/life
- A sense of hopelessness/helplessness
- Anxiety
- Hyperactivity (remember, mania is closely associated with depression)

It is unclear, however, whether therapy itself causes depressive symptoms or whether these symptoms are due to poor adherence to therapy and/or an inability to cope with MS.22,23 Therefore, many clinicians prefer to start therapy when the patient is, for the most part, emotionally stable or receiving effective treatment for depression.

#### Interventions may include:

- Evaluating and monitoring baseline mood state and monitor changes in mood over time (including hyperactivity)
- Informing patient and family of depressive symptoms and their possible association with therapy
- Referral of patient for psychotherapy or psychiatric treatment (if needed)
- Monitoring of patient for signs of suicidal ideation

#### Desired patient outcomes

- Patient reports mood changes
- Patient’s support person and family physician recognise and report any changes in the patient’s mood

### 3.2.6 Insomnia

#### Description of problem

Insomnia may occur upon initiation of therapy and may continue indefinitely.22

#### Interventions may include:

- Time injections so that side effects are most pronounced during the deepest part of the sleep cycle or administer therapy early in the day
- Instruct patient to consult physician regarding medications such as the night time formulation of paracetamol and the treatment of refractory sleep disturbances (eg sedatives, analgesics, and/or hypnotics)
- Instruct patient on methods of relaxation and meditation techniques
- Instruct patient to avoid stimulants before bedtime

#### Desired patient outcomes

- Resumes normal sleeping patterns
- Adheres to injection schedule that supports normal/regular sleeping patterns
- Uses analgesics and sedatives appropriately

---

**Table 3-3. Proposed limits of tolerable laboratory values with therapy.**

<table>
<thead>
<tr>
<th>Laboratory Test</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Blood count</strong></td>
<td></td>
</tr>
<tr>
<td>Haemoglobin (g/dL)</td>
<td>115-160</td>
</tr>
<tr>
<td>Platelets (10⁹/L)</td>
<td>150-400</td>
</tr>
<tr>
<td>White Cells (10⁹/L)</td>
<td>4.0-10.0</td>
</tr>
<tr>
<td>Neutrophils (10⁹/L)</td>
<td>1.0-3.50</td>
</tr>
<tr>
<td>Lymphocytes (10⁹/L)</td>
<td>2.0-8.0</td>
</tr>
<tr>
<td><strong>LFTs</strong></td>
<td></td>
</tr>
<tr>
<td>Bilirubin (µmol/L)</td>
<td>1-19</td>
</tr>
<tr>
<td>ALP (IU/L)</td>
<td>35-104</td>
</tr>
<tr>
<td>ALT (IU/L)</td>
<td>0-31</td>
</tr>
<tr>
<td>AST (IU/L)</td>
<td>0-32</td>
</tr>
</tbody>
</table>
Module 3 - Disease-Modifying Therapies

3.2.7 Other side effects

Other, less frequent side effects of therapy may include:

• Menstrual disorders*
• Weight change
• Digestive disorders (eg diarrhoea and abdominal cramping)
• Cardiovascular complications (eg arrhythmias, palpitations and shortness of breath)

If these symptoms are severe or persist for several months after therapy has been initiated, refer the patient for evaluation and possible treatment.

Fuller descriptions of other potential side effects are available in the respective approved product information.

*Patients with menstrual disorders, particularly older patients nearing the age of menopause, should be advised to consult their doctor if concerned by changes in bleeding patterns.

3.2.8 Natalizumab

Natalizumab is a monoclonal antibody approved for relapsing-remitting MS. It is contraindicated in those who have or have had progressive multifocal leucoencephalopathy (PML); its use is associated with an increased risk of PML and the product information carries a boxed warning to this effect.

*Tysabri is associated with an increased risk of progressive multifocal leucoencephalopathy (PML), an opportunistic viral infection of the brain that usually leads to death or severe disability. Healthcare professionals should monitor patients on Tysabri for any new symptoms that may be suggestive of PML. Tysabri dosing should be withheld immediately at the first sign or symptoms suggestive of PML. For diagnosis, an evaluation that includes a gadolinium-enhanced magnetic resonance imaging (MRI) scan of the brain and when indicated, cerebrospinal fluid analysis for JC viral DNA are recommended (see Contraindications and Precautions, Progressive Multifocal Leucoencephalopathy). (Source: Tysabri Product Information).
3.3 Patient Education & Promoting Adherence to Therapy

Introduction

Education about MS and the disease-modifying therapies empowers patients to take control of their disease. This sense of empowerment, in turn, increases the likelihood that patients will adhere to the therapeutic regimen.

Adherence is best defined as the active, voluntary and collaborative involvement of the patient in a mutually acceptable course of behaviour that results in a desired preventive or therapeutic outcome. Thus, the term adherence implies that the patient, nurse and other healthcare professionals work together to develop the treatment regimen and ensure adherence to this regimen.

It has recently been suggested that the term adherence be used to replace the term compliance when referring to therapy since many patients feel compliance is value-laden (i.e. implies that the patient is subordinate to the healthcare professional). 27

In this section, methods for providing effective patient education and strategies for promoting patient adherence to therapeutic regimens are discussed.

3.3.1 Patient education

Psychoeducational approach to patient education

Psychoeducation is a complex educational process that has been found to be effective in promoting adherence to medication regimens and treatment protocols. Unlike the traditional learning model that sets educational objectives according to predetermined learning material, the psychoeducation model requires

LEARNING OBJECTIVES

After completing this section, the reader will be able to:

• Describe and apply the psychoeducational approach to patient education
• List and apply strategies for effective patient education
• List barriers to adherence
• Describe the role of the nurse in promoting adherence to therapy
• Ensure patients set realistic expectations for therapy
• Reinforce the role of the multidisciplinary team involved in the management of patients with MS

in setting the goals and objectives of education as well as the educational process itself (see Table 3-4).

Using the psychoeducation model, nurses can respond to each patient’s individual needs and concerns regarding the complex injection protocol of the disease-modifying therapies. Furthermore, the model allows for continual assessment of patients’ understanding of anticipated side effects and their skill development in the injection process.
Strategies for effective patient education using the psychoeducation model are shown in Table 3-5.

Specific instructions

Since the PBS approved disease-modifying therapies are currently only available in injectable form (natalizumab is administered in hospital as an infusion), the introduction of these therapies requires extensive patient and family education on the following:

- Drug handling and reconstitution (see individual product information sheets)
- Appropriate self-injection technique
- Site selection and rotation (see Figure 3-1)
- Monitoring of side effects
- Use of contraception during therapy and pregnancy (when applicable)31-33
- Safe contaminated sharps disposal.

An important first step in this educational process is to establish whether the patient, the nurse or the patient’s caregiver will give the first injection. Ideally, patients should perform the first injection themselves with the assistance of the nurse. It is also important that patients understand the need to administer the drug as directed especially during the titration period and that any changes from this dosing can result in either an overdose or treatment inefficacy. Once full dose is achieved, ensure the full dose is taken as prescribed.

Furthermore, all patients must be taught a safe sterile self-injection technique. Appropriate site selection and rotation help to prevent erythema and possible necrosis at the injection site. To help facilitate injection technique, instruction demonstration kits are provided by the manufacturers of disease-modifying therapies.

Desired patient outcomes of education

- Describes rationale of therapy
- Correctly administers medication
- Sets expectations for therapy that fit with the known efficacy of disease-modifying therapies
- Describes the possible side effects of therapy and manages these side effects appropriately
- Identifies injection sites and discusses the importance of site rotation
- Identifies and uses resources for further information
- Demonstrates proper storage and handling of medication

3.3.2 Promoting adherence to therapy

Barriers to adherence

The following may act as barriers to patient adherence to disease-modifying therapy:34

- Perceived low value of treatment
- Lack of information on therapies and misconceptions regarding these therapies
- Number and frequency of drugs currently being taken by the patient
- Patient’s perception of MS (eg patient is in denial)
- Cognitive deficits (eg memory and judgment problems)
- Temporary worsening of MS symptoms after therapy has been initiated
- Drug administration challenges and/or fears of self-injection
- Difficulty coping with transient symptoms (eg flu-like with IFN-β and cardiovascular with glatiramer acetate) and other side effects of therapy
- Social situations and/or cultural beliefs that are incongruent with therapy regimen
**Role of the nurse in promoting adherence to therapy**

Since nurses are the main healthcare professional to have day-to-day contact with patients, they play a pivotal role in promoting patient adherence to therapy. In fact, the active involvement of nurses in the overall management of patients with MS increases patient adherence to MS treatment regimens.

The role of nurses in promoting adherence includes:

- Establishing a trusting nurse-patient relationship
- Educating patients about MS and the therapies available for treatment of the disease
- Ensuring that patients set realistic expectations for treatment outcomes
- Reinforcing the role of the multidisciplinary team involved in the care of patients with MS
- Assisting patients in establishing a network of resources
- Performing continuous patient follow-up and monitoring.

Establishing such a trusting relationship should begin during the patient’s first contact with the nurse; it requires that the nurse take time to empathise with the patient and his/her family and that the patient feels a sense of unbiased support from the nurse.

**Patient education**

See ‘Patient Education’ section earlier.

**Ensuring realistic expectations for therapy**

It is important for nurses to assess patients’ knowledge of MS and their expectations for treatment outcomes before therapy begins. Nurses should ensure that patients have realistic expectations of the effect of treatment since symptoms and exacerbations will continue. Furthermore, it should be made clear to patients that the aim of disease-modifying therapies is to reduce the number and severity of attacks and slow the rate of progression of MS.

Nurses should also ensure that patients realise that disease-modifying therapies:

- Are not cures for MS
- Do not always reduce MS symptoms
- Do not reverse existing damage to the central nervous system
- Do not completely reduce future disease activity
- Are to be taken on an indefinite basis
Reinforcing the role of the multidisciplinary team

As nurses often have day-to-day contact with patients, 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.

Establishing a network of resources

Another important role of MS nurses is to inform patients and their families of clinic, community and company-funded patient support programs since these programs provide comfort and also serve as mediums for the exchange of information and release of emotions. Support programs have also been shown to promote patient adherence to therapy.36

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre–assessment to education</td>
<td>Level of understanding, Allergies, Needle phobia</td>
</tr>
<tr>
<td>Provide information in a clear and concise manner</td>
<td>Increased understanding of information by patient helps reduce patient anxiety regarding therapy</td>
</tr>
<tr>
<td>Provide a non-distracting, relaxing and comfortable learning environment</td>
<td>Minimises distractions during learning process, Increased understanding of information by patient helps reduce patient anxiety regarding therapy, Minimises fears associated with the disease and self-injection of therapy, Helps identify barriers to adherence and thereby facilitates the learning process</td>
</tr>
<tr>
<td>Use a variety of educational tools (eg oral and written information videocassettes, practice vials and syringes, and one-on-one demonstrations)</td>
<td>Patients with MS often have some degree of cognitive impairment; therefore, instruction often needs to be repeated, Patients experiencing stress or fear regarding MS or injection therapy may forget even the simplest verbal instructions, therefore, provide learning material in a variety of media to complement verbal instructions</td>
</tr>
<tr>
<td>Provide patients with reinforcement and acknowledge success</td>
<td>Reinforcement of efforts made will increase patients’ sense of control over their disease and promote adherence to the treatment plan, Ongoing communication and reinforcement of treatment outcomes reduce unrealistic expectations of being completely exacerbation-free during treatment</td>
</tr>
<tr>
<td>Involve family members in the teaching process (but assess if patient wants family involvement first)</td>
<td>Involvement of family members in patient education has been shown to minimise patients’ fears regarding therapy, reinforce learning, and promote adherence to therapy</td>
</tr>
</tbody>
</table>

Table 3-5. Strategies for effective patient education.
Follow-up and monitoring

Follow-up and monitoring of the patient should include:
• Regular telephone contact
• Neurological follow-up (eg annual examination and MRI)
• Follow-up with patient support programs (if necessary)
• Re-evaluation of the patient’s treatment expectations
• Review of the goals and objectives of therapy
• Consideration of a drug holiday if the patient needs a break from therapy (rather than having the patient quit therapy altogether)
• Informing all team members if a particular patient is at high risk of non-adherence or has actually been non-adherent
• Continually assessing patient and family adjustment to the disease

Desired outcomes of adherence

The desired patient outcomes of adherence to therapy include:
• Feels a sense of control over MS
• Improved quality of life (for both patient and family)
• Decrease in the number of complications associated with the disease
• Decrease in the number of hospital admissions

Further reading


Halper J. In: *Advanced Concepts in Multiple Sclerosis Nursing Care. Second edition 2007*
  - Chapter 7, Promoting Adherence to Complex Protocols, Marie A Namey, Page 91-100.
  - Chapter 16, Skin Care in Multiple Sclerosis, June Halper, Page 219-223.

www.ucsf.edu/bmrc/
References

1. MIMS Annual 2008 [see latest product information sheet on Avonex, Betaferon, Copaxone, Rebif or Tysabri for any subsequent update].


34. Denis L. Promoting adherence to therapeutic regimens in multiple sclerosis. Presentation made at the Ottawa Hospital, General Campus, in Ottawa, Ontario. November 1999.


4. Signs & Symptoms

**MODULE OVERVIEW**

This module contains ten sections:

- **Section 1**: Fatigue
- **Section 2**: Incontinence
- **Section 3**: Pain
- **Section 4**: Spasticity
- **Section 5**: Tremor
- **Section 6**: Ataxia
- **Section 7**: Vision
- **Section 8**: Cognition
- **Section 9**: Speech & Swallowing Difficulties
- **Section 10**: Depression

**Introduction**

Patients through all stages of MS experience a wide variety of symptoms that can adversely affect their ability to perform daily living activities. The symptoms that affect individuals with MS are often multifactorial and change over time, and as with each individual’s disease course, the effectiveness of treatment for these symptoms is very individual. Addressing symptoms in a multidisciplinary fashion and helping patients identify problems as they occur with early recognition and intervention is the key to successful management.

Successful management involves not only treating the more readily recognised manifestations of MS but also the less obvious manifestations, including fatigue, cognitive loss, mood disturbance and pain, and the impact they have on other symptoms and quality of life for people with MS.

Described in this module are some internationally acknowledged assessment guides and management options for MS symptoms. The desired outcomes of treatment interventions for these symptoms are also discussed. These are derived from the Canadian Multiple Sclerosis Nursing Care Plan and the United Kingdom Multiple Sclerosis Clinical Management Manual, and adapted to current Australian best practice by the authors.

Where medications have been named, although considered relevant in Australia, please check that these are still relevant and applicable to your local practice. Many of the drug names given are meant to be representative rather than exhaustive.
4.1 Fatigue

Introduction

Fatigue is now recognised as the most common symptom of MS, and patients rank fatigue as one of the symptoms that most impairs their quality of life (QoL). Surveys and case control studies indicate that 75 to 95% of individuals with MS experience fatigue, and 50 to 60% report fatigue as one of their worst problems. The Australian Multiple Sclerosis Longitudinal Study (AMSLS) newsletter reports that 73.8% of respondents have suffered fatigue as part of their MS.

Fatigue has been defined as “a subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with usual and desired activities”.

Fatigue is considered a chronic condition that can be accompanied by neurological exacerbations or no change in neurological symptoms. The impact of fatigue on a person’s quality of life cannot be overstated. Not only does fatigue exacerbate impairment and disability, it is also intimately related to an individual’s sense of control over the illness and mental health.

Fatigue in MS is often characterised as either focal muscle fatigability or a generalised sense of lassitude. Despite more than 10 years of investigation, the pathophysiological basis of MS-related fatigue remains unknown. Scientists’ lack of understanding is in part a result of the biological complexity of fatigue. Physiologic and metabolic studies of people with MS, other neurologic disease states, and normal populations suggest that primary sources of fatigue can emanate from multiple levels within the neural hierarchy, beginning with ideation of an activity within the cortex and ending with the process of muscle contraction and force generation.

Default conduction of the demyelinated fibres and the presence of circulating cytokines in serum and cerebrospinal fluid may be contributing factors. Furthermore, many MS-related symptoms may contribute to fatigue, including depression, pain, insomnia, or mobility impairment. Therefore, before appropriate treatment can be administered, the origin of fatigue should be determined.
4.1.1 Fatigue and heat

Many people with MS experience a temporary worsening of their symptoms when the weather is very hot or humid, when they run a fever, sunbathe, get overheated from activity, or take hot showers or baths. A definitive symptom of MS ‘heat’ fatigue is where some people notice that their vision becomes blurred when they get overheated, this is a phenomenon known as Uhthoff’s sign. These temporary changes can result from even a very slight elevation in core body temperature, as little as 0.5°C. An elevated temperature further impairs the ability of a demyelinated nerve to conduct electrical impulses.7

For many years, the “Hot Bath” test was used to diagnose MS. A person suspected of having MS was immersed in a hot tub of water, and the appearance of neurologic symptoms or their worsening was taken as evidence that the person had MS. It is important to remember that heat generally produces only temporary worsening of symptoms and does not cause actual tissue damage (demyelination or damage to the axons themselves), however the use of the “Hot Bath” test has been erroneously associated with permanent tissue damage. The symptoms are generally rapidly reversed when the source of increased temperature is removed.7,8

As with so many other MS symptoms, fatigue can be exacerbated by, or conversely cause exaggeration to cognitive/emotional symptoms, spasticity, exercise tolerance and weakness poor nutrition, speech and swallowing problems.

4.1.2 Fatigue and exercise

People with MS who suffer with fatigue often comment on how physical exertion (exercise) increases their level of fatigue and how this deters them from wanting to participate in physical activities in the future. In fact several studies over the years have shown that hard physical exertion does in fact increase fatigue levels, and that the muscles of people with MS do fatigue more quickly than those of the general population.

A recent small study10 conducted at the MS Society of NSW in Australia, found that “when people with MS undertake exercise at a commencement level, they can expect that sensory symptoms may change temporarily, but they are unlikely to have any deleterious changes in fatigue and function”. This result can be beneficial in encouraging people with MS to continue to maintain fitness despite experiencing transient sensory symptoms. In fact, maintaining or improving fitness is an important part of any fatigue management plan.

4.1.3 Fatigue terminology

“A subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with usual and desired activities.”9

- Chronic persistent fatigue is defined as:5
  - Fatigue that is present for any amount of time on 50 percent of the days for more than 6 weeks.
  - Fatigue that limits functional activities or quality of life.

- Acute fatigue is defined as:5
  - New or a significant increase in feelings of fatigue in the previous 6 weeks.
  - Fatigue that limits functional activities or quality of life.

4.1.4 Management of MS fatigue

The management of MS fatigue can be incredibly useful in helping improve QoL for people with MS at any stage of life whether studying, working, raising a family, retired, ambulant, non ambulant or living in an aged care facility.

It is important to understand that there are several steps in the process to achieve a positive result in fatigue management.11,12 The first step is to consider which factors may be contributing to the fatigue.
A thorough assessment should include looking at diet, fitness, sleep, activity, depression and stress, heat, MS status (exacerbation or worsening of MS). The second step is to use strategies that will help manage the effects of fatigue. Non-pharmacological strategies recommended are: emotional support, energy management, planning and scheduling and communication. A qualified Occupational Therapist can work with anyone who has fatigue to create a plan that helps minimize the impact of this frustrating symptom.

Most MS Societies in Australia have specialist Occupational Therapists who run dedicated programs to teach fatigue management skills to people with MS or work with them individually.

MS Societies can provide information about MS fatigue and how best to manage it.

Following is a summary of points to consider when identifying fatigue as an MS issue.

---

### Table 4-1. Medications that may be prescribed for MS patients that can cause fatigue.

<table>
<thead>
<tr>
<th>Analgesics</th>
<th>Anti-inflammatory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Codeine phosphate</td>
<td>Ketorolac</td>
</tr>
<tr>
<td>Dihydrocodeine</td>
<td>Naproxen</td>
</tr>
<tr>
<td>Morphine</td>
<td></td>
</tr>
<tr>
<td>Oxycodone</td>
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<tr>
<td>Tramadol</td>
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<table>
<thead>
<tr>
<th>Anticonvulsants</th>
<th>Anti-inflammatory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carbamazepine</td>
<td>Ketorolac</td>
</tr>
<tr>
<td>Gabapentin</td>
<td>Naproxen</td>
</tr>
<tr>
<td>Phenobarbitone</td>
<td></td>
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<tr>
<td>Primidone</td>
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<table>
<thead>
<tr>
<th>Antidepressants</th>
<th>Anti-inflammatory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clomipramine</td>
<td>Ketorolac</td>
</tr>
<tr>
<td>Doxepin</td>
<td>Naproxen</td>
</tr>
<tr>
<td>Fluoxetine</td>
<td></td>
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<tr>
<td>Fluvoxamine</td>
<td></td>
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<tr>
<td>Sertraline</td>
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<tr>
<td>Venlafaxine</td>
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<table>
<thead>
<tr>
<th>Anti-inflammatory</th>
<th>Anti-inflammatory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Glipizide</td>
<td>Cardiac</td>
</tr>
<tr>
<td>Medroxy progestrone</td>
<td></td>
</tr>
<tr>
<td>Progesterone cream</td>
<td></td>
</tr>
<tr>
<td>Leuproline</td>
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<table>
<thead>
<tr>
<th>Antihistamines</th>
<th>Anti-inflammatory</th>
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</thead>
<tbody>
<tr>
<td>Azatadine</td>
<td>Anti-inflammatory</td>
</tr>
<tr>
<td>Chlorpheniramine</td>
<td>Ketorolac</td>
</tr>
<tr>
<td>Diphenhydramine</td>
<td>Naproxen</td>
</tr>
<tr>
<td>Loratadine</td>
<td></td>
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<table>
<thead>
<tr>
<th>Antihypertensive</th>
<th>Anti-inflammatory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amlodipine</td>
<td>Anti-inflammatory</td>
</tr>
<tr>
<td>Atenolol</td>
<td>Ketorolac</td>
</tr>
<tr>
<td>Clonidine</td>
<td>Naproxen</td>
</tr>
<tr>
<td>Diltiazem</td>
<td></td>
</tr>
<tr>
<td>Labetalol</td>
<td></td>
</tr>
<tr>
<td>Metoprolol</td>
<td></td>
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<tr>
<td>Nifedipine</td>
<td></td>
</tr>
<tr>
<td>Perindopril</td>
<td></td>
</tr>
<tr>
<td>Prazosin</td>
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<tr>
<td>Sotalol</td>
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<table>
<thead>
<tr>
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<td>Ketorolac</td>
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<tr>
<td>Fluoxetine</td>
<td>Naproxen</td>
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<tr>
<td>Fluvoxamine</td>
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<tr>
<td>Sertraline</td>
<td></td>
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<tr>
<td>Venlafaxine</td>
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<table>
<thead>
<tr>
<th>Cardiac</th>
<th>Anti-inflammatory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amiodarone</td>
<td>Anti-inflammatory</td>
</tr>
<tr>
<td>Flecainide</td>
<td>Ketorolac</td>
</tr>
<tr>
<td>Quinine</td>
<td>Naproxen</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Diabetic agents</th>
<th>Anti-inflammatory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Glipizide</td>
<td>Anti-inflammatory</td>
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<table>
<thead>
<tr>
<th>Immune modulators</th>
<th>Anti-inflammatory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interferon beta-1a</td>
<td>Anti-inflammatory</td>
</tr>
<tr>
<td>Interferon beta-1b</td>
<td>Ketorolac</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Antihistamines</th>
<th>Anti-inflammatory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Azatadine</td>
<td>Anti-inflammatory</td>
</tr>
<tr>
<td>Chlorpheniramine</td>
<td>Ketorolac</td>
</tr>
<tr>
<td>Diphenhydramine</td>
<td>Naproxen</td>
</tr>
<tr>
<td>Loratadine</td>
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<table>
<thead>
<tr>
<th>Antihypertensive</th>
<th>Anti-inflammatory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amlodipine</td>
<td>Anti-inflammatory</td>
</tr>
<tr>
<td>Atenolol</td>
<td>Ketorolac</td>
</tr>
<tr>
<td>Clonidine</td>
<td>Naproxen</td>
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<tr>
<td>Diltiazem</td>
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<tr>
<td>Labetalol</td>
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<tr>
<td>Metoprolol</td>
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<tr>
<td>Nifedipine</td>
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<tr>
<td>Perindopril</td>
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<tr>
<td>Prazosin</td>
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<td>Sotalol</td>
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<table>
<thead>
<tr>
<th>Sedative hypnotics</th>
<th>Anti-inflammatory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alprazolam</td>
<td>Anti-inflammatory</td>
</tr>
<tr>
<td>Clonazepam</td>
<td>Ketorolac</td>
</tr>
<tr>
<td>Diazepam</td>
<td>Naproxen</td>
</tr>
<tr>
<td>Lorazepam</td>
<td></td>
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<tr>
<td>Oxazepam</td>
<td></td>
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<tr>
<td>Temazepam</td>
<td></td>
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<tr>
<td>Triazolam</td>
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</table>

<table>
<thead>
<tr>
<th>Other</th>
<th>Anti-inflammatory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dantrolene</td>
<td>Anti-inflammatory</td>
</tr>
<tr>
<td>Hyoscine</td>
<td>Ketorolac</td>
</tr>
<tr>
<td>Metoclopramide</td>
<td>Naproxen</td>
</tr>
</tbody>
</table>

This information was derived from the 1998 Physicians’ Desk Reference (Medical Economics, Incorporation), and is meant to be representative rather than exhaustive.

Please refer to approved product information before any drug is prescribed, and note that use in MS is not necessarily an approved indication for that drug.
Assessment

1. Determine:
   - 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:
   - Relapse
   - Medications
   - Concurrent illness (eg infection)
   - Level of activity
   - Heat
   - Lifestyle patterns such as
     - sleep (exclude primary sleep disorders)
     - diet
     - exercise (types and levels of tolerance and endurance)
   - Psychosocial issues
   - Pain

3. Assess the severity of fatigue by:
   - Administering fatigue measurement scales (see Appendix B: Modified Fatigue Impact Scale [MFIS])

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

Non-pharmacological interventions

1. Promote patient understanding of MS-related fatigue
   - Provide written information sources as appropriate

2. Implement energy conservation strategies through:
   - Referral to an occupational therapist
   - Adaptations to home and work environments

3. Encourage appropriate lifestyle modifications with regards to:
   - Nutrition and fluid balance
   - Sleep patterns

   - Activity and rest patterns
   - Temperature control
     - cooling techniques
     - environmental temperature control (eg air conditioning)
     - avoiding temperature extremes
   - Refer patient to a physiotherapist for:
     - assistive devices

Pharmacological interventions

Advise patient to discuss modification fatigue-contributing medication regimens with their doctor (see Table 4-1), and inform patient of pharmacological treatment options as well as their side-effect profiles (see Table 4-2).

Pharmacological management of fatigue is rarely used in Australia. Some of these medications have been shown to have limited success at treating fatigue and while they are available on PBS (Pharmaceutical Benefits Scheme) their cost may still be prohibitive. However, it is still important to discuss their use with the GP and/or Neurologist as they may be considered as part of an overall fatigue management plan. Their role is adjuvant to non-pharmacological management of MS fatigue rather than treatment on their own.
<table>
<thead>
<tr>
<th>Medication</th>
<th>Brand names</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fluoxetine</td>
<td>Auscap</td>
<td>An antidepressant (selective serotonin reuptake inhibitor -SSRI) often used for patients who do not respond to amantadine treatment</td>
</tr>
<tr>
<td></td>
<td>Fluohexal</td>
<td>Usual dose: 20-60 mg/day</td>
</tr>
<tr>
<td></td>
<td>Lovan</td>
<td>Side effects may include nervousness, anxiety, insomnia, and nausea</td>
</tr>
<tr>
<td></td>
<td>Prozac</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Zactin</td>
<td></td>
</tr>
<tr>
<td>Methylphenidate</td>
<td>Attena</td>
<td>A central nervous system (CNS) stimulant often used to reduce fatigue and improve alertness in MS</td>
</tr>
<tr>
<td></td>
<td>Ritalin</td>
<td>Usual dose: 10-30 mg/day</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Side effects may include insomnia, decreased appetite, and hyperactivity</td>
</tr>
<tr>
<td></td>
<td></td>
<td>There is potential for addiction with this agent; therefore it should be used with caution, particularly in patients with depressive disorders</td>
</tr>
<tr>
<td>Modafinil</td>
<td>Modavigil</td>
<td>A CNS stimulant often used to treat the excessive daytime sleepiness associated with narcolepsy</td>
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<tr>
<td></td>
<td></td>
<td>Usual dose: 200-400 mg/day</td>
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<tr>
<td></td>
<td></td>
<td>Side effects may include headache, asthenia, and nausea</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Should not be used in patients with mitral valve prolapse (MVP) or left ventricular hypertrophy (LVH)</td>
</tr>
<tr>
<td>Sertraline</td>
<td>Zoloft</td>
<td>Another SSRI used to treat depression</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Usual dose: 25-200 mg/day</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Side effects may include agitation, insomnia, male sexual dysfunction, somnolence, dizziness, headache, tremor, anorexia, diarrhoea/loose stools, and nausea</td>
</tr>
</tbody>
</table>

Please refer to approved product information before any drug and its dose is prescribed, use in MS is not necessarily an approved indication. 4-aminopyridine (4-AP) is a potassium-channel blocker that improves conduction in demyelinated axons, and it has been shown to reduce MS-related fatigue. However, use of this agent is restricted to particular centres that have access to the drug mainly within North America, and it is currently not approved for use in Australia.
4.2 Incontinence

4.2.1 Bladder dysfunction

Approximately 75% of patients with MS experience some type of bladder dysfunction during the course of their disease. Two neural circuits are thought to control bladder function: the sacral spinal cord for storage and the pontine micturition centre for emptying. Any disruption in the pathways between these circuits may result in dysfunction.\(^8\)

The three types of bladder dysfunction most commonly associated with MS are:\(^{14-16}\)

1. Failure to store
2. Failure to empty
3. Combination failure to store and failure to empty

Failure to store (detrusor hyperreflexia)

This is the most common type of bladder dysfunction in MS, with reported incidences ranging from 26-50\%. Failure to store occurs when the bladder is unable to accommodate increasing urine volumes, causing spontaneous contractions within the bladder. Symptoms of this dysfunction include urgency, frequency, urge incontinence, and nocturia.\(^{14,15}\)

Failure to empty

This is less common (i.e. incidence 19-40\%) but can result in more serious complications than failure to store. It may be caused by one or more of the following:\(^{8,14-17}\)

- atonic bladder
- detrusor hyperreflexia with poorly sustained contractions
- detrusor-sphincter dyssynergia

Symptoms of failure to empty include frequency, nocturia, retention, overflow incontinence, and urinary tract infections.
Combination failure to store and failure to empty

This occurs in 24-46% of patients with bladder dysfunction in MS. It is often associated with detrusor-sphincter dyssynergia. Symptoms of this type of bladder dysfunction include those associated with both failure to store and failure to empty. If not treated appropriately this condition can lead to recurrent urinary tract infections, urinary reflux, hydronephrosis and in extreme cases renal failure.

Assessment

1. Determine the nature of the bladder problem.
   • Describe symptoms
      – 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:
   • Failure to store (ie presenting symptoms include frequency, urgency, and incontinence)
   • Failure to empty (ie presenting symptoms include hesitancy, dribbling and leaking, retention, and sensations of incomplete emptying)
   • Combination failure to store and failure to empty (ie presenting symptoms include a combination of the above-mentioned symptoms)

3. Identify possible contributing factors, such as:
   • 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:
   • Sexual activity
   • Recreation/social activities
   • Employment
   • Quality of life

5. Assess for the presence of the following secondary complications:
   • Infection – including the presence of Candida
   • Skin breakdown
   • Renal calculi

6. Determine the impact of the dysfunction on other MS-related symptoms

7. Assess the severity of the dysfunction by administering quality-of-life scales (see Appendix C: Bladder Control Scale [BLCS])

8. Identify existing management strategies and coping behaviours

Interventions

1. Follow the algorithm for the management of bladder dysfunction (see Figure 4-1)

2. Rule out urinary tract infection through urinalysis and urine culture

3. Instruct the patient to keep a 24-hour “urolog” (ie log of fluid intake-output; see Appendix D)

4. Perform a post-void residual (PVR) test
   • 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)

5. Educate the patient on the role of medications and intermittent catheterisation in controlling symptoms

6. Instruct the patient to perform clean, intermittent catheterisation (if the patient is willing and able and if PVR is greater than 100 ml)

7. Assist the patient to develop a drinking and voiding schedule
8. Educate the patient about factors that may influence symptoms, such as:
   - Caffeine
   - Aspartame
   - Alcohol
   - Infection
   - Constipation

9. Refer patient to a urologist if symptoms remain unmanageable or if complications develop or are suspected

10. Inform patient of pharmacological treatment options as well as their side-effect profiles (see Table 4-3)

11. Provide ongoing evaluation of management strategies for bladder dysfunction including advice on the use of pads if appropriate

**Desired patient outcomes**

- Reduction or elimination of bladder symptoms through adaptive strategies
- Continence
- Prevention of complications

**Intermittent self-catheterisation**

Intermittent self-catheterisation is a simple technique used to empty the bladder of people with MS with urinary retention. It is important to ensure the bladder is emptied regularly throughout the day to reduce the risk of urinary tract infections, due to urinary stasis, and also because a bladder which is constantly stretched loses function which may then cause renal damage and urinary leakage.

---

**Figure 4-1. Algorithm for management of bladder dysfunction.**

[Diagram of bladder dysfunction management algorithm]
The technique of clean intermittent self-catheterisation is easy to learn and quickly becomes acceptable. Once the simple technique has been mastered through practice, patients find peace of mind by once again being in control of their bladder. People with MS learning this technique, need to be able to use both hands, have reasonable memory function, and minimal leg spasms.

Intermittent self-catheterisation is usually performed 4 times a day. If the person finds it necessary to do this more frequently they may require some anticholinergic medication or they may have a urinary tract infection. They should restrict their fluid intake to 1500 ml per day. Intermittent self-catheterisation can be taught at home, with the person sitting on the toilet. The local community nurse or continence advisor is able to teach this technique to anyone who may need it.

**Indwelling urethral catheters and suprapubic catheters**

Sometimes it is inevitable that people with MS may require long-term catheterisation. For long-term catheter management a suprapubic catheter is the preferred method for the following reasons:

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### Table 4-3. Pharmacological options that may be used in Australia for treating bladder dysfunction in MS.

<table>
<thead>
<tr>
<th>Medication</th>
<th>Examples of Brand names</th>
<th>Description</th>
</tr>
</thead>
</table>
| Desmopressin acetate | Minirin nasal spray     | An antidiuretic hormone analogue used to alleviate nocturia  
Usual dose: 20 µg nightly  
Side effects may include headaches, nausea, rhinitis, and abdominal cramps |
| Hyoscyamine         | Donnatab                | An antispasmodic agent used to treat bladder spasms  
Usual dose: 1-2 mg/day on an empty stomach  
Side effects may include dry mouth and throat, difficulty swallowing, urinary hesitance and retention, blurred vision, cycloplegia, palpitations, dizziness, headache, insomnia, mood changes, oedema, impotence, interference with normal heat regulation, and severe allergic reactions |
| Oxybutynin          | Ditropan                | An anticholinergic/antispasmodic agent used to reduce urgency  
Usual dose: 5 mg 1-3 times daily on an empty stomach  
Side effects may include dry mouth and throat, difficulty swallowing, urinary hesitance and retention, blurred vision, cycloplegia, palpitations, dizziness, headache, insomnia, mood changes, oedema, impotence, interference with normal heat regulation, and severe allergic reactions |
| Propantheline       | Pro-Banthine            | An anticholinergic agent used to treat storage dysfunction  
Usual dose: 7-15 mg 1-3 times daily  
Side effects may include dry mouth, decreased sweating, ophthalmic problems, urinary retention, insomnia, nausea, constipation, bloated feeling, and drowsiness |
| Tolterodine         | Detrusitol              | An anticholinergic/antispasmodic agent used to treat bladder spasms that cause urgency  
Usual dose: 2 mg twice daily  
Side effects may include dry mouth, constipation, abnormal vision, urinary retention, and xerophthalmia |
| Imipramine/Amitriptyline | Tofranil/Endep        | Tricyclic antidepressants  
Side effects may include dry mouth, abnormal vision, urinary retention, and constipation |

Please refer to approved product information before any drug and its dose is prescribed, use in MS is not necessarily an approved indication.
• It is easier to change
• There is a reduced risk of infection
• The catheter is easier to care for
• It is possible for the patient to have a normal sexual relationship
• People with MS with a long-term urethral catheter very quickly develop a patulous urethra, because of their lack of muscle tone, and consequently become incontinent. Surgery is then required to repair the patulous urethra and insert a suprapubic catheter

Whether a person has a suprapubic or indwelling urethral catheter the following rules will ensure good catheter management:

1. Use 18 or 20 Fg silicone or silastic catheters only
2. Use 5ml balloon catheters only
3. Secure dependant drainage
4. Change the catheter every 4 weeks using a sterile technique
5. Ensure that the patient drinks at least 3 litres of fluid evenly throughout the day*
6. Anchor the catheter to the patient’s thigh
7. Maintain a closed drainage system
8. Use anticholinergic medications to suppress bladder spasms
9. †Take specimens for culture only after sterile catheter change
10. †Treat symptomatic and Proteus infections
11. Schedule IVP annually

†Considered the most important points
Source: Catheter Rules provided by Professor Richard Millard
Prince of Wales Hospital Sydney March 2002

*Check that the person with MS has not been prescribed fluid restriction for other health reasons.

Rationale

1. Silicone and silastic catheters encrust less easily and are non-toxic. Catheters should conform to Australian standards. 18Fg is the ideal size to give good drainage and fewer blockages.
2. A 5ml balloon is adequate to hold the catheter in place and is less irritating to the bladder than a 20ml balloon. Bladder spasms are minimised.

Note: Do not put 5ml in a 20ml balloon; it does not inflate the balloon properly.

3. Even today water only flows downhill! Make sure the drainage tubing doesn’t kink.
4. Despite manufacturer’s claims, all catheters tend to become encrusted and colonised. It is false economy to try to make catheters last extra time. The money saved is much less than the cost of a course of antibiotics.
5. A high flow of urine reduces encrustation and infections. Inform patients to drink sufficient fluid to make the urine look like gin: they remember such advice. The best way to irrigate a catheter is to get the patient to drink more fluids.
6. By preventing both catheter avulsion and yawning, there is less likelihood of infection being carried alongside the catheter if it is not moving.
7. Every time closed drainage is breached there is a very high risk of introducing bacteria into the system. This is the commonest cause of recurrent infections. Catheter irrigation is dangerous and largely unnecessary. If the catheter blocks repeatedly change it and commence irrigation orally.
8. Bladder spasms are the commonest cause of leakage around the catheter and may be painful. They are best suppressed by using anticholinergic agents, some examples are Ditropan®, Donnatab®, Pro-Banthine® taken on an empty stomach an hour before food or two hours after food.
9. †All catheters become colonised after a few days. There is a 50% false positive rate in cultures taken from such catheters. A specimen taken after a sterile change of catheter gives the only reliable guide to the bacteria present in the bladder.
10. †Only symptomatic and proteus infections require treatment. Significant infections are pure rather than mixed growth. Treat with the simplest antibiotic for 7-10 days and re-culture the urine to ensure complete eradication.

Persistent or recurrent growths of the same organism may indicate urinary tract calculi. An intravenous pyelogram (IVP) should be performed and catheter management should be reviewed.
Some patients require low dose prophylaxis (eg Macrodantin® 50 mg daily). Hiprex® is almost ineffective with suprapubic catheters.

11. The upper urinary tract should not be neglected. Look for renal scars and stones, ureteric dilatation, and egg-shell calculi in the bladder.

†Considered the most important points

Source: Catheter Rules provided by Professor Richard Millard Prince of Wales Hospital Sydney March 2002

4.2.2 Bowel dysfunction

Like bladder dysfunction, bowel dysfunction is common among people with MS (ie prevalence approximately 68%). It should be noted that many individuals with bladder symptoms do not experience bowel problems. Furthermore, bowel dysfunction does not appear to be associated with the degree of disability. However, it is associated with duration of MS.21-25

Neural control of defaecation is not as well understood as that of micturition. However, it has been suggested that the pons controls defaecation along with influence from spinal cord neural centres and other cortical centres.

The two main types of bowel dysfunction in MS are constipation and faecal incontinence.

**Constipation** is defined as two or fewer bowel movements per week and/or the use of suppositories, laxatives, or enemas more than once per week to promote bowel movements. Constipation occurs in approximately 36–53% of MS patients. Factors that contribute to constipation include certain medications, weakened abdominal muscles, pubococcygeal spasticity, diet, lack of fluids and immobility.14,21-23,26,27

**Faecal incontinence** is defined as the involuntary passage of stool. It occurs in about 25% of patients with MS once a week and 51% of patients less than once a month. Factors contributing to faecal incontinence include constipation that causes rectal distension and overflow, diminished rectal sensation, sphincter dysfunction, certain medications and diet.14,21,22

### Assessment

1. Determine the nature of the bowel problem
   - Determine onset and duration of symptoms
   - Describe symptoms:
     - constipation  - bloating
     - diarrhoea  - cramping
     - incontinence  - rectal urgency
     - flatulence

2. Categorise bowel dysfunction into one of the following categories according to presenting symptoms:
   - Constipation
   - Faecal incontinence

3. Identify possible contributing factors, such as:
   - Concurrent medical conditions
   - Medications
   - Reduced mobility
   - Altered nutrition and/or fluid intake

4. Assess the impact of the bowel dysfunction on the following aspects of daily living:
   - Sexual activity
   - Recreation/social activities
   - Employment
   - Quality of life

5. Assess the severity of the dysfunction by administering quality-of-life scales (see Appendix E: Bowel Control Scale [BWCS])

6. Assess for the presence of the following secondary complications:
   - Haemorrhoids
   - Impaction or bowel obstruction
   - Infection

7. Determine the impact of the problem on other MS-related symptoms

8. Identify existing management strategies and coping behaviours

9. Identify behaviours that may be contributing to the dysfunction
Table 4-4. Pharmacological options that may be used in Australia for treating constipation in MS.

<table>
<thead>
<tr>
<th>Medication</th>
<th>Examples of Brand names</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Bulk forming agents</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psyllium</td>
<td>Metamucil</td>
<td>A laxative/fibre supplement used for relief of chronic, atonic, spastic, or rectal constipation. Usual dose: 2 spoonfuls 1-3 times daily. May cause minor bloating. Increased fluid intake essential.</td>
</tr>
<tr>
<td>hydrophilic mucilloid</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Stool softeners</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Docusate</td>
<td>Coloxyl or Coloxyl with Senna</td>
<td>Used for relief of occasional constipation. Usual dose: 50-250 mg/day. Usually well tolerated if used for short periods of time in recommended doses. Overuse may cause diarrhoea, weak bones, liver disease, poor absorption of fats, colon problems, and low blood levels of potassium, calcium, and magnesium.</td>
</tr>
<tr>
<td><strong>Lactulose</strong></td>
<td>Duphalac</td>
<td>Used for relief of constipation. Usual dose: 10-30 ml/day. Common side effects may include increased thirst, cramps, nausea, diarrhoea, and gas. Less common side effects include irregular heartbeat, dizziness, confusion, and fatigue.</td>
</tr>
<tr>
<td><strong>Other therapies</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sodium citrate</td>
<td>Microlax</td>
<td>A suppository used to promote defaecation. Can be used alone or in combination with bulk-forming agents or stool softeners. Usual dosage and administration: one adult or paediatric suppository inserted in the rectum and held for 15 minutes. Side effects may include irritation of the mucus membrane in the rectum, nausea, vomiting, headache, confusion, severe dehydration, cardiac arrhythmias, and hyperosmolar nonketotic coma.</td>
</tr>
<tr>
<td>Magnesium hydroxide</td>
<td>Myalanta and Mucaine</td>
<td>A saline laxative and antacid used for relief of occasional constipation. Can be used alone or in combination with bulk-forming agents or stool softeners. Usual dose: 5-10 ml/day; should be taken with 240 mL of water. Usually well tolerated.</td>
</tr>
<tr>
<td>Standardised sennosides</td>
<td>Senokot</td>
<td>A peristaltic stimulant used for relief of constipation. Can be used alone or in combination with bulk-forming agents or stool softeners. Usual dose: 1-4 tablets/day (each tablet contains 8.6 mg of standardised sennosides and 50 mg of docusate sodium). Usually well tolerated.</td>
</tr>
<tr>
<td>Bisacodyl</td>
<td>Bisalax and micro-enema</td>
<td>Used to evacuate bowel contents. Usual dose: 1 enema prn. Side effects are electrolyte loss, diarrhoea, nausea and rectal irritation.</td>
</tr>
</tbody>
</table>

Please refer to approved product information before any drug and its dose is prescribed, use in MS is not necessarily an approved indication.
Module 4 - Signs & Symptoms

General interventions

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)
   • 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
   • Assist the patient in determining a regular time for bowel defaecation
5. Encourage dietary changes such as:
   • 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
   • 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 (see Table 4-4):
   • Bulk-forming agents
   • Stool softeners
   • Therapies that may be used alone or in combination with bulk-forming agents or stool softeners

Table 4-5. Pharmacological treatment options that may be used in Australia for faecal incontinence in MS.

<table>
<thead>
<tr>
<th>Medication</th>
<th>Examples of Brand names</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psyllium hydrophilic mucilloid</td>
<td>Metamucil</td>
<td>A laxative/fibre supplement that may be used for the treatment of faecal incontinence; however, should be taken with less water than when used for the treatment of constipation Usual dose: 2 spoonfuls 1-3 times daily May cause minor bloating</td>
</tr>
<tr>
<td>Propantheline</td>
<td>Pro-Banthine</td>
<td>An anticholinergic agent used to treat storage dysfunction Usual dose: 7-15 mg once to 3 times daily Side effects may include dry mouth, decreased sweating, ophthalmic problems, urinary retention, insomnia, nausea, constipation, bloated feeling and drowsiness</td>
</tr>
<tr>
<td>Oxybutynin</td>
<td>Ditropan</td>
<td>An anticholinergic/antispasmodic agent used to reduce urgency Usual dose: 5 mg 1-3 times daily Side effects may include dry mouth and throat, difficulty swallowing, urinary hesitance and retention, blurred vision, cycloplegia, palpitations, dizziness, headache, insomnia, mood changes, oedema, impotence, interference with normal heat regulation and severe allergic reactions</td>
</tr>
<tr>
<td>Loperamide</td>
<td>Imodium</td>
<td>An antidiarrhoeal agent used only in acute, severe cases of faecal incontinence Usual dose: 2 mg 2-4 times daily Side effects may include skin rash, urticaria, nausea, altered taste, headache, chills, dry mouth, cough and constipation</td>
</tr>
</tbody>
</table>

Please refer to approved product information before any drug and its dose is prescribed, use in MS is not necessarily an approved indication.
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:
   • Avoid bowel irritants such as:
     – alcohol
     – caffeine
     – spicy foods
     – other identified dietary triggers
   • Avoid unnecessary use of antibiotics
   • Use medication(s) for control of faecal incontinence/involuntary bowel movement (see Table 4-5)
5. Recognise that anxiety and stress may play a role in this problem
6. Provide ongoing evaluation of bowel dysfunction

Desired patient outcomes

Maintains bowel control as shown by:
• A regular elimination pattern
• Continence
• Prevention of complications
Identifies and manages causes of bowel dysfunction
4.3 Pain

Introduction

“Pain is an individualistic, physiologic, learned and social response to a noxious stimuli” [International Association of Pain 1994].

The human reaction to pain is a psychophysiological process which is influenced by social and family support, culture, religion, age, gender and responsibilities.28-30 It is, in essence, subjective and can be associated with actual or potential tissue damage.

Pain in MS is related to the inflammatory demyelinating injury process and the disability that it produces and was first described by Charcot in 1872. The prevalence of a painful condition is reported to be as high as 80%, with half of patients with this symptom at some time describing their pain as severe.29,31-33 The incidence of pain tends to increase with prolonged disease history, advancing age and increasing disability.29,30,34

To effectively manage MS pain a detailed objective assessment is essential. Information required for evaluation would include 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.28,29,31,35,36

Anxiety, fear and depression do not necessarily increase the pain experience however it does affect an individual’s reaction to pain.28,37

The goal of treatment approach is to promote comfort and quality of life, promote independence and self-management, and provide patients with a sense of control over their disease.

The experience of pain

Sensory/Discriminative: This is how pain is processed by perceptions of strength, intensity as well as the temporal and spatial aspects of the experience.

LEARNING OBJECTIVES

After completing this section, the reader will be able to:

• Identify and understand acute, subacute and chronic pain syndromes associated with MS

• Obtain a comprehensive pain assessment

• Identify, implement and rationalize pain management strategies

• Identify specific medications and why they are chosen in MS pain management

• Effectively monitor and reassess pain management

Motivational/Affective: Describes the conditioned or learned avoidance behaviours that can be demonstrated in life preserving or “escape” behaviour, and illustrated in affective impulses and mood. These responses are mediated through the interaction of the reticular formation, limbic system and brain stem.

Cognitive/Evaluative: This overlies the learned behaviour to block, modulate or enhance the pain experience. The interpretation of these responses requires an understanding of the cultural, gender, role and life experiences of the person responding to the stimuli.
4.3.1 Mechanisms of pain

Nociceptors are free nerve endings and, except for the brain, exist in all of the body tissue. Pressure, temperature and chemical mediators can stimulate the polymodal fibres and result in pain stimulation. Pain can occur without nociception. This is known as central or deafferentation pain.\(^{37,39}\)

Once the nociceptors are stimulated pain is transmitted via:
- small myelinated A delta fibres resulting in sharp pain
- small non-myelinated C fibres resulting in dull aching pain

Once stimuli are transmitted, the pain message is received and modulated in the dorsal horn cells and certain areas of the brain stem. The message is then relayed via the dorsal horn of the spinal cord, or the sensory fibre of the cranial nerves to pain specific areas within the cerebral cortex.\(^{22,31}\) Segmental reflexes can be generated all along the pain pathway signalling withdrawal or response to noxious stimuli. The stimulated reflexes associated with the sympathetic and endocrine responses contribute to spasm of peripheral vessels, increased muscle tone, a high cardiac output, an increase in blood pressure and anxiety.\(^{30,38,39}\)

4.3.2 Pain syndromes

There are four types of pain categorised.

Neuropathic nociceptive/deafferentation

This occurs in the absence of a stimulus and produces electric, burning shooting, stabbing sensations. Trigeminal neuralgia, causalgia, spinal cord disruption and dysaesthetic limbs are placed under this pain syndrome.\(^{30,38,40,41}\)

Somatic nociceptive

Often described as localised and aching pain. It is due to an ongoing noxious stimulation, which originates from bone, the fascia joints, tendons, ligaments and muscles.

Somatic nociceptive pain includes back pain, degenerative disease, osteoporosis, fractures and painful spasms.\(^{38,40,41}\)

Visceral nociceptive

This is dull, diffuse, and poorly localised. It occurs through the stimulation of the nociceptors in a hollow viscus such as the heart, lungs, bowel or bladder. The discomfort usually occurs through stretching, tension, bladder spasms, pressure, pelvic pain, contraction or chemical irritation.\(^{38,41}\)

Psychogenic syndrome

Fear, worry, anxiety and depression. Not all pain is related to MS. It can also occur through cognitive and psychiatric disturbances.\(^{31,40,42}\)

4.3.3 Pain classification

Acute pain

This has a sudden onset, is brief in time, and can occur repeatedly. In MS this pain is paroxysmal, meaning sharp, intermittent spasms that are sudden and spontaneous in nature. These pain sensations have been described as intense, shooting, electric shock like, tic like and burning. They can occur continuously throughout a day and can be both frightening and disabling.\(^{29,36,40}\) Although the underlying pathophysiological mechanism is unknown it is hypothesised that ephatic (cross talk) transmission is the likely, but not the sole cause, of paroxysmal symptoms. It is believed that demyelination and axonal damage, changes the microenvironment of nerve fibres and results in the production of scattered spontaneous electrical discharges thus causing dramatic paroxysmal motor or sensory episodes.\(^{34,38,40,41}\)
Subacute pain
This can vary from days to weeks. It can be the result of an acute inflammatory demyelinating episode, which is causing conduction block,\textsuperscript{29,36,41} or as a result of treatment.\textsuperscript{39}
A common condition that causes subacute pain is optic neuritis. Other conditions include urinary tract infection, urinary retention, influenza, neuropathic bladder spasming and decubitus ulcerers.\textsuperscript{29,34,36,40}

Chronic pain
This is defined as pain that persists for longer than 1 month, without resolution. It is estimated that the majority of MS patients will experience a chronic pain syndrome, which is multifactorial and refractory to treatment.\textsuperscript{29,30,35} The most common chronic pain syndrome is neuropathic or dysaesthetic extremity pain. It has an insidious onset and more often occurs in the lower extremities, however it can involve the torso and arms. The pain is often described as pricking, constrictive, tingling, aching, dull, burning, nagging and troublesome. The transmission of abnormal electrical discharges laterally across demyelinating plaques within the posterior columns of the spinal cord is thought to be the probable cause of chronic pain syndrome as it is almost always accompanied by posterior column sensory loss.\textsuperscript{29,30,36,40}

4.3.4 Pain categories

Acute
• Trigeminal neuralgia: is an acute neuropathic pain syndrome, which affects the face, cheek and jaw. The trigeminal nerve sends impulses of touch, pain, pressure and temperature to the brain from the face, jaw, gums, forehead and around the eyes. In MS, trigeminal neuralgia is usually caused by demyelination of one or more branches of the fifth cranial nerve. It is reported to often affect the trigeminal sensory fibres either in the nerve root or less commonly the brainstem.\textsuperscript{29,43,44} Trigeminal neuralgia is characterised by paroxysmal, sudden facial pain which occurs in the area of the 5th cranial nerve or trigeminal nerve and often triggered by touch, chewing, shaving or even a light breeze.

Chronic
• Tonic spasms/seizure: muscular spasms of the limbs and trunk. The tonic contraction frequently spreads to the other limb on the same side. The face can also experience involuntary contortion.
• Extremity pain: arms and legs. Paroxysmal limb pain is burning, aching or itching that tends to last for seconds or minutes. Although it can affect any part of the body including the perineum it most commonly involves the extremities.\textsuperscript{29}
• Lhermitte’s signs: when the neck is flexed, a sharp electric shock sensation travels down the spine. The occurrence of this electrical experience has been reported to occur at some time in up to 25% of people with MS. The cause of this electrical like experience is thought to arise from spinal cord lesions affecting the posterior columns and cervical nerve roots.\textsuperscript{40,41,45}

Subacute
• Optic neuritis: inflammation of the optic nerve. It is not uncommon for this to be the first symptom experienced. Optic neuritis usually begins with acute or sub acute visual blurring or loss in one eye with the most profound deficit being in the central visual field. Pain commonly occurs and is made worse with eye movement. Optic neuritis pain usually resolves in 7-10 days.\textsuperscript{35,40}
• Steroid-induced compression fractures: spine.
• Neural palsies: nerve numbness or paraesthesia.

• Central/radiculopathy/neuropathic: involvement of the nerve root.
• Musculoskeletal: muscles and bone. As MS advances it is more likely that chronic pain develops due to mechanical stress. As the disease progresses postural abnormalities, weakness immobility and the improper use of compensatory muscles worsens. A demyelinating lesion in the cervical, thoracic, or lumber spinal cord may also be a causative factor of back pain.\textsuperscript{29,41}
• Headache / Migraine: Whether MS can cause headaches is controversial. However it is suggested that when the person with MS develops midbrain plaques there is an increased incidence of the likelihood of headache with migraine characteristics.\textsuperscript{40,41,46}
• **Dysaesthetic**: impairment of sense, especially touch. Dysaesthetic extremity pain is the most common type of chronic pain syndrome in MS.

It occurs more in people with greater disability scores, and could be attributed to demyelinating lesions in the posterior or dorsal column of the spinal cord. It is described as a constant nagging, burning sensation, mostly in the feet, or a painful tingling or throbbing “like toothache”. It worsens at night and on walking. Pain tends to be aggravated by changes in the weather or temperature.29,41

### Pain assessment

When collecting data, consideration must be given to people who experience cognitive impairment, sensory impairment, as well as their cultural, language and educational needs.

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:
   - 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:
   - Relapse
   - Poor access to health care
   - Immobility
   - Concurrent illness (eg osteoporosis, disc herniation, migraine)
   - 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
   - Daily activities
   - Sexuality
   - Employment
   - Other MS-related symptoms
   - Psychological wellbeing (eg depression, anxiety, fear)
   - Psychosocial wellbeing (eg isolation, avoidance, family dynamics)

### Treatment options

**Specific interventions for acute pain**

1. Discuss pain relief options (Table 4-6) and their possible side effect profile
   - Anticonvulsants
   - Surgical treatments such as percutaneous glycerol rhizotomy
2. Ensure patient is aware that the pain of trigeminal neuralgia may worsen particularly during:
   - Smiling
   - Chewing
   - Touching
   - Exposure to wind and extreme temperatures
   - Hyperventilation
   - Certain facial movements/positions

**Specific interventions for subacute pain**

1. Ensure that the patient is aware that pain may worsen with:
   - Eye movements (in optic neuritis)
   - Prolonged immobility
2. Ensure patient understands the contribution of concurrent illness to pain
3. Discuss pain relief drugs and their possible side effect profile (Table 4-6)
## Table 4-6. Pharmacological options that may be used in Australia for treating MS-related pain.

<table>
<thead>
<tr>
<th>Medication</th>
<th>Mechanism of action</th>
<th>Common side effects</th>
<th>Uses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carbamazepine (eg Tegretol) [Anticonvulsant]</td>
<td>Reduces the amount of sodium ions which causes a blockade effect on sodium channels</td>
<td>Impaired alertness, dizziness, bone marrow depression, dysarthria, constipation, hyponatraemia, altered taste, sedation, ataxia, GI upset, diplopia</td>
<td>Trigeminal neuralgia, Lhermitte’s, facial pain, paroxysmal pain, tremor, neuropathic pain</td>
</tr>
<tr>
<td>Phenytoin (eg Dilantin) [Anticonvulsant]</td>
<td>Blocks voltage dependant sodium channels thus reducing spasmodic discharges</td>
<td>Tremor, dysarthria, ataxia, sedation, confusion nystagmus, diplopia</td>
<td>Neuropathic pain, tonic spasms, trigeminal neuralgia, facial pain</td>
</tr>
<tr>
<td>Gabapentin (eg Neurontin) [Anticonvulsant]</td>
<td>Increases gamma-aminobutyric acid (GABA) in the brain and decreases excitatory neurotransmitter glutamate</td>
<td>Sedation, ataxia, fatigue, nystagmus, tremor, GI upset, diplopia</td>
<td>Trigeminal neuralgia, facial pain, Lhermitte’s, paroxysmal pain, dysesthetic pain</td>
</tr>
<tr>
<td>Celecoxib (Celebrex) Ibuprofen, naproxen [NSAID]</td>
<td>A cyclooxygenase-2 (COX-2) inhibitor COX-1 and 2 inhibitors</td>
<td>GI upset, diarrhoea, haematological toxicity, fluid retention</td>
<td>Treatment of varying mild-to-moderate inflammatory pain</td>
</tr>
<tr>
<td>Methylprednisolone (intravenous) (eg Solu-Medrol) [Anti-inflammatory]</td>
<td>A synthetic corticosteroid which influences carbohydrate, protein, fat and purine metabolism</td>
<td>Steroid myopathy, osteoporosis, pathologic fractures, transient nausea, vomiting, cardiac arrhythmias, sleep disturbance, GI upset, psychiatric disorders</td>
<td>Optic neuritis, paraplegia, brain stem symptoms</td>
</tr>
<tr>
<td>Baclofen (eg, Baclo, Clofen, Lioresal, Stelax) [Muscle relaxant]</td>
<td>Reduces excitatory trigeminal nerve transmission. Increases latency of response</td>
<td>Weakness, transient drowsiness, dizziness, fatigue GI upset, seizures</td>
<td>Trigeminal neuralgia, episodic facial pain</td>
</tr>
<tr>
<td>Amitriptyline (eg Endep) [Tricyclic antidepressant]</td>
<td>Interrupts the reuptake of neurotransmitters which modulate pain pathways descending to the spine</td>
<td>Dry mouth, drowsiness, sedation, blurred vision, urinary retention, constipation</td>
<td>Episodic facial pain, paroxysmal limb pain, headache</td>
</tr>
<tr>
<td>Clonazepam (eg Paxam, Rivotril) [Anticonvulsant]</td>
<td>Activates the GABA A-receptors that open the chloride channel and hyper-polarises the cell. This process results in postsynaptic inhibition</td>
<td>Sedation, ataxia lethargy, dizziness</td>
<td>Paroxysmal limb pain, tremor, neuropathic pain, tics</td>
</tr>
<tr>
<td>Lamotrigine (eg Lamictal) [Anticonvulsant]</td>
<td>Blocks voltage sodium channels, inhibiting the release of neurotransmitters particularly glutamate and aspartate</td>
<td>Dizziness, diplopia, ataxia, blurred vision, insomnia, headache, irritability</td>
<td>Tonic spasm, trigeminal neuralgia, episodic facial spasm</td>
</tr>
<tr>
<td>Dantrolene (eg Dantrium) [Skeletal muscle relaxant]</td>
<td>Depresses calcium mediated myofibril contractions thus directly reducing muscle tone</td>
<td>Drowsiness, weakness, dizziness, fatigue, diarrhoea, drooling, nausea</td>
<td>Spasticity pain</td>
</tr>
</tbody>
</table>

Please refer to approved product information before any drug and its dose is prescribed, use in MS is not necessarily an approved indication.
Specific interventions for chronic neuropathic pain

1. Instruct patient on the following coping strategies to help minimise pain:
   • Behaviour-modification techniques
   • Relaxation techniques
   • Stress-management techniques
   • Cognitive-behaviour techniques
   • Transcutaneous nerve stimulation

2. Discuss pain relief drugs and their possible side effect profile (Table 4-6)

3. Refer the patient back to their neurologist

4. Refer the patient to a designated pain specialist

Assess efficacy of interventions

1. Review their pain diary

2. Assess the person’s physical and psychological ability to comply with pain management strategies

3. Ensure education and information is given to families and other relevant health care providers

4. Accurately record assessment details to facilitate regular assessment and later review

5. Ensure staff are competent in pain assessment and management

Discuss pain management interventions

1. Explain and educate the person on the possibility of coexisting conditions contributing to chronic musculoskeletal pain:
   • Osteoporosis
   • Degenerative disc disease

2. Refer patient to a physiotherapist and occupational therapist for assessment and rehabilitation interventions such as:
   • 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
   • Resting for periods throughout the day
   • Restricting mobility
   • Regular medications
   • Support aids
   • Relaxation techniques
   • Hot packs/cold packs

5. Acknowledge and discuss complementary therapies
   • Acupuncture
   • Reflexology
   • Yoga
   • Tai-chi
   • Massage
   • Relaxation
   • Visualisation
   • Aromatherapy
   • Reiki
   • Meditation

Desired patient outcomes

• The person identifies the type of pain experienced
• The person is reassured that the healthcare provider acknowledges the pain experience as real
• Pain symptoms are eliminated or reduced through the use of behavioural strategies, rehabilitation, drugs and other interventions
• Compliance is adopted and maintained with recommended pain control interventions
• The person experiences an improved quality of life when performing activities of daily living
• The person is pro-active and will initiate pain review if and when required
4.4 Spasticity

Introduction

Spasticity, a velocity-dependent increase in tonic stretch reflexes, is a common MS-related symptom, particularly in patients experiencing weakness in the lower limbs due to plaque formation in the brain and spinal cord.\(^4^7\) Spasticity can be both phasic (spasms) and tonic (constant stiffness).\(^8\) MS patients usually experience spinal spasticity, in which the limbs are flexed and adducted, and exaggerated responses to cutaneous stimulation are present.\(^8,^4^7\) Spasticity in MS is usually of a progressive nature.\(^4^8\)

Spasticity is frequently found in the muscles that are responsible for maintaining upright posture. In the lower limbs the muscle groups most often affected by spasticity and at risk for developing contractures are the quadriceps, hamstrings, the iliopsoas and the gastrocnemius.\(^4^7\) Spasticity does not always cause discomfort or inconvenience for people with MS. The muscle stiffness can compensate for weakness in some cases, and can assist activity that would not otherwise have been possible, as well as assisting with some components of physiotherapy.\(^4^9\) However, in most cases spasticity does cause problems. The increased stiffness in the muscles consumes a great deal of energy, can hinder coordination and exacerbate other MS symptoms such as fatigue.\(^4^7\)

Treatment for spasticity is usually considered when the increased muscle tone interferes with adequate function for the individual. These may include impeding transfers, bed or chair positioning in the more severely disabled, when it causes pain or when it may lead to more serious complications such as skin breakdown and contractures.\(^8\)

LEARNING OBJECTIVES

After completing this section, the reader will be able to:

- Describe and apply strategies for the assessment of spasticity
- Implement interventions for the management of spasticity
- List and describe the medications for the treatment of spasticity
- Describe the desired outcome(s) of treatment interventions for spasticity

4.4.1 Physiotherapy

The essential aim of physiotherapy is muscle lengthening. This can be achieved in many ways including passive and active stretching programs and a range of motion exercises. Involving the patients, carers and family is important to assist with any exercise program, as depending on the extent of spasticity, significant ongoing assistance may be required beyond the time spent with the therapists.\(^4^9\)

For more significant spasticity, more aggressive measures may be needed such as splints or casting. Physical therapy is the most important component in reducing the harmful effects of spasticity. Medications and surgery can assist physiotherapy, but alone will have little lasting benefit.
4.4.2 Medications

Table 4-7 lists a number of medications that may be prescribed for the management of spasticity. The drugs may come from a number of therapeutic classes such as specific antispasmodics/muscle relaxants (eg baclofen), anticonvulsants (eg gabapentin, carbamazepine), benzodiazepines (eg diazepam), or even clonidine, an antihypertensive agent. Again, medications should be a supplement to a physical therapy program, not a sole management strategy.

**Baclofen**

This is possibly the most commonly used medication for MS spasticity. It is a GABA agonist and acts presynaptically to reduce the release of excitatory neurotransmitters from the descending corticospinal tracts and spinal cord 1a afferent fibres. In addition to reducing tone, baclofen can diminish both painful extensor and flexor spasms.

<table>
<thead>
<tr>
<th>Medication</th>
<th>Examples of Brand names</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baclofen</td>
<td>Baclo, Clofen, Lioresal, Stelax</td>
<td>A muscle relaxant Usual dose: 30-75 mg/day Side effects may include transient drowsiness, daytime sedation, dizziness, weakness, and fatigue</td>
</tr>
<tr>
<td>Carbamazepine</td>
<td>Tegretol, Teril</td>
<td>An anticonvulsant Usual dose: 200-1200 mg/day Side effects may include dry mouth and throat, constipation, impaired urination, decreased sense of taste, dizziness, drowsiness, unsteadiness, loss of appetite, nausea, vomiting, indigestion, and diarrhoea</td>
</tr>
<tr>
<td>Clonidine</td>
<td>Catapres</td>
<td>An antihypertensive agent that has been shown to reduce muscle resistance and tension Usual dose: 0.1-0.6 mg/day Side effects are generally mild and transient in nature but may include drowsiness, dizziness, dry mouth, sedation, and constipation</td>
</tr>
<tr>
<td>Dantrolene</td>
<td>Dantrium</td>
<td>A skeletal muscle relaxant Usual dose: 50-200 mg/day Side effects may include drowsiness, weakness, dizziness, fatigue, and diarrhoea May cause drug-induced hepatitis; therefore, patients should be monitored regularly</td>
</tr>
<tr>
<td>Diazepam</td>
<td>Valium</td>
<td>A sedative that may be used to relieve muscle tension Usual dose: 2-10 mg 2-4 times daily Side effects may include fatigue, drowsiness, muscle weakness, and ataxia</td>
</tr>
<tr>
<td>Gabapentin</td>
<td>Neurontin</td>
<td>An anticonvulsant Usual dose: 300-1200 mg/day Side effects may include drowsiness, dizziness, fatig, ataxia, nystagmus, tremor, nausea, and rhinitis</td>
</tr>
<tr>
<td>Phenytoin</td>
<td>Dilantin</td>
<td>An anticonvulsant Usual dose: 300-600 mg/day Side effects may include ataxia, drowsiness, confusion, and nystagmus</td>
</tr>
</tbody>
</table>

Please refer to approved product information before any drug and its dose is prescribed, use in MS is not necessarily an approved indication.
The use of baclofen is limited by its sedative effects and as doses increase, muscle weakness and possible fatigue override the benefit to spasticity. Dosages must be carefully tailored to each individual by the treating physician. Baclofen must be withdrawn gradually if it is to be stopped, as sudden withdrawal can precipitate rebound flexor spasms and hallucinations.

Intrathecal baclofen: a small number of patients who do not tolerate oral doses will benefit from having baclofen administered via an intrathecal pump. This is an expensive process including surgery, pump costs, medications and refill costs, but it is extremely effective for reducing tone and disability from lower limb spasticity.48-51

**Botulinum toxin**

Patients with a focal, ie increased, tone isolated to a particular muscle group may gain benefit from direct injection of this toxin. Botulinum toxin will only be of benefit when the spasticity is the direct cause of a functional problem or limitation. Symptomatic relief is the most common aim of this treatment.

For example, it may alleviate pain that allows the use of an orthosis or allow greater physiotherapy participation.47,49

**4.4.3 Surgery**

A number of orthopaedic and neurosurgical procedures may be performed in cases of severely disabling spasticity, contractures or pain. It must be remembered that these are not reversible, it often causes additional pain during recovery and the results are variable. Often medications must be ceased to allow appropriate assessment of the underlying cause before directing a surgical option.

Procedures undertaken include:
- Nerve blocks with phenol, alcohol or glycerine
- Tenotomies, tendon transfers and tendon lengthening procedures
- Dorsal root rhizotomy
- Myelotomy
- Partial or complete cordotomies

**Assessment**

1. Determine the nature of spasticity
   - Determine location
   - Describe symptoms
     - stiffness
     - weakness
     - flexor or extensor spasms
     - clonus
     - pain
   - Determine onset and duration

2. Identify possible contributing factors, such as:
   - Relapse
   - Infection
   - Constipation
   - Bladder dysfunction
   - Altered skin integrity
     - pressure sores
     - ingrown toenails
   - MS immunotherapies

3. Assess the impact of spasticity on the following aspects of daily living:
   - Gait
   - Seating
   - Comfort
   - Energy level
   - Sexual activity
   - Hygiene
   - Quality of life

4. Assess severity of spasticity using:
   - Ashworth Scale (see Appendix F)
   - Spasm Frequency Scale

5. Determine impact of spasticity on other MS-related symptoms

6. Identify existing coping strategies for the management of spasticity
Interventions

1. Consider following an algorithm for the management of spasticity (see Figure 4-2)

2. Inform the patient of the following factors that may contribute to spasticity:
   • Temperature changes
   • Infection
   • Anxiety/stress
   • Constipation
   • Pain
   • Immobility
   • Disruption of skin integrity
   • Bladder dysfunction
   • Medications

3. Educate the patient about the causes of spasticity

4. Inform the patient about available rehabilitative therapies and lifestyle modifications for the management of spasticity

5. Refer the patient to a rehabilitation therapist for:
   • Stretching and exercise programs (physiotherapist)
   • Assistive devices (occupational therapist)
   • Seating modification and positioning (occupational therapist)

6. Inform the patient about possible pharmacological therapy options as well as their side-effect profiles (see Table 4-7)

7. Inform the patient about the following surgical treatment options:
   • Cord or tendon cutting
   • Rhizotomy
   • Myelotomy
   • Injection of botulinum toxin
   • Intrathecal baclofen pump

8. Provide ongoing evaluation of the effectiveness of management strategies for spasticity

Desired patient outcomes

• Experiences a reduction in the frequency of spasms as demonstrated by:
  - Self-reported improved comfort
  - Improvements in Ashworth Scale scores
  - Improvements in Spasm Frequency Scale scores
• Implements rehabilitative strategies
• Able to identify the type and cause of spasticity
• Able to describe the rationale for pharmacologic and non-pharmacologic interventions for the management of spasticity
Figure 4-2. Algorithm for management of spasticity.

1Tizanidine is used overseas
4.5 Tremor

Introduction

Tremor in MS can affect the limbs, trunk, vision and speech. It has been described, as the most frustrating MS symptom to treat.8,25,52,53 Action tremor is the most common form of tremor followed by postural tremor. Resting tremor is rare in MS and is not considered to be one of the clinical manifestations.24,54

This module will only discuss tremor as an entity although it is often associated with other MS symptoms such as ataxia, spasticity, diplopia and nystagmus, and speech problems. These topics are covered elsewhere in this Module.

4.5.1 Definitions

**Action** tremor (also known as intention, goal-directed, or hyperkinetic tremor) is associated with voluntary movement and may range from mild to severe in nature. Action tremor amplifies in magnitude the harder the patient tries to be accurate around a target. It is caused by lesions in the cerebellum or in the cerebellar outflow pathways.34,52,54

**Postural** tremor is present while voluntarily maintaining a position against gravity, and sometimes appears, or is exaggerated, during specific postures.52,55 This type of tremor is common in patients with MS and may include titubation of the head and neck.

**Resting** tremor occurs when the patient is relaxed or at rest and is completely supported against gravity.55 Most often seen in Parkinson’s disease, resting tremor may occasionally be seen in individuals with MS who have a demyelinating lesion within or near the substantia nigra or nigrostriatal tract.36

**LEARNING OBJECTIVES**

After completing this section the reader will be able to:

- Describe and apply strategies for the assessment of tremor
- Implement interventions for the management of tremor
- List and describe the medications available for the treatment of tremor
- Describe the desired outcome(s) of treatment interventions for tremor

**Assessment**

1. Determine the nature of tremor
   - Determine onset and duration
   - Determine location, degree of motion (gross or fine), and velocity (fast or slow)
   - Describe symptom characteristics (ie tremor at rest, with position, or with voluntary movement)

2. Assess severity of the problem using:
   - Spiral test
   - Nine-hole peg test

3. Identify possible contributing factors, such as:
   - Lifestyle issues (ie alcoholism, recreational drug use)
   - Metabolic disorders
   - Coexisting conditions
4. Categorise tremor into one of the following categories:
   • Resting tremor (tremor without voluntary movement)
   • Postural tremor (tremor with certain positioning; e.g., head titubation)
   • Action tremor (tremor with voluntary movement or activity)
5. Determine the impact of tremor on the following:
   • Activities of daily living
   • Other MS-related symptoms
6. Identify existing coping strategies for the management of tremor

Interventions

1. Educate the patient about the types and causes of tremor
2. Plan interventions according to the type of tremor
3. Inform patient of the following possible treatment options:
   • Medications and their side effects (see Table 4-8)
   • Surgical treatments
   • Thalamic electrostimulation
   • Thalamotomy
4. Refer the patient to a rehabilitation specialist for instruction on activities / strategies to help manage tremor
5. Patterning (i.e., tracing and repeating basic movement patterns until they become automatic)
   • Immobilisation
   • Weighting
6. Inform the patient of the following factors that may affect tremor:
   • Anxiety
   • Caffeine
   • Alcohol
7. Provide ongoing evaluation of tremor management

Potential/desired outcomes

Experiences a reduction in the frequency of tremor as measured by:
   • Improvement in spiral drawing scores
   • Improvements in nine-hole peg test scores
   • Able to define cause of tremor
   • Adheres to rehabilitative and pharmacologic treatment regimens to reduce and compensate for tremors
   • Demonstrates improved performance in daily activities

4.5.2 Tremor surgery

In 1967, Cooper reported that ventral thalamotomy provided an effective therapy for tremor complicating MS. More than 30 years later, no consensus has been reached as to the role of this procedure in treating the severe tremor associated with MS. There have been many reported surgical series for both stereotactic thalamotomy and Deep Brain Stimulation but results vary greatly in perceived benefits particularly dependent on length of follow-up. A recent review of the literature of surgical therapy for MS tremor concluded that the question of efficacy required “scrupulous clinical trials, with multidimensional outcome measures”.57

Thalamotomy: neuroablative procedures

During neuroablation, a specific deep brain target is destroyed by thermocoagulation. A radiofrequency generator is most commonly used to heat the lesioning electrode tip to the prescribed temperature in a controlled fashion. The most commonly performed neuroablative procedure is thalamotomy, in which lesions are created in the ventro-lateral thalamus.58
Table 4-8. Pharmacological options that may be used in Australia for treating tremor.33,36,56

<table>
<thead>
<tr>
<th>Medication</th>
<th>Examples of brand names</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clonazepam</td>
<td>Rivotril</td>
<td>An anticonvulsant. Dosage should be individualised according to the patient’s age, clinical response and tolerance for the agent. Side effects may include CNS depression and alterations in behaviour such as increased aggression, agitation, depression, euphoria, irritability and forgetfulness.</td>
</tr>
<tr>
<td>Levodopa</td>
<td>Sinemet</td>
<td>An antiparkinson agent. Dosage should be individualised to reduce the incidence of adverse reactions and achieve maximal efficacy. Side effects may include choreiform, dystonic, and other involuntary movements, paranoid ideation and psychotic episodes, depression, dementia and nausea.</td>
</tr>
<tr>
<td>Ondansetron</td>
<td>Zofran</td>
<td>A selective 5-HT3 antagonist used for the prevention of nausea and vomiting after chemotherapy; also used in the treatment of MS-related tremor. Generally well tolerated.</td>
</tr>
<tr>
<td>Propranolol</td>
<td>Inderal</td>
<td>A beta-adrenergic receptor-blocking agent indicated for the treatment of essential tremor. Side effects may include congestive heart failure, bronchospasm, anorexia, nausea, vomiting, diarrhea, and abdominal pain.</td>
</tr>
<tr>
<td>Primidone</td>
<td>Mysoline</td>
<td>The drug reduces the sensitivity of the central nervous system to fit inducing stimuli but its precise mode of action is obscure, although enhancement of release of inhibitory transmitters may possibly occur.</td>
</tr>
<tr>
<td>Gabapentin</td>
<td>Neurontin</td>
<td>Neurontin has been shown in some studies to be of benefit with neuropathic pain also associated with MS. The mechanism by which gabapentin exerts its anticonvulsant action is unknown. Gabapentin is structurally related to the neurotransmitter GABA, but its mechanism of action is different from that of several other drugs that interact with GABA synapses.</td>
</tr>
<tr>
<td>Clozapine</td>
<td>Clopine Clozaril</td>
<td>Clozapine has been shown to be an antipsychotic agent different from classical neuroleptics. It has weak D2 and D1 receptor blocking activity, but potent noradrenolytic, anticholinergic, antihistaminergic and arousal reaction inhibiting effects. It has also been shown to possess antiserotonergic properties. Clinically, clozapine produces rapid and marked sedation, and exerts antipsychotic effects. Extrapyramidal symptoms such as tremor may occur but these are milder and less frequent than those seen during classical neuroleptic treatment.</td>
</tr>
</tbody>
</table>

Please refer to approved product information before any drug and its dose is prescribed, use in MS is not necessarily an approved indication.
Deep brain stimulation (DBS)

Thalamic DBS initially was used contralaterally to previous thalamotomies to reduce the risk associated with bilateral thalamotomy. However, the results were so encouraging that thalamic DBS has become an accepted alternative to thalamotomy for medically refractory tremor. It is the procedure of choice for patients who require bilateral procedures for tremor. A decade of experience indicates that thalamic DBS is equivalent to thalamotomy for tremor suppression. As with thalamotomy, thalamic DBS uncommonly provides significant functional improvement for patients with Parkinson’s disease because their resting tremor is not usually a source of functional disability. Because the lesion is eliminated, haemorrhage rates and adverse cognitive effects may occur less frequently than with thalamotomy.58,59

Cannabinoids

There are numerous reports of cannabinoids providing relief to people with MS for a variety of symptoms, including tremor.60-62 The first study to examine the effect of cannabinoid’s on tremor consisted of only eight patients.60 Oral tetrahydrocannabinol (THC) was titrated against adverse effects in 5mg increments, compared with single-blinded placebo. Final doses ranged between 5mg and 15mg. Two of the 6 patients experienced an objective response, as measured by handwriting, spiral drawing and, in one case, movement artifact from EEG electrodes.60 A recent randomised double-blind placebo-controlled crossover study in 14 patients with MS and upper limb tremor found no significant functional improvement.62

The CAMS (Cannabis in Multiple Sclerosis) trial randomised 667 patients to receive cannabis or placebo for 16 weeks.63 The results of this study for cannabis are mixed with no objective improvement in spasticity (using Ashworth scale), but subjective improvements in pain, sleep quality, spasms and spasticity, though none in irritability, depression, tiredness, tremor or energy.

It must be stressed here that at present there is no legal medicinal prescription for cannabis in Australia, and that as such no healthcare professional should recommend illegal drug taking.
4.6 Ataxia

Introduction
Ataxia is uncoordination caused by dysfunction to sensory nerve inputs, motor nerve outputs or the processing of both. The term ataxia is most often applied to describe unsteadiness in walking but it also refers to upper body coordination and dysfunction in eye movement and speech.64-68

4.6.1 Types
There are three types of ataxia.64-68

Cerebellar ataxia
This is caused by demyelinating lesions in the cerebellum or in the parts of the brain that connect to it. It can result in:
• Uncoordinated walking – gait ataxia
• Reduced control of range of movement such as over or under shooting targets – dysmetria
• An inability to maintain a steady rhythm – dysdiadochokinesia
• Inability to maintain a steady posture, decreased muscle tone – hypotonia
• Shaking when attempting fine movements – intention tremor
• An inability to coordinate the muscles involved in speech – dysarthria
• Jittery eye movements – nystagmus

Vestibular ataxia
This is caused by lesions to the brain stem and the vestibular nuclei, and by damage to the VIII cranial nerve.

Sensory ataxia
Demyelination of sensory pathways results from dysfunction to position sensing nerve inputs (proprioception). This means that the brain is confused as to the position of limbs.
• Loss of position sense
• The inability to detect vibrations
• An unstable stance – Romberg’s sign

LEARNING OBJECTIVES
After completing this section, the reader will be able to:
• Describe and apply strategies for the assessment of ataxia/mobility
• Implement interventions for the management of ataxia/mobility
• Describe the desired outcomes of treatment intervention for ataxia/mobility

Supporting references
Assessment

1. Determine the nature of the ataxia
   • Determine onset and duration
   • Determine severity
   • Describe symptom characteristics
     – loss of sense of balance
     – tripping
     – falling
     – inability to transfer
     – inability to walk

Other symptoms that may accompany ataxia include difficulty with swallowing, speech and visual problems and fatigue.

2. Assessment of the severity of ataxia/mobility can be made using the following techniques
   • Timed walk for 100m (see Appendix F)
   • Kurtzke Expanded Disability Status Scale (EDSS) for ambulation (see Appendix A)
   • Berg Balance Scale (administered by a trained therapist; see Appendix G)

3. Identify possible coexisting factors, such as:
   • Weakness – there is a need to differentiate weakness from ataxia
   • Fatigue
   • Pain
   • Spasticity
   • Lack of coordination
   • Loss of balance
   • Sensory loss/or visual impairment
   • Environmental barriers
   • Co-existing conditions such inner ear disturbance, Meniere’s

4. Determine the impact of ataxia on the following aspects of daily life:
   • Self care
   • Communication - speech
   • Employment
   • Recreation
   • Social activities
   • Sexual activity
   • Determine the impact of ataxia on other MS related symptoms (eg bladder)

5. Determine the impact of ataxia on other MS related symptoms (eg bladder)

6. Identify existing management strategies (including assistive devices used) and coping behaviours

7. Identify potential or co-existing exacerbating factors
   • Illness including infection and elevated temperature
   • Stress and anxiety
   • Sudden noise or movement
   • External forces that may demand a fast response
   • Increased muscle tone

8. Refer patient to rehabilitation specialist for:
   • Seating posture and wheelchair prescription to maximise support

Interventions

1. Educate patient about the following:
   • Causes of ataxia
     – weakness
     – loss of balance
     – sensory changes
   • Potential risks of altered mobility
     – falls
     – fractures
     – reduced capacity for safe driving
   • Potential complications
     – contractures
     – skin breakdown
     – compression neuropathies
     – pain

2. Inform patient of therapy options for the management of ataxia
   • Rehabilitative therapies
   • Lifestyle modifications
   • Medications and their side effects
     – antispasticity drugs such as baclofen (see Tables 4-6 and 4-7 in this Module for a more detailed description)
3. Refer patient to a rehabilitation specialist for:
   • Gait assessment and retraining
   • Mobility aids
   • Stretching and strengthening programs
   • Balance training
   • Energy – conservation training
   • Environmental accessibility and adaptive equipment

4. Provide patient with information on community resources that assist persons with mobility problems (see housing, transportation, and accessibility listing)

5. Provide ongoing evaluation of changes in ataxia

**Desired patient outcomes**

• Defines ataxia in terms of causes and risk
• Maintains a safe level of activity, as demonstrated by a reduction in the number of falls and complications
• Demonstrates improved mobility
• Becomes increasingly involved in activities requiring mobility
4.7 Vision

Introduction

Acute demyelinating optic neuritis associated with MS is the most common cause of inflammation of the optic nerve in young adults. Visual disturbance is one of the most commonly reported symptoms in MS, with figures up to 80%, and is the presenting symptom in 25 to 50% of cases. The Australian Multiple Sclerosis Longitudinal Study (AMLS) reports that 31.1% of respondents indicate a loss of visual acuity as part of their MS symptom complex. Other vision related problems reported include:

- optic atrophy 27.8%
- nystagmus 18.1%
- diplopia 15.3%
- vertigo 18.7%

Visual problems that are common with MS include visual loss, visual blurring, loss of colour vision and scotomata. The two main components that promote effective visual interpretation are the ability to correctly image what the eye sees and the coordination and strength of the muscles of the eye to control its movements. Both these facets of vision may be affected by MS. It is important to acknowledge that MS is commonly described as a disease of the CNS but that CN II (optic), CN III (oculomotor), CN IV (trochlear) and CN VI (abducens) are part of the peripheral nervous system (PNS).

Appropriate assessment by a GP and then an ophthalmologist is recommended and can include:

- Basic vision test
- Sloan eye tests
- Optical Coherence Tomography (OCT)

LEARNING OBJECTIVES

After completing this section the reader will be able to:

- Understand the implications for the patient on many aspects of vision
- Discuss the nature of visual changes with people with MS and encourage early assessment of any new visual problems
- Assist the patient with treatment, if indicated, for acute visual changes
- Recognise the importance of visual safety and advise patients accordingly

OCT is now being used in most clinical studies, and is becoming increasingly popular with the possibility of more remote places using it to assist with the diagnosis of MS in the absence of an MRI.

Optical coherence tomography (OCT) is a relatively new imaging technique that uses photonics and fibre optics. OCT is based on the principles of ultrasound, but uses infrared light waves that reflect from the internal microstructure of biological tissues. Imaging resolution is much higher than traditional imaging techniques. Current OCT systems have resolutions of 4-20 microns.
4.7.1 Clinical terminology

Optic neuritis

Optic neuritis (ON) is often used as a general term to describe any inflammatory optic neuropathy. Its usual reference is to an acute disease of the optic nerve caused by focal inflammation associated with demyelination. It is usually accompanied by periocular pain, especially on movement,70,72,75 accompanied by varying degrees of visual loss. Some patients can effectively become blind in the affected eye.

Nystagmus

Nystagmus, involuntary rapid movement of the eyeball, is a classical sign of MS. The nystagmus may be first-degree symmetrical horizontal nystagmus, acquired pendular nystagmus, jelly nystagmus, or vertical up-beat nystagmus. The lesion causing nystagmus is usually brain stem although it can be of cerebellar in nature.34

Diplopia

Double vision that may be either vertical or horizontal.

Internuclear ophthalmoplegia (INO)

The patient will manifest an adduction deficit on the involved side and a nystagmus of the fellow eye in extreme abduction. Occasionally, the condition is bilateral with medial rectus palsy and adduction deficit in each eye and nystagmus upon abduction in both eyes (bilateral internuclear ophthalmoplegia, or BINO). While there appears to be medial recti palsy, most patients will be able to converge (posterior INO or BINO). In some cases, the patient will not be able to converge (anterior INO or BINO).

To produce synchronous eye movements, cranial nerves III, IV and VI communicate through the medial longitudinal fasciculus (MLF), the neural pathway connecting the cranial nerve nuclei responsible for eye movements. In INO, a lesion disrupts this pathway, preventing communication between cranial nerves.76

Colour vision

This is often diminished, especially red.78 This is easily assessed using Ishihara plates.

Afferent pupillary defect

Otherwise known as Marcus Gunn pupil. On examination, the consensual light reflex is greater than the direct light reflex.78

Uhthoff’s phenomenon, symptom or sign

This is described as a dimming or reduction in visual acuity as a result of increased temperature or exercise.78

Saccades

This is a jerky movement of the eye in response to “follow” commands. The muscles lose the coordination to promote smooth eye movements. It is seen in demyelination of the descending supranuclear occipital pathway or involvement of the cerebellum on eye movements.34

Cataracts

Cataracts can be caused by the increased use of corticosteroids in people with MS.79 Surgical removal usually brings about an improvement in vision.
4.7.2 Special conditions

Devic’s disease (neuromyelitis optica)

This is characterised by a confluent demyelination of the optic nerves and the optic chiasm as well as spinal cord demyelination and symptoms.

These spinal cord lesions are often necrotising rather than demyelinating, and these can then form cavities making the disabilities more permanent than demyelination lesions. Debate continues as to whether Devic’s disease is a separate disease or a variant of MS. Studies have shown that in some Northern European series there is a very low conversion to MS, and the syndrome is seen as a demyelinating pattern in Japanese populations in which MS is rare.34,80,81

4.7.3 Patient management

As with most MS symptoms, the pattern, frequency, recovery and disability associated with visual disturbance is unpredictable. Even apart from discrete attacks affecting vision, symptoms can fluctuate with fatigue, heat, stress and infection.79

Optic neuritis treatment

Corticosteroids have been the mainstay of treatment for optic neuritis both as a monosymptomatic episode and as an exacerbation in definite MS, but until the Optic Neuritis Treatment Trial (ONTT)82 there has been little evidence to support this. A number of reviews into trials of optic neuritis treatment illustrated an improved short-term speed of recovery but no definable long-term benefit.82,83

Ocular pain

NSAIDs have proven effective and are usually well tolerated. Regular use of paracetamol during recovery from an exacerbation has also been effective.78,79

Involuntary eye movements

Eye glasses with prisms have been shown to be of benefit to some people with a variety of visual disturbances such as nystagmus, diplopia and oscillopsia,76,79 but this can be expensive and may need to be adjusted over time.

Medications such as clonazepam, baclofen, gabapentin and isoniazid have anecdotal evidence supporting some improvement in these involuntary eye movements.78

Patching should only be done when performing essential tasks such as driving or when fatigue is an issue and should be alternated where possible to encourage both eyes to function. Often over time the brain can learn to accommodate for mild double vision or nystagmus but patching reduces this ability.79

Given the varied affect on vision that can result from MS, including loss of acuity, visual loss or disturbance, including field defects and the presence of abnormal eye movements, such as nystagmus, attention should be paid to potential safety issues. The suitability of the individual to continue driving and or operating machinery should be evaluated, recommendations made and the individual counselled where appropriate.

Low vision aids/resources including large print texts and talking books can improve quality of life. Contact your local MS Society for information.
Cognitive impairments are common in MS, occurring in approximately 50% of patients. These impairments range significantly from mild through to severe, remaining relatively mild for most patients, but occasionally progressing further to resemble a form of subcortical dementia in a small proportion (around 10%). These impairments can occur early in the course of the disease, sometimes even prior to the formal diagnosis, and can also occur in the absence of significant physical impairments. Once cognitive impairments become clinically apparent, they tend not to remit, though they may well fluctuate from day to day. They tend to get slightly worse very gradually, and at an unpredictable pace, over many years. The rate of change depends largely upon the degree of disease activity in the brain.

The sort of cognitive impairments most commonly experienced involve short-term memory and new learning, speed of information processing, complex attention (including “working memory”), cognitive flexibility and other ‘executive’ functions (such as planning and problem-solving). On the other hand, general language functions, routine social skills, and orientation to person, place and time are rarely significantly affected (even when cognitive impairment becomes severe overall), although some degree of mild word-finding difficulty is common. It is worth noting the wide range of individual variation in the experience of these impairments. Many people with MS experience none of these cognitive impairments. Others may experience impairment in one area only; whilst others may experience a combination of these more common areas of impairments.

Even well-circumscribed or mild cognitive impairment can have a significant impact on a patient’s capacity to function in their daily lives. A significantly slowed speed of information processing, alone, for instance, has been linked with an increased risk for car accidents, and also with a greater risk of misunderstanding what’s been said, which in turn can lead to an increase in interpersonal conflict. Even mildly reduced problem-solving and organising skills can impact greatly on a patient’s ability to successfully juggle the complex and multiple competing demands on their time and energy each day, such as maintaining a busy job, keeping-up with the ever-changing after-school activities of their children, and managing their own personal MS symptom care plans which might require scheduled fatigue- or toilet-breaks. Therefore, evaluation of cognitive functioning should be part of the ongoing neurological and nursing assessment of people with MS.

It is also worth noting that motor, sensory and fatigue symptoms may affect a person’s cognitive functioning, and thus these symptoms need to be taken into account when evaluating cognitive impairment. Emotional state can also affect a person’s cognitive functioning.
For instance, patients who are severely depressed or highly anxious may appear to be (temporarily) cognitively impaired, until their mood state improves and their cognitive skills improve again.

On the other hand significant cognitive impairment can sometimes be incorrectly attributed to depression or other emotional disturbances. So, accurate evaluation of cognitive impairment, in spite of the presence and influence of these other factors, is necessary for the development of appropriate management and treatment strategies and for better client outcomes.79

4.8.1 Evaluation

Evaluation of cognitive impairment can occur in many ways, and at many levels of professional specialisation. At the most simple level the patient with MS can report to the MS nurse on their areas of concern. Research has shown that this is somewhat unreliable at a group level, as the presence of depression in particular, heavily influences patients' reporting of their own cognitive status. Nevertheless, patients' concerns about their cognitive status should always be followed-up and investigated. Family members and carers of patients with MS have been shown to be somewhat more reliable, again at a group level, in identifying cognitive impairment in loved-ones with MS. On the basis of these findings, a cognitive screening questionnaire, the MSNQ, has recently been developed, which shows great promise in identifying the likely presence or absence of cognitive impairment. This is a 15-item self-report questionnaire, and when used with a family member or carer of a patient with MS along with a brief depression screen, is able to predict the likelihood of finding, or not finding, cognitive impairment on full neuropsychological assessment (see below) with remarkably good accuracy.

This tool may prove especially useful to nurses caring for patients with MS in many different clinical settings. Indeed, evaluation of cognitive impairment by nurses should generally take the form of cognitive screening, rather than cognitive assessment per se. Cognitive screening activities should be conducted in an environment in which the patient feels comfortable, relaxed, safe and private.

The most suitable environment is a quiet interview room in a community health centre, or in another calm and neutral environment. While the MSNQ can be used by health professionals with limited training in the wider issues surrounding cognitive screening, the more psychometrically advanced cognitive screening tools (such as the SEFCI – the Screening Examination for Cognitive Impairment), should only be used by a specifically trained occupational therapist or psychologist, because appropriate clinical application of these sort of tools require a wider knowledge of cognitive screening issues, and they are more complex to interpret accurately. It should also be noted that the Modified Mini Mental Status Examination is not sensitive enough or accurate enough to be used for people with MS; it will miss even severe cognitive impairment in a substantial proportion of MS patients.

Another level of evaluation of cognitive impairment in patients with MS is offered by occupational therapists. Occupational therapists are usually able to provide either cognitive screening, or more detailed cognitive assessment embedded within the broader context of evaluating the patient’s capacity to function, from a practical point of view, within their everyday life.

For a thorough understanding of the precise nature of a patient’s cognitive impairment, per se, a full neuropsychological assessment is recommended. 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.
<table>
<thead>
<tr>
<th>Problems</th>
<th>Management strategies</th>
</tr>
</thead>
</table>
| **Impaired short-term memory and new learning** |  - Encourage the use of external memory aids such as appointment diaries, lists, calendars, hand held computers, electronic diaries, daily activity logs, alarm clocks, wrist-watch alarms, pill dispenser packs, etc. (Note: if patients have not previously used a specific memory aid, they will need structured support in learning how to use it, and plenty of practice. This may take much longer than expected as this is, in and of itself, a new learning task).  
- To create an environment that supports a poor memory, create an area (in the house or office) where all the main memory prompt systems can be based (eg the diary, calendar, keys, bills that need to be paid etc). Also, ensure that frequently used items are kept in the same place, and put back each time after use.  
- For important new information that needs to be committed to memory (eg learning a new exercise routine or a new bed transfer technique), provide both written and visual aids (eg video-tapes, photos, and a written instruction sheet), and allow plenty of opportunity for supervised practice. Ensure family and carers understand and learn this information too.  
- Ensure that educational sessions are short in duration and don’t cover more new information than the patient can handle (eg maybe only 3 or 4 ‘bits’ of new information in one session).  
- Provide simplified, step-by-step instructions for the learning of complex information, or for the learning of long sequences of actions.  
- Ensure that each ‘bit’ of new information is well-learned before moving on to the next bit of information.  
- Consider using ‘errorless learning’ teaching techniques. |
| **Impaired speed of processing and complex attention** |  - Allow longer for completion of all tasks.  
- Encourage the performance of one task at a time, rather than attempting to do two tasks at once (eg turn off the radio when cooking on a hot stove, avoid holding a conversation whilst practicing new exercises).  
- Encourage the avoidance of dangerous tasks that require fast reaction times for safety (eg avoid the use of power tools in the backyard shed, or the use of a scooter at high speed etc).  
- Provide important information a number of times if it needs to be “taken in” properly.  
- Provide new instructions at a slightly slower pace with longer pauses between new items.  
- Encourage the video-taping of favourite TV shows to allow replaying of parts that are missed.  
- Provide a quiet and non-distracting environment when concentration is required (eg advocate for the patient to have their own closed office at work, rather than working in an open-plan environment, or to work-out at the gym in a quiet corner facing a wall rather than in the middle of the busy room). |
| **Impaired cognitive flexibility and other ‘executive’ functions such as planning, problem-solving, and decision-making** |  - Encourage the performance of one task at a time rather than switching between tasks.  
- When providing important new information, don’t switch topics too often – stick to the one theme and complete that discussion before moving on to another topic.  
- Encourage the use of organisational and problem-solving templates when approaching new problems (these can usually be prescribed by occupational therapists).  
- Provide a variety of alternative ways of approaching new problems, rather than expecting the patient to generate these themselves, but then systematically explore the pros and cons of each option with the patient.  
- Help set-up a trusted ‘problem-solving buddy’ for the patient, for help with important and complex decisions (eg considering changing jobs, choosing between MS treatment options, deciding when to move house). At the more severe end of the spectrum of decision-making support options, this might require the appointment of an informal or formal guardian, power of attorney, or Public Officer (from the protective commissioner) etc. If possible, get the patient to appoint an enduring power of attorney or guardian while their decision-making skills are still adequate, and long before it might actually become necessary.  
- Help to set up a formal driving assessment if driving safety is uncertain.  
- Help to set up formal occupational therapy assessment of potentially unsafe activities (eg preparing food, cooking, showering), to ensure that the environments and procedures being used are as safe as possible, and that the safest ‘habits’ are formed at the earliest time possible. |
Broaching the issue of cognitive impairment with patients can sometimes be difficult. However, if cognitive impairment is present and this is not evaluated, understood or managed, the patient is at grave risk of avoidable, adverse outcomes. As mentioned above, even mild cognitive impairment can result in risks to a patient’s safety, interpersonal relationship quality, their capacity to manage their other MS symptoms, or their ability to manage work or family responsibilities. So, early recognition and appropriate evaluation of this area of impairment, and the subsequent establishment of appropriate management strategies and support are essential. Ideally, both the patient with MS, their family and carers, nurses, and other members of their support team, should all gain a thorough understanding of the patient’s cognitive strengths and impairments, and be taught appropriate cognitive management skills.

4.8.2 Intervention and Management

Evaluate cognition using:

- Client and family/carer interview
- MSNQ (Benedict 2003, 2005)\textsuperscript{86,87}

Approaches to helping patients to manage cognitive impairment:

Intervention and management of cognitive impairment in MS is best performed by specially trained health professions, such as occupational therapists, clinical neuropsychologists, clinical psychologists, or speech therapists experienced in cognitive rehabilitation. However, MS nurses can help significantly by making patients aware of the availability of specialist services of this kind, linking patients into these services, and facilitating and supporting the uptake of any recommended rehabilitative plans. They can also help to make sure that the patient’s families, carers, and other support people are included in communications about any recommended rehabilitative plans, and that everyone involved gains a good understanding of what they can best do to help the patient.

MS nurses can also make sure that they themselves are aware of which cognitive impairment management approaches tend to work best with patients with MS, and ensuring that they use these approaches when working with MS patients on other aspects of their symptom management (eg. when teaching patients new injection techniques or catheterising techniques). They can also make sure they are aware of what medications are beneficial or harmful to cognitive functioning in MS, and arrange for review of medications when necessary. Certain medications are regularly being explored for their potential use in ameliorating the effects of cognitive impairment in MS, but these currently remain largely experimental. There is emerging evidence that MS immunotherapies are beneficial to the cognitive symptoms of MS, as they are to the physical symptoms.\textsuperscript{88}

In general terms, the management of cognitive impairment in patients with MS mostly involves using compensatory, rather than restorative, approaches. These compensatory rehabilitative approaches are informed by research findings from both the narrow (and still emerging) scientific literature on cognitive rehabilitation of MS patients specifically, but also by research findings from the broader scientific literature on cognitive rehabilitation in other groups of people with acquired brain injury, such as those who have suffered traumatic brain injuries or stroke. The same compensatory rehabilitation principles apply.

Adapting emotionally to the unpredictable, gradual worsening of cognitive skills over many years can be challenging and distressing for both the patients’ and their families and carers. Timely counselling can be helpful in the process of redefining a sense of a worthwhile self, and in coping with the elements of grief and loss. Using language derived from theoretical models of positive, ongoing adaptation to loss of ability in chronic illness,\textsuperscript{89} rather than those derived from the grief-focused processes more applicable to fatal illnesses, can help everyone stay focused on what can be done to maximise wellbeing and ongoing participation of the MS patient in a meaningful life.
4.9 Speech & Swallowing difficulties

4.9.1 Speech difficulties

As with so many of the symptoms associated with MS it is very difficult to ascertain the percentage of people who will experience speech and communication difficulties with their MS. Various studies have illustrated variations in the reported incidence of speech/language problems in MS patients with authors citing ranges from 44 to 77%. Speech and swallowing problems can be exacerbated by other MS related problems such as fatigue, and can even be evident of a discrete exacerbation or attack.

It is important to differentiate here between a deficit in speech – dysarthria (e.g. stammering, stuttering), and a deficit in language – dysphasia or aphasia (e.g. words in incorrect order).

Language deficits can be the result of either a receptive problem, i.e. the patient does not understand/comprehend what has been said to them; or expressive in that they are unable to find or form the appropriate words. These are rare in MS but have been reported. They can usually be attributed to cortical lesions directly affecting the primary language areas of the cerebral cortex, such as Wernicke’s area (reception), Broca’s area and the primary motor cortex (expression) in the dominant cerebral hemisphere, but also what must not be overlooked is the possible cognitive effects of the disease process, particularly in late stage MS.

Speech deficits in MS usually present as spastic and/or ataxic dysarthrias. Dysarthrias can be divided into two major classifications, by location of deficit:

• Upper motor neurone (UMN) or pseudobilbar palsy
• Lower motor neurone (LMN) dysarthria or bulbar palsy

A study by Darley et al cited in Merson and Rolnick stated that speech disturbances correlated well with severity of demyelination and progressive disease but not with duration of illness, age or onset of MS.

LEARNING OBJECTIVES

After completing this section, the reader will be able to:

• Describe and apply strategies for the assessment of speech and swallowing
• Implement interventions for the management of speech and swallowing difficulties
• Describe the desired outcomes of treatment interventions for speech and swallowing difficulties

Dysarthrias are commonly associated with other symptoms caused by brain stem lesions such as head (tremor) and incoordination of fine motor control.

This study reported the following symptoms in order of frequency of occurrence:

• Impaired loudness control
• Voice harshness
• Defective articulation
• Impaired emphasis
• Impaired pitch control

A study by Darley et al cited in Merson and Rolnick stated that speech disturbances correlated well with severity of demyelination and progressive disease but not with duration of illness, age or onset of MS.
Dysarthria terminology\textsuperscript{90,91,93}

Spastic dysarthria (UMN): harsh voice, low pitch, imprecise articulation, and decreased rate of speech.
Ataxic dysarthria (LMN): excess and equal speech stress, irregular articulation and distorted vowels.
Flaccid dysarthria (cerebellar): hyper-nasally, breathy voice and weak consonant strength.

4.9.2 Swallowing difficulties

Swallowing disorders are common in MS, particularly if demyelination occurs in the brain stem’s sensorimotor pathways (ie cranial nerves VII, IX, X or XII).\textsuperscript{93} Self-reports of chewing and swallowing problems generally increase as the disease progresses (ie incidence of these problems is 51\% in late stages of MS compared to 19\% in early stages of the disease).\textsuperscript{39} Depending on the location and extent of demyelination, swallowing disorders can relapse and remit along with MS exacerbations\textsuperscript{93}

The medulla controls the complex swallow process, involving the coordination of the lips, tongue, jaw, pharynx, palate, oesophagus and multiple cranial nerves. Any one or a combination of interruptions to the function of these structures can impede the ability to swallow safely.\textsuperscript{90}

Swallowing (or deglutition) has been recognised as one of the most basic biological functions, but the real process is by no means basic. The act of swallowing consists of 3 phases:
- Oral
- Pharyngeal
- Oesophageal

The oro-pharyngeal phases last no longer than 1.5 seconds but involve the coordination of no less than 31 paired muscle groups.\textsuperscript{90,92}

Impairment to the neurological control of swallowing results in dysphagia, and may lead to potentially serious effects on respiratory function, nutrition and quality of life.

It is not unusual for people with MS to deny swallowing difficulties\textsuperscript{91} even when family members report concerns.

Early signs may include intermittent choking, especially if fatigued, and at this stage examination may be normal. Early management strategies at this time may include just making the person more aware of distractions at meal times, heightened awareness of sensory clues, appropriate body positioning and even the temperature of the food.\textsuperscript{91,95}

Assessment

1. Determine the nature of symptoms – History
   - Determine onset and duration
   - Determine severity
   - Describe symptom characteristics
     - speech problems
     - dysarthria
     - dysphonia
     - dysphasia
     - swallowing problems
     - choking
     - coughing
     - delayed swallowing
     - chewing difficulties

2. Identify possible contributing factors, such as:
   - Fatigue
   - Emotional upset
   - Cognitive changes
   - Coexisting conditions
   - Other MS-related symptoms

3. Determine whether speech and swallowing problems may be causing the following:
   - Weight loss
   - Malnutrition
   - Dehydration
   - Respiratory compromise
   - Sleep disturbances
   - Changes in social and recreational activities

4. Determine the impact of speech and swallowing difficulties on other MS-related symptoms

5. Identify existing coping strategies for the management of speech and swallowing problems
Interventions

1. Inform patient about the causes of speech and swallowing problems

2. Refer patient to a Speech Pathologist for an assessment and modified barium swallow examination. In this test, the patient drinks or eats contrast material of different consistencies
   - thin liquid, thick liquid, and solid.
   A videofluoroscope, which can trace the path of the contrast material, is used to film the swallowing. The precise location and manner of a swallowing defect can then be identified, and treatment prescribed.

3. Assist patient in implementing the recommendations of the Speech Pathologist as follows:
   - Speech
     - oral motor exercises
     - appropriate timing and rate of speech
     - new strategies to help patient communicate
     - signing
     - facial gestures
     - use of assistive devices (eg computer and/or letterboard)
   - Swallowing
     - alertness at mealtimes
     - meal supervision, as required
     - proper positioning for swallowing
     - dietary modifications
     - consistency and texture of food
     - balance of fluids and solids

4. Educate patient, family, and/or caregivers on how to manage swallowing difficulties safely
   - Heimlich manoeuvre
   - Suctioning
   - Signs and symptoms of aspiration pneumonia

5. Inform and support patient in the placement of a feeding tube to maintain nutritional status when swallowing difficulties are severe

6. Provide ongoing evaluation of management strategies for speech and swallowing difficulties

Desired patient outcomes

- Able to describe the cause of speech and swallowing difficulties
- Practices safe eating habits through the utilisation of compensatory strategies
- Patient reports reductions in choking and coughing at mealtimes
- Maintains adequate nutritional status as demonstrated by the following:
  - BMI
  - weight
  - serum albumin levels
  - exhibits improved communication

*BMI is calculated by dividing weight in kilograms (kg) by the square of the patient’s height in metres (m).

Example:

Weight: 75 kg
Height: 180 cm = 1.8 m

BMI = 75/(1.8)^2 = 23

Generally, a BMI between 19 and 25 is considered ideal. If the patient’s BMI falls below 19 or exceeds 25, the patient is at risk for serious health complications and should consult a physician.
4.10 Depression

4.10.1 Incidence and aetiology

Depression is very common amongst people with MS, with a reported incidence of 50%. The prevalence of major depression has recently been estimated at 26% in those in the 18 to 45 age range. The uncertainty of the future, coupled with the perceived loss of a ‘normal’ life, causes most people to feel depressed at least occasionally.

Researchers believe that MS-related depression may be due to a combination of the following:

• Psychological reactions to the diagnosis of a chronic illness
• Neuropathology of the disease process
• Anxiety related to the uncertainty of future events
• Grieving over the perceived loss of former self

Few diseases are as affected by emotional status as MS. Research has shown, for example, that function and performance are much better when people are in good emotional health than when they are depressed or anxious.

4.10.2 Symptoms

Depression and anxiety are the most prevalent psychiatric symptoms in MS, with anxiety being significantly related to depression in MS. Other symptoms of depression include:

• Feelings of hopelessness, despair and guilt
• Fatigue
• Insomnia
• Suicidal ideation

The incidence of suicide is 7 times higher in people with MS than that in the general population; at highest risk are young males under 30 years, and within the first 5 years of the onset of illness.

Depression and anxiety do not necessarily correlate with type, duration of illness or level of disability in MS. In a study comparing the relative impact of anxiety, depression, level of disability and duration of illness on self-assessed quality of life, depression was found to be the strongest predictor of a decreased quality of life in persons with MS. Depression however has been shown to correlate with the degree of neurological impairment; patients with MS and depression tend to have a higher lesion load in the medial orbital frontal cortex than non depressed patients with MS. Overall, there is converging evidence that the aetiology of depression in MS is complex and multifactorial.

LEARNING OBJECTIVES

After completing this section, the reader will be able to:

• Understand its incidence and aetiology
• Describe the presentation of depression in MS
• List the treatment options available
The presentation of depression in people with MS frequently varies from that of the general population. It is increasingly recognised that people with MS often present with symptoms of subsyndromal depression, rather than those most commonly associated with clinical depression which include appetite and weight changes, sleep changes, feelings of hopelessness, loss of interest or pleasure in usual activities and motor retardation. In MS, symptoms such as sadness, irritability and anxiety may be the first indicators of an underlying depression.

**4.10.3 Diagnosis and management**

The diagnosis and management of depression in MS does not necessarily require psychiatric intervention. Any tests must be conducted in a setting/environment in which the person with MS feels comfortable and relaxed, and not be in a threatening or stressful situation. The most suitable environment is in the person’s own home.

Some medications may be of assistance. Current research indicates that the selective serotonin reuptake inhibitors (SSRIs) and the serotonin noradrenaline reuptake inhibitors (SNRIs) are useful in managing the subsyndromal symptoms associated with depression in MS. In addition, the monoamine oxidase inhibitor moclobemide is also used with some success in treating depression in persons with MS.

Nurses can play an important role in the recognition of depressive symptomatology in patients with MS, and the referral process to ensure patients access appropriate treatment. As in any clinical depression, medication combined with psychotherapy or counselling may optimise treatment outcomes.
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Introduction

MS is a chronic, demyelinating disease of the central nervous system for which there is no known cause or cure. While certain symptoms are characteristic of the illness, such as loss of balance and coordination, blurred or double vision, numbness, speech distortions, bladder and bowel problems and cognitive dysfunction, there is a great individual variation making it difficult to predict with any certainty the course and progression of the disease. Many patients have to cope with an ambiguous and unpredictable illness, loss of function, alteration of life roles and the experience of a range of debilitating and changeable symptoms.

Importantly, patients also have to cope with a loss of expectation they had for themselves. Chronic illness and disability require mourning the loss of body parts, their functions and potentials. If a person does not acknowledge that such mourning is necessary or is not allowed such activity, an overriding negative emotional state such as depression may develop (see Module 4 Section 10).

The psychosocial component needs to be addressed, using an orderly and systematic approach to assessing psychosocial problems, determining appropriate interventions, and initiating a collaborative plan. Evaluating the efficacy of this plan can significantly increase patient adherence to therapy, improve self care skills and assist patients in adapting to MS.

This Module discusses how to live a healthier life, how this disease impacts on the patient, how the patient can cope, ways to assess and evaluate psychosocial problems, the role of carers, and the use of complementary medicine.
5.1 Living a Healthier Life

Introduction

According to the World Health Organization, chronic diseases are now the major cause of death and disability worldwide. Non-communicable conditions, including cardiovascular diseases, diabetes, obesity, cancer and respiratory diseases or conditions now account for 59% of the 56.5 million deaths annually and 45.9% of the global burden of disease. Research has shown that a change in dietary habits, physical activity and tobacco control has a major effect on reducing the rates of these chronic diseases, often in a relatively short time. Therefore it is important to understand what is meant by good nutritional health.

Good nutritional health is characterised by a well-developed ideal body weight for body composition (ratio of muscle mass to fat), healthy skin, hair and mental alertness. Over the decades, but more frequently in the past few years, many diets have been published in regards to MS, some advising improvement in well being, others claiming to boost the immune system and also cure MS. The advice given within this section is based upon the guidelines of the WHO Strategy for Diet and Physical Well-being, along side researched based evidence proven to enhance the well being of the individual with MS. This brief overview will cover areas such as healthy balanced diet, fats and fatty acids, vitamins and supplementation, physical exercise, vaccinations, travel advice, tobacco and alcohol.

LEARNING OBJECTIVES

After completing this section the reader will be able to:

• Understand the impact of living a healthier life
• Describe how to live a healthier life
• Advise on eating a balanced diet
5.1.1 A healthy balanced diet

The World Health Organization (WHO) recommendations for a balanced diet include:

- Eating more fruit and vegetables as well as nuts and whole grains,
- Moving from saturated animal fats to unsaturated vegetable oil based fats,
- Cutting the amount of fatty, salty and sugary foods in the diet.

A general guide to the advised daily intake is best shown through the traditional diet pyramid (Figure 5-1).

Water and decaffeinated drinks are advised as the first choice for fluids. Caffeine acts as a diuretic and is rich in beverages such as coffee, tea, cola and other soft drinks.

Caffeine may cause irritations on the bladder. Some individuals with MS have been found to be sensitive to their hydration status and heat sensitivity, therefore they are encouraged to drink plenty of fluids, such as water.

There are many diets that have claimed to “cure” MS but they have not been supported by research and prove to be very expensive. There is some evidence that a diet low in saturated fats and supplemented by Omega 3 (from fatty fishes, cod-liver oil, or flaxseed oil) and Omega 6 (fatty acids from sunflower or safflower seed oil and possibly evening primrose oil) may have some benefit for people with MS. Some special diets may be harmful because they include potentially toxic amounts of certain vitamins, or exclude important nutrients. Others conform to the low fat, high fibre diet recommendations of World Health Organization.

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**Figure 5-1. The Traditional Healthy Diet Pyramid.**

- **2-3 Servings Daily**
  - Fats, Oils, Sweets
  - Dairy Products (Meat, Fish, Eggs, Poultry, Nuts, Beans)
- **3-5 Servings Daily**
  - Vegetables
- **6-11 Servings Daily**
  - Bread, Cereal, Rice, Pasta

Daily Physical Activity

Daily Beverage Recommendations:
6 Glasses of water
Alcohol in moderation
Fats and fatty acids

According to the American Heart Association guidelines, saturated fat should be 7-10% of the total calorie intake.

- 30% of total calories should come from fat,
- 7-10% from saturated fat sources (butter, cheese, whole milk, ice-cream, fatty meats, coconut and palm oils),
- 10% from polyunsaturated fat sources (seeds, nuts, avocado, lean meat, eggs, legumes, oily fish, seafood, sunflower, corn or soybean oils),
- 10% from monounsaturated fat sources (olive and canola oils).

## Omega 3 and omega 6

Approximately 1/3 of nervous tissue consists of polyunsaturated fatty acids (PUFA). These are described as Omega 6 (linoleic acid) and Omega 3 (alpha-linolenic acid). Previous research studies have shown that people with MS benefit from increasing the intake of these fatty acids, which are normally found to be in low levels in individuals with MS. The importance of these fatty acids is their immunosuppressive (Omega 6) and anti-inflammatory (Omega 3) properties; see Figure 5-2 showing which foods are rich in these properties.\(^5,6\)

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### Figure 5-2. Sources of Omega 3 and Omega 6 polyunsaturated fatty acids.\(^5,6\)

<table>
<thead>
<tr>
<th>Omega 6</th>
<th>Omega 3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Linoleic acid</strong></td>
<td><strong>Alpha-linolenic acid</strong></td>
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</table>

<table>
<thead>
<tr>
<th><strong>Gamma-linolenic acid</strong></th>
<th><strong>Eicosapentaenoic acid (EPA)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Dietary sources: evening primrose oil, borage oil</td>
<td>Dietary sources: fish, seafood, cod liver oil, fish oil.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Arachidonic acid (AA)</strong></th>
<th><strong>Docosahexaenoic acid (DHA)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Dietary sources: liver, kidney, lean meat, eggs.</td>
<td>Dietary sources: fish, seafood, liver, egg, cod liver oil, fish oil.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Prostaglandin E2</strong></th>
<th><strong>Prostaglandin E3</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>(Immunosuppressive)</td>
<td>(Anti-inflammatory)</td>
</tr>
</tbody>
</table>
Vitamins and supplements

Vitamins are organic compounds that are used by the body, in very small amounts, for a variety of metabolic processes. It is best to get vitamins from eating a varied diet. With the exception of vitamin D3, due to its difficulty to get from diet, taking vitamin and mineral supplements instead of eating a nutritious diet is not recommended. The body only needs a small amount of vitamins every day. A varied diet generally provides enough of each vitamin and mineral.

Research indicates that most of the vitamins you get from the food are better than those contained in pills. Even though the vitamins in supplements are synthesized to the exact chemical composition of naturally occurring vitamins, they still don’t seem to work as well. The main exception to this is folate. The synthetic form (in a supplement or fortified food) is actually better absorbed by the body than folate from food sources. If vitamin supplementation is required then a basic multivitamin is suggested as opposed to expensive variations manufactured and advertised to help MS.

Antioxidants

The process of oxidation in the human body damages cell membranes and other structures including cellular proteins, lipids and DNA. When oxygen is metabolised, it creates ‘free radicals’ which steal electrons from other molecules, causing damage. The body can cope with some free radicals and needs them to function effectively. However, an overload of free radicals has been linked to certain diseases. Antioxidants are found in certain foods that neutralise free radicals. These include the nutrient antioxidants, vitamins A, C and E, and the minerals copper, zinc and selenium. Other dietary food compounds, such as the phytochemicals in plants and zoochemicals from animal products, are believed to have greater antioxidant effects than either vitamins or minerals. These are called the non-nutrient antioxidants and include phytochemicals, such as lycopenes in tomatoes, and anthocyanins found in cranberries.

Sources of antioxidants

Good sources of antioxidants include:

- **Allium sulphur compounds** - leeks, onions and garlic.
- **Anthocyanins** - eggplant, grapes and berries.
- **Beta-carotene** - pumpkin, mangoes, apricots, carrots, spinach and parsley.
- **Catechins** - red wine and tea.
- **Copper** - seafood, lean meat, milk and nuts.
- **Cryptoxanthins** - red capsicum, pumpkin and mangoes.
- **Flavonoids** - tea, green tea, citrus fruits, red wine, onion and apples.
- **Indoles** - cruciferous vegetables such as broccoli, cabbage and cauliflower.
- **Isoflavonoids** - soybeans, tofu, lentils, peas and milk.
- **Lignans** - sesame seeds, bran, whole grains and vegetables.
- **Lutein** - leafy greens like spinach and corn.
- **Lycopene** - tomatoes, pink grapefruit and watermelon.
- **Manganese** - seafood, lean meat, milk and nuts.
- **Polyphenols** - thyme and oregano.
- **Selenium** - seafood, offal, lean meat and whole grains.
- **Vitamin C** - oranges, blackcurrants, kiwi fruit, mangoes, broccoli, spinach, capsicum and strawberries.
- **Vitamin E** - vegetable oils (such as wheat germ oil), avocados, nuts, seeds and whole grains.
- **Zinc** - seafood, lean meat, milk and nuts.
- **Zoochemicals** - red meat, offal and fish. Also derived from the plants animals eat.
The best way to gain antioxidants is by eating 2–4 servings of fruits and 3–4 servings of vegetables a day. Antioxidants can stimulate the immune system. In MS, suppressing the immune system is advised, therefore antioxidant supplements are not advised and should only be used in moderation. Herbs which may stimulate the immune system and may be toxic if too much is taken include arnica, echinacea, ginseng, garlic, cats claw and liquorice!

Vitamin B₁₂

Vitamin B₁₂ is also called cobalamin because it contains the metal cobalt. This vitamin helps maintain healthy nerve cells and red blood cells. Vitamin B₁₂ is naturally found in animal foods including fish, meat, poultry, eggs, milk, and milk products.

Characteristic signs, symptoms, and health problems associated with B₁₂ deficiency:

• Include anaemia, fatigue, weakness, constipation, loss of appetite, and weight loss,

• Deficiency also can lead to neurological changes such as numbness and tingling in the hands and feet,

• Additional symptoms of B₁₂ deficiency are difficulty in maintaining balance, depression, confusion, dementia, poor memory, and soreness of the mouth or tongue,

• Signs of vitamin B₁₂ deficiency in infancy include failure to thrive, movement disorders, delayed development, and megaloblastic anaemia.

Many of these symptoms are very general and can result from a variety of medical conditions other than vitamin B₁₂ deficiency. It is important to have a physician evaluate these symptoms so that appropriate medical care can be given.

Vitamin D

Vitamin D is a fat soluble vitamin that is found in food (see Table 5-1) and can also be made in your body after exposure to ultraviolet (UV) rays from the sun.

Sunshine is a significant source of vitamin D because UV rays from sunlight trigger vitamin D synthesis in the skin. Research also suggests that vitamin D may help maintain a healthy immune system and help regulate cell growth and differentiation, the process that determines what a cell is to become as well as reduce the risk of osteoporosis.

Sun exposure

Sun exposure is perhaps the most important source of vitamin D because exposure to sunlight provides most humans with their vitamin D requirement. UV rays from the sun trigger vitamin D synthesis in skin. Season, geographic latitude, time of day, cloud cover, smog, and sunscreen affect UV ray exposure and vitamin D synthesis. Sunscreens with a sun protection factor (SPF) of 8 or greater will block UV rays that produce vitamin D, but it is still important to routinely use sunscreen to help prevent skin cancer and other negative consequences of excessive sun exposure. An initial exposure to sunlight (10 -15 minutes) allows adequate time for Vitamin D synthesis and should be followed by application of a sunscreen with an SPF of at least 15 to protect the skin. Ten to fifteen minutes of sun exposure at least two times per week to the face, arms, hands, or back without sunscreen is usually sufficient to provide adequate vitamin D. It is very important for individuals with limited sun exposure to include good sources of vitamin D in their diet.
5.1.2 Physical exercise

Daily physical activity is advised alongside a healthy well-balanced diet to maintain a normal body weight within the body mass index (BMI range of 18.5–24.9) (see Figure 5-3).12

Exercise is thought to help people with MS control pain, stiffness, balance, weakness, depression, anxiety, insomnia and fatigue when done appropriately. Exercise is also seen as an essential component of health and well-being. Exercise should be seen as an enjoyment rather than as a chore. Regardless of the type of exercise program, it is important to stay cool. This can be done by drinking cool fluids, using a fan and a spray bottle or cooling device.

Research carried out in Australia documented that when people with MS undertake exercise, at a commencement level there can be some temporary changes in sensory symptoms, but these were unlikely to have any detrimental effect in fatigue or function.13
5.1.3 Complementary therapies

Potentially beneficial complementary or alternative medicines, of which exercise comes under, are activities such as massage, Tai Chi, hydrotherapy, yoga, meditation, pilates, relaxation techniques and self hypnosis/guided imagery.

5.1.4 Smoking

In a paper on cigarette smoking and the risk for developing MS, researchers studied this relationship in 22,312 people between the ages of 40 and 47 living in Hordaland, Norway. The risk for developing MS was nearly twice as high in people who currently smoked or had ever smoked than 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. Smoking also increased the risk for heart attacks, angina, and asthma for both men and women. A further study supports the hypothesis that cigarette smoking is associated with an increased risk of MS, and suggests that smoking may be a risk factor for transforming a relapsing-remitting clinical course into a secondary progressive course.

A recent meta-analysis on smoking as a risk factor for MS concluded that the evidence is weak but it is a significant factor for subsequent development of MS, with more weight on the evidence for supporting that there is an effect on the underlying progression change.
5.1.5 Alcohol

Alcohol is high in calories and so can cause weight gain. It is also a diuretic so when individuals drink alcohol, it is essential to also have non-alcoholic drinks that aren’t diuretics. Dehydration can lead to exacerbating symptoms experienced in MS. Heavy drinking can lead to a wide range of health problems, including cancer, liver disease, stroke, high blood pressure and can affect mental health.

5.1.6 Travel and vaccinations

Travel advice

It is recommended that people with MS contact their Nurse and Neurologist before booking an overseas trip. This ensures that all options and issues can be discussed. A letter from the Neurologist is needed for international travel that discusses their condition and medication. They will also need to notify the airline. For domestic travel, a prescription may be all that is required for a security check although a letter from the Neurologist is recommended.


Vaccinations

Before travelling, people with MS should discuss vaccinations with their Neurologist and travel doctor well in advance (at least 6 to 8 weeks before departure).

Useful websites

United States Department of Agriculture, Center for Nutrition Policy and Promotion. www.cnpp.usda.gov/


NIH Clinical Center, National Institutes of Health www.cc.nih.gov/


Multiple Sclerosis Trust publications list. www.mstrust.org.uk/default.jsp

Multiple Sclerosis International Federation. www.msif.org/en/

Consortium of MS Centres (CMSC). www.mscare.org/

National MS Society (USA). www.nationalmssociety.org/WIG/home/
5.2 Grief & Loss

5.2.1 Definition and causes\textsuperscript{17-22}

Grief can be defined as an intense emotion felt when someone experiences a significant loss. It is the process of working through the pain of loss; it is a functional necessity not a weakness.

There are life changes and transitions which produce grief and loss. Grief is the reaction to loss; sometimes it is physical (palpitations, stress, headaches), and/or psychological (anger, distress, hopelessness). There is a sense of powerlessness, a behavioural reaction and a spiritual nature of loss. Who am I? What is meaningful? What matters?

5.2.2 Acceptance\textsuperscript{17-22}

Acceptance of MS is not a one-off achievement, but an ongoing process. Commonly this process is divided into the Elizabeth Kübler-Ross five stage theory of grief:\textsuperscript{23}

1. denial and isolation
2. anger
3. bargaining
4. depression
5. acceptance

With the diagnosis of MS, people may need to adjust to a number of changes including the loss of their health, future plans, economic viability, independence and self-concept.

People with MS need to adjust to a range of threats - to life, fear of dying, body integrity and comfort (fear of disability, permanent physical changes, pain and incapacitation) and to emotional equilibrium. There are threats to the fulfilment of customary roles and activities, reduced cognitive function, and reduced sexual function, including loss of libido and erectile dysfunction.

5.2.3 Assistance\textsuperscript{17-22}

Voluntary and self-help groups can provide a powerful sense of identity and control over the illness. They can facilitate growth in confidence, trust, self-value, pride, identity, determination, responsibility, ability, knowledge and sensitivity to others.

The majority of people diagnosed with MS need to be given the information, the know how and the support to be able to live with their illness or disability and maximise their potential. The return of a sense of control allows someone to come to terms with the reality of their own lives. The experience of loss is integrated, it becomes part of us, and therefore there is the potential for both personal growth and deterioration.
Assessment

1. Assess how the patient, family, and/or primary caregiver are coping with the physical and functional disabilities associated with MS through assessment of coping behaviours.

2. Assess whether the following factors may influence coping strategies:
   - Support systems
   - Concurrent stressors
   - Educational needs
   - Previous experience with health problems
   - Spirituality
   - Alterations in social/leisure activities
   - Financial stability

3. Assess how the patient is coping with the diagnosis
   - Perception of event (ie does the patient feel this is a crisis situation?)
   - Preservation of emotional balance and self-image
   - Maintenance of significant relationships
   - Preparedness for an unpredictable future

4. Assess the patient’s level of dependence on others

5. Assess type of coping skills
   - Problem-focused
     - seeks information
     - establishes goals
     - rehearses alternatives
   - Emotion-focused
     - denies or minimises problems
     - requests reassurance or support
     - finds a general purpose or meaning in life

6. Assess for the following non-pharmacological health-maintenance behaviours:
   - Exercise
   - Proper diet
   - Use of stress-reduction techniques
   - Adequate rest/sleep
   - Use of alternative therapies

7. Assess whether any of the following issues need to be immediately addressed:
   - Employment
   - Disability
   - Financial
   - Child care

8. Identify therapy options and make appropriate referrals

Desired patient outcomes

Table 5-2 describes the desired outcomes of treatment intervention for the grief process.
<table>
<thead>
<tr>
<th>Nursing diagnosis</th>
<th>Intervention</th>
<th>Rationale</th>
<th>Desired patient outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grief</td>
<td>Encourage patient to identify source of fear. Educate patient on MS. Refer patient to appropriate counsellor and community support group. Assist the patient in understanding the grieving process. Ensure the patient understands that feelings of grief are “normal” under the circumstances.</td>
<td>Identifying the source of fear reduces the likelihood that the nurse will implement ineffective interventions by making false assumptions. Educate and support the patient to cope with MS.</td>
<td>Use supports to reduce fear. Communicate feelings of comfort and understanding. Develop or refine coping strategies that enable the patient to accommodate the demands of the illness.</td>
</tr>
<tr>
<td>Denial</td>
<td>Assess the patient’s knowledge of the disease and disease process. Educate the patient on the diagnosis and the disease process. Provide patients with the opportunity to express their interpretation of the situation. Acknowledge denial as a reasonable response to a potentially devastating diagnosis. Support the patient through the disease process.</td>
<td>Refusal may be due to lack of information. Understanding the patient’s own interpretation of the situation reduces the possibility that the nurse will make erroneous assumptions when planning appropriate care. Acknowledging denial legitimises the patient’s initial response as acceptable under the circumstances. Education and support improves the families’ understanding of MS and their response to the disease. Provides an opportunity to revisit the potential problematic responses to denial and promotes future acceptance of the disease.</td>
<td>Acknowledge disease. Increase level of trust in the nurse. Facilitate opportunity to revisit potential problematic response to denial and promote future acceptance of the disease.</td>
</tr>
<tr>
<td>Anger</td>
<td>Provide patient with outlets for expressing anger. Educate patient on behaviours that restrict exaggerated emotional responses.</td>
<td>Recognition of anger leads to the development of more positive coping strategies.</td>
<td>Vent anger in a positive fashion.</td>
</tr>
<tr>
<td>Depression related to disease process</td>
<td>Assess for suicidal ideation. Involve care provider and/or family in interventions. Inform family physician and consulting psychiatrist of diagnosis. Document all assessments and conversations with the patient. Provide patient with plan for follow up with clinician or clinic (as appropriate).</td>
<td>Depression is treatable, regardless of cause. Involving care provider and/or family in intervention helps ensure that the patient adheres to treatment. Documentation ensures professionalism and provides a record for determining accountability Reassuring the patient that MS management is a team effort.</td>
<td>Experience no or fleeting suicidal ideation. Verbalises acceptance of the unpredictability of the disease course. Verbalises and acknowledges the symptoms of depression and expresses a willingness to seek treatment. Verbalises understanding that depression is common in MS. Building of trust with patient and helps to prevent isolation and sense of loneliness.</td>
</tr>
<tr>
<td>Acceptance</td>
<td>Assess patient has accepted that he or she has MS. Ongoing support from family or caregiver. Ongoing support from health professionals.</td>
<td>Document that the patient has adjusted to the MS. Patient is aware of ongoing support whether it is individual or group counselling.</td>
<td>Verbalises acceptance of the unpredictability of the disease course. Has made adjustment and adaptation to a different way of life. Time allows the individual an opportunity to resolve the range of feelings that surface. Healing occurs when the loss becomes integrated into the individual’s set of life experiences.</td>
</tr>
</tbody>
</table>
**5.3 Financial & Vocational**

**Introduction**

The Australian MS Longitudinal Study (AMSLS) has estimated the direct and indirect cost of MS in Australia at over $600 million per annum, to which can be added another $1.400 million per annum for suffering and loss of quality of life making $2 billion per annum total. Costs of having MS include employment loss or reduced hours (sometimes for carers as well as patients), specialist, primary and allied health care, hospitalisation, informal care by family or others (valued at 43% of total financial cost), pharmaceuticals, etc.

A major economic issue currently being researched by the Australian MS Longitudinal Study is how people diagnosed with MS can best maintain their employment, which is important for independence and self-management for people with MS.

Vocational rehabilitation is used to assist people with physical, cognitive and psychological disorders to increase their productivity via employment. Vocational rehabilitation services in Australia are governed by the Department of Employment and Workplace Relations (DEWR) and must comply with twelve disability service standards. The Disability Services Act 1986 and the Workplace relations Act 1996 underpin these standards. Vocational rehabilitation programs are “goal orientated and provide people with disabilities with resources and training needed to find employment or to further education, which can lead to vocational opportunities”.

**5.3.1 Financial implications**

For advanced MS these can be far reaching and must be considered in any nursing assessment and plan of care. Financial planning is important at any stage of life and under any circumstances; however, with a chronic illness it becomes perhaps more essential if optimal quality of life is to be the aim.

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**LEARNING OBJECTIVES**

After completing this section the reader will be able to:

- List tools for the assessment of financial and vocational issues
- Develop and apply care plans for financial and vocational financial and vocational difficulties
- Understand the implications for clinical care

Financial issues are directly related to an individual’s ability to earn money and to balance their needs with their income, whatever the source may be. Therefore MS may be detrimental in essentially two ways, either by depriving people with MS the opportunity to earn an income or by increasing their needs in terms of “special” equipment or resources that they may require due to their disability, or usually a combination of both.

Their relationships will have a bearing on their financial situation in regards to the level of support provided, and shared earning capacity. As well a person’s premorbid financial situation will impact on future decision-making.

The potentially negative aspects of a perception of increasing dependence on others must also be taken into consideration when assessing the implications of financial disadvantage on a person’s emotional wellbeing.
An individual without supportive relationships may require the appointment of an advocate or guardian to protect their interests if they are no longer able to deal with their own financial management. They may need assistance with planning current and future care needs and their associated financial costs.

5.3.2 Implications for clinical care

Thorough assessment should be performed by the nurse in relation to a concern about financial issues and the potential and/or actual impact of MS. The MS nurse should be aware of services available in the community for financial and vocational support including Centrelink payments and vocational rehabilitation services. The MS nurse has the opportunity to advocate and refer to appropriate services and allied health professionals such as social workers. The MS nurse should provide continuity for people with MS as they negotiate the complex systems of health and disability.

Nursing diagnoses related to financial issues may include, anxiety, depression, loss of self-esteem, related to loss of income/prior earning potential, social isolation, decreased social interaction, decreased standard of living, inability to provide for oneself and/or dependents, fear of the future, suicidal thoughts or actions, breakdown or change in relationships.

5.3.3 Rehabilitation

This is an important aspect of the care planning for a person with MS. The main focus of any MS centred rehabilitation plan should be preventative and aim for maintenance of function in regards to all the activities of daily living. The acceptance of realistic goals is vital to the success of a rehabilitation plan for a person with a chronic disease such as MS.

The goals of the multidisciplinary plan should essentially be to allow function at its highest level despite functional loss or accumulation of disability due to progression of the disease.

It should involve a collaborative approach between the person with MS and all the healthcare professionals involved.

Assessment

While nurses espouse nursing management encompassing a psychosocial model, these forms of assessment tools are infrequently used by nurses as they are unfamiliar with them and few assessment tools deal with specific quality of life issues. Financial and vocational issues are two psychosocial components that are not routinely thoroughly clinically examined or closely researched.33,34

As self reported by people with MS these two issues may have an effect on quality of life and this form of assessment is under used by health professionals as an evaluation of the efficiency of nursing interventions. However, it has been shown that use of these types of assessments and measures are integral to quality nursing care management and are necessary for identification and assessment of successful change associated with clinical nursing interventions.27,35

The following areas are identified as integral considerations when reviewing patients’ financial and vocational status:28

- Income source
- Related impact of MS on people with MS and their capacity to fulfil vocational roles
- Support persons availability
- Inherent characteristics of the current occupation undertaken by the person with MS
- Transport and environmental accessibility issues
- Employer created accommodations facilitating accessible environment and modifications to vocational duties for the person with MS
- Knowledge of financial resources that can assist the person with MS during relapse events.
The tools currently available for use in assessing the impact of MS on vocational role and functional status include the Work Assessment Scale, the MS Stressor Scale, the Jalowiec Coping Scale, the Life Situation Survey, the MS-Related Symptom Scale, and the Activities of Daily Living (ADL) Self-Care Scale.

As few of these assessment tools are routinely used by nurses and do not assess all the areas mentioned above; it is imperative for nurses to recognise the need to document the results of these assessment areas elsewhere in patients’ documentation.28

To facilitate a decreased impact from the areas of finance and vocational issues associated with MS, nurses need to be cognisant of legislation and employment support services for people with disabilities, therefore empowering people with MS with this knowledge. Furthermore, nurses need familiarity with the provisions of Commonwealth and State government disability discrimination and industrial laws that advocate legal and financial support for people with disabilities; and similarly the financial support programs available through disability pensions. In addition, nurses should direct patients and their families to community/employee support programs that may help address issues specific to their situations.36-38

In addition, nurses need to be cognisant of the impact symptoms and their associated management strategies have on financial and vocational issues. Continence and fatigue are just two symptoms that impact on vocational issue and have financial considerations.

Implement a care plan for anxiety/anger resulting from financial and/or vocational difficulties (see example in Table 5-3).27-32
<table>
<thead>
<tr>
<th>Underlying causes of anxiety/anger</th>
<th>Intervention</th>
<th>Rationale</th>
<th>Expected patient outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduced social financial status, earning potential, ability to work and/or inability to work at a regular job</td>
<td>Identify patient limitations</td>
<td>Allows nurse to verify patient’s perceived limitations</td>
<td>Expresses specific limitations in ability to perform vocational roles</td>
</tr>
</tbody>
</table>
|  | Direct patient to appropriate resources: Employment for persons with disabilities  
  • Social worker  
  • Housing referral  
  • Renovation fund  
  • Travel resources  
  • Income support  
  • Tax credits  
  Refer patient to the appropriate rehabilitation or vocational services | Guiding the patient through the social/employment system empowers the patient to take the measures necessary to ensure personal wellbeing |
|  | Helps the patient come to terms with the losses imposed by MS by providing a structure within which the patient’s capabilities are assessed and matched to an appropriate activity or type of work. |  |
| Discrimination and prejudice in the workplace | Provide patient with an opportunity to express feelings and describe events that were deemed discriminatory | Allows patient to express feelings about a discriminatory incident | Aware of rights |
|  | Determine whether treatment based on disability discrimination was an isolated event. Determine whether the discriminatory event was due to the behaviour of a single person (eg colleague or superior) Determine whether services in the workplace exist that address the patient’s concerns and encourage the patient to make the appropriate report Refer patient to a social worker for further guidance Direct patient to a local ombudsman/human rights centre Inform patient of legislation and services supporting the employment of persons with disabilities | Validates the patient’s right not to expect discrimination Clarifies details of the discriminatory event Social workers can implement strategies to help the patient cope with anger, anxiety, and frustration Education about legal rights empowers the patient to secure these rights Collaboration with large organisations dedicated to meeting the quality-of-life needs of patients with MS helps identify common concerns and influence public-policy making initiatives | Expresses satisfaction or a sense of achievement as demonstrated by avoidance of helpless behaviours and appropriate expression of anger |
| Financial difficulties | Examine the patient’s financial needs and how well these needs are currently being met Discuss the availability of alternate financial support (eg family, friends) Inform patient of possible eligibility for financial assistance Inform patient of eligibility for group insurance coverage Refer the patient to websites on insurance planning or a resource/information consultant specialising in insurance planning Refer patient to financial assistance services Inform patient of labour laws that mandate temporary financial support from employers and government-linked financial support programs available through disability pension programs | Identification of the patient’s specific financial needs helps to develop realistic patient expectations about available resources Knowledge of financial services and resources may help the patient achieve greater financial independence | Identifies areas of financial need and available financial resources |
|  | Follows up on suggestions to contact social services, a social worker, and/or other appropriate community resources |  |  |
5.4 Sexuality & Sexual Functioning

The WHO defines sexuality as:39

Human sexuality is a natural part of human development through every phase of life and includes physical, psychological, and social components.

Sexual health implies a positive approach to human sexuality and is therefore an essential component of reproductive health. It includes the integration of somatic, emotional, intellectual, and social aspects of an individual in ways which positively enrich and enhance personality, communication, love and human relationships.

Introduction

The private and intimate nature of issues relating to sexuality presents a challenge to both patients and healthcare professionals in discussing sexual matters. Patients who are experiencing sexual problems may be unaware of the extent to which these can be attributed to MS; whilst others may be concerned about the potential impact of MS on their sexuality. It is important, therefore, for nurses working with people diagnosed with MS to be alert to the varying needs of patients for assessment, information and reassurance about sexuality and sexual matters.

5.4.1 Pathogenesis

MS related disturbances in sensory, motor and cognitive functions frequently manifest adversely on sexuality. These, like the disease in general, are extremely variable in frequency, duration and impact on the patient.

LEARNING OBJECTIVES

After completing this section the reader will be able to:

- Describe and apply strategies for the assessment of sexuality
- Develop and apply care plans for difficulties related to sexuality

Foley et al40 point out that the effect of MS on sexual problems may be ‘primary’ (direct physical manifestations), ‘secondary’ (indirect physical impacts, such as fatigue, spasticity, pain and disturbed continence), or ‘tertiary’ (psychosocial impacts, such as altered self-image, dependency and embarrassment).

Considerable complexity can therefore be involved in addressing these, and the range of potential interventions includes (but is not limited to) those which directly enhance sexual activity, the pharmacological management of MS symptoms, and counselling directed at self-image or improved communication skills.

The causative mechanisms, impact of and therapeutic interventions for sexual dysfunction are discussed in Appendix H.

5.4.2 Communicating

Sensitivity is required in addressing sexuality, and it is important to ensure that any intervention is at a level appropriate to the needs of the patient and the level of expertise of the nurse.
It is essential for healthcare professionals to assess their own knowledge about, and personal attitudes to, human sexuality; and to be aware that their own comfort level in discussing sexual matters will have an impact on the effectiveness of interventions. This type of counselling is very specialised and if a nurse can identify and initiate discussion on issues they can assist in ensuring appropriate referrals are made and support follow-up.

In broaching the subject with patients, it can be helpful to suggest that by ‘sexuality’ we mean the way we feel about ourselves as men or as women, rather than simply meaning sexual activity. Such an approach is in keeping with the WHO definition of sexuality.

When dealing with sexual issues, the PLISSIT model provides a systematic way of addressing sexual health concerns, and can assist nurses in deciding the level of intervention appropriate for a particular patient (see Figure 5-4). PLISSIT is an acronym for Permission, Limited Information, Specific Suggestions, and Intensive Therapy. The level of nursing intervention will vary according to both the requirements of the patient and the nurse’s confidence and professional expertise in this domain.

It is preferable, when discussing sexual matters with patients, to avoid the negative connotations of descriptors such as ‘dysfunction’, in favour of more neutral terms such as ‘changes’ or ‘concerns’. ‘Changes in erections’, for instance, may have a less negative impact on a patient’s self esteem than ‘impotence’. As well as being more sensitive, neutral terminology may more accurately reflect the patient’s position. Research indicates that the adverse effect on sexual response and/or activity commonly associated with MS is not necessarily viewed in negative terms by patients. In a study by McCabe et al of 74 women and 37 men with MS, only 20.4% of the men and 35.4% of the women reported no sexual difficulties, however over half of those surveyed were not overly concerned about this.

In identifying patients’ sexual concerns, and determining appropriate interventions, nurses can be guided by assessment guidelines based on the work of Szasz. This involves consideration, where relevant, of patients’ sexual knowledge, self-view, activity, response, interest and behaviour. It is essential that assumptions are not made about any of these, and that the nurse appreciates the considerable variability not only between individual patients, but also in the broader community. This further highlights the need for neutral language, with words such as ‘partner’ avoiding interpretations that judgments are being made regarding marital status or sexual orientation.

MS is frequently diagnosed at a time in people’s lives when intimacy, sexual identity and relationships are being explored, or becoming established. McCabe reports a strong association between sexual satisfaction and relationship satisfaction, but observes that there is limited research into sexuality and relationships of people with MS. There is a lower level of relationship satisfaction among people with MS and levels of disability are apparently not implicated. McCabe points out, however, that partners’ perceptions may well differ from those of patients, and further studies into this are warranted.

When dealing with sexual issues, the PLISSIT model can assist nurses in deciding the level of intervention needed for a particular patient. These components of the acronym form the levels of the pyramid shown below. Permission, at the base of the pyramid, applies to the majority of patients while intensive therapy, at the top of the pyramid, applies to relatively few patients. Each of these levels is described below in detail.

Permission

As the foundation of the pyramid, permission is the most important level because it provides an opportunity for patients and/or their partners to begin discussing their sexual concerns. Permission includes verbally acknowledging patients’ concerns about their sexuality and telling them that these concerns are normal.
Limited Information

At this level of the pyramid, patients are asked to discuss their concerns in more detail and are also offered some general information aimed at dispelling myths about sexuality and disabilities.

Specific Suggestions

At this level, patients and/or their partners receive specific information in response to their questions and concerns about sexuality. Although this level of intervention requires a broader knowledge base than is needed for the limited information level, nurses can successfully intervene at this level by applying their knowledge of MS to individual patients’ situations. For example, the nurse may give a particular patient suggestions on how to manage spasticity during sexual activity, based on information about what triggers and relieves spasms.

Intensive Therapy

This level of intervention requires specialised knowledge and training in the area of sexuality and MS. Therefore, it may be necessary to refer the patient to a healthcare professional who is qualified to implement intensive specialised therapy, and able to address patients’ concerns at this level.44

Reasons to refer patients to other services are:45

• If the issue is beyond the competence of the nurse
• Rape or sexual abuse

Table 5-4. Specific Suggestions for different problems and/or concerns.
(adapted from Taylor and Davis 2006)45

<table>
<thead>
<tr>
<th>Problem or concern</th>
<th>Specific Suggestions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Muscle spasm from MS</td>
<td>Experiment with different sexual positions eg from behind</td>
</tr>
<tr>
<td>Hemiplegia impeding sexual activity</td>
<td>Lie on affected back or side</td>
</tr>
<tr>
<td>Discomfort or pain</td>
<td>Use lubricant and consider other sexual activities</td>
</tr>
<tr>
<td>Catheter in situ</td>
<td>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)</td>
</tr>
<tr>
<td>Altered perception of their masculinity/femininity</td>
<td>Discuss what this means to them and identify what enhances these feelings</td>
</tr>
</tbody>
</table>

Figure 5-4. The PLISSIT model (reproduced with permission from Annog).41
• Psychosexual problems should be referred to a psychosexual therapist.

• Relationship problems should be referred to a relationship counsellor.

Taylor and Davis have recently identified limitations of the PLISSIT model and suggest a modified ‘extended’ version – the Ex-PLISSIT model.\(^{45,46}\) Whereas the PLISSIT model tends to be interpreted as a linear one-way progression from one level to the next, the Ex-PLISSIT model features reflection and review of interventions and on-going revisiting of Permission-giving to continually re-assess patients’ needs.

The proactive approach to seeking Permission recognises the dynamic nature of sexuality and is particularly relevant to patients who have a chronic illness such as MS. Nurses should be alert to opportunities to make patients aware that it is appropriate to discuss sexual matters with them.

The Ex-PLISSIT model allows for interventions at various levels simultaneously. Hence, even if the patient has been referred on for expert advice (the highest level of intervention, Intensive Therapy), permission seeking should continue to allow the nurse to ascertain if other, lower level, interventions are indicated.

Importantly, Taylor and Davis warn that practitioners who provide Limited Information (eg information booklets) to patients are disregarding the Permission level if they do so without specifically inviting comment from the patient about the information’s relevance and applicability.

The level of nursing intervention will vary according to both the requirements of the patient and the nurse’s confidence and professional expertise in this domain.

Figure 5-5. The Extended PLISSIT model.\(^{45,46}\)
5.4.3 Sexual health assessment framework

The Sexual Health Assessment Framework (see Table 5-5) can assist nurses in identifying patients’ sexual concerns and can also be used to guide nursing assessments and interventions for managing changes to sexuality resulting from MS.43,44,47,48

<table>
<thead>
<tr>
<th>Assessment</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexual knowledge</td>
<td>Determine the patient’s understanding of changes to sexuality that result from MS. Determine the patient’s values and beliefs about sex and sexuality. Do not make any assumptions regarding the patient’s knowledge or values; always clarify the patient’s perceptions of the impact of MS on sexual function and sexuality.</td>
</tr>
<tr>
<td>Sexual self-view</td>
<td>Determine the patient’s sexual self-view (ie patients with MS may remain sexual but may be challenged to define their sexual self-view; for example, prior to requiring a wheelchair, patients may view persons in wheelchairs as not being sexual; this belief will influence how patients may view themselves once they require a wheelchair).</td>
</tr>
<tr>
<td>Sexual activity</td>
<td>Determine the patient’s ability to engage in sexual activity by assessing motor abilities, balance, strength, and bowel and bladder function. Determine whether activities such as dressing and undressing, transferring, and affectionate activities such as hugging and petting need to be re-examined. Instruct the patient on new positions and techniques; instruction will need to be individualised according to patients’ comfort level, interests, and physical abilities; this function may require referral to a specialist in sexual health.</td>
</tr>
<tr>
<td>Sexual response</td>
<td>Determine the patient’s sexual response. Sexual response in women refers to general physiological changes (eg increased heart rate and blood pressure, skin flush) as well as genital vasodilatation, vaginal lubrication, nipple erection, and orgasm. Sexual response in men includes general physiological changes (as above), penile erection, testicular elevation, pre-ejaculation, ejaculation, and orgasm. Changes to sexual response will vary greatly from patient to patient and are dependent upon the level of disability.</td>
</tr>
<tr>
<td>Sexual interest and behaviour</td>
<td>Determine the patient’s ability to initiate or maintain social/sexual relationships; maintaining such relationships is a fundamental concern for most patients. More detailed assessments of the patient’s values and beliefs, social and communication skills, and sexual history may be needed. Assess whether the patient’s partner has assumed any care-giving activities that may threaten the patient’s role as a lover.</td>
</tr>
</tbody>
</table>

5.4.4 Care plan to help patients discuss sexual matters

The care plan in Table 5-6 can be followed to facilitate the discussion with patients about sexual issues and needs.
<table>
<thead>
<tr>
<th>Intervention</th>
<th>Rationale</th>
<th>Expected patient outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide an open, non-judgmental atmosphere for discussion</td>
<td>Facilitates open expression of feelings about perceived changes in sexuality</td>
<td>Effectively communicates sexual concerns and needs Expresses actual or perceived limitations imposed by MS and openly verbalises feelings regarding changes in sexual identity</td>
</tr>
<tr>
<td>Ensure privacy</td>
<td>Conveys respect for the patient and the sensitive nature of the patient’s concerns</td>
<td>Effectively communicates sexual concerns and needs Expresses actual or perceived limitations imposed by MS and openly verbalises feelings regarding changes in sexual identity</td>
</tr>
<tr>
<td>Ask the patient’s permission before moving on to an area of assessment (eg “Is it okay if I ask you some questions about the sexual part of your life?” Later on in the interview ask, “May I ask about what changes you’ve experienced in body sensations?”)</td>
<td>Conveys respect for the patient and the sensitive nature of the patient’s concerns</td>
<td>Effectively communicates sexual concerns and needs Expresses actual or perceived limitations imposed by MS and openly verbalises feelings regarding changes in sexual identity</td>
</tr>
<tr>
<td>Begin with general questions and then move to more specific questions</td>
<td>Conversation should progress from the least sensitive areas to most sensitive areas (eg ask about changes in bladder and bowel function before asking about changes in sexual function)</td>
<td>Effectively communicates sexual concerns and needs</td>
</tr>
<tr>
<td>Use neutral language</td>
<td>Allows patient to express concern without fear of being judged Neutral words such as “partner” facilitate a more open discussion of sexual concerns – regardless of sexual orientation – than words such as “husband” or “wife” Neutral phrases such as “changes in erections” have less of a negative impact on patients’ self-esteem than words such as “impotence”</td>
<td>Demonstrates an increased understanding of the limitations imposed by MS Expresses a willingness to seek more expert assessment and treatment Demonstrates an improved level of knowledge of available options</td>
</tr>
<tr>
<td>Normalise and validate the patient’s concerns (eg say “Many people feel this way” or “Women often ask that question.”)</td>
<td>Ensures that the patient does not feel alone or unusual for having sexual concerns</td>
<td>Demonstrates an improved self-perception of desirability and self-image Explores alternate sexual behaviours/patterns</td>
</tr>
<tr>
<td>Provide reassurance based on facts</td>
<td>Kind words that are not based on factual information may instill false hope in the patient</td>
<td>Demonstrates an improved understanding of the limitations imposed by MS</td>
</tr>
</tbody>
</table>
5.5 Pregnancy

Introduction

The incidence of MS is highest in young women between the ages of 20 to 40 years. This period 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.

Issues concerning a pregnant woman with MS and her developing baby are not dissimilar to those of a woman without MS. However, 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 bladder.

5.5.1 Planning phase of pregnancy

MS has no physiological effect on fertility. 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). General education pertaining to issues such as nutrition, exercise, rest and relaxation are as relevant to the woman with MS as to any other.

Consideration also needs to be given to any drugs a woman is taking, or considering starting prior to pregnancy. For example, following a diagnosis of MS, some women may decide to delay commencing immunomodulatory treatment with a view to becoming pregnant within the next 3-12 months.

There is no conclusive research addressing this issue, therefore all forms of immunomodulatory therapy should be ceased 1-3 months prior to conception (see individual product information for recommendations). As in all pregnancies, all potentially teratogenic drugs should be avoided; for example, baclofen should be avoided particularly in the first trimester.

LEARNING OBJECTIVES

After completing this section the reader will be able to:

• Describe the issues with pregnancy
• Help advise the patient before and after birth

Pregnancy tends to have a protective effect on MS, the disease process is generally less active and relapses less common. This protective effect is understood to be related to hormonal changes and normal suppression of the immune system during pregnancy. Discussing this with patients can ease concerns over (temporarily) ceasing medications. However, in the first 3 months post partum, there is an increased rate of relapse, although there is no overall increase in lifetime relapse rate.

MS has little or no effect on the course of pregnancy or delivery. Decisions regarding management of labour should reflect obstetric issues alone.

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 pregnancy. 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 post partum period.

Further reading

Sponiar MC. The motherhood choice: development and evaluation of a decision aid for women with multiple sclerosis. A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy, School of Psychology, Faculty of Science, University of Sydney, September 2007.
Introduction

Many patients with multiple sclerosis (MS) are increasingly turning to complementary and alternative medicines (CAMs) for a variety of reasons, including:

- Frustration with conventional medicines and the lack of a cure for MS
- Increased desire to play a role in the management of their disease
- Potential for relief of symptoms
- Increased desire for self-care decision
- Desire to access "more natural" treatments with potentially less side effects

Disclaimer: Some healthcare professionals do not support the use of CAMs for the management and treatment of MS since there have been few scientific studies conducted in this area.

5.6.1 Definitions

The terms natural therapies, traditional medicine and complementary or alternative therapies are often used interchangeably in common language to describe any therapy that is not prescribed by the traditional medical doctor. Likewise, the terms conventional therapies, western, allopathic or orthodox medicine are also used interchangeably. In general, therapies for any illness, chronic or acute, can be classified into one of the following categories:

- Conventional (western medicine, allopathic)
- Alternative (natural)
- Complementary

Conventional therapy

The term conventional therapy describes commonly accepted pharmacological agents that have been carefully studied using the scientific method, and have been proven to be safe and efficacious in the treatment of particular illnesses.

Alternative therapy

The term alternative therapy refers to drugs, diets, food supplements, mental exercises, hands-on techniques, and lifestyle regimens used to promote wellness or treat illnesses. Generally, alternative therapies aim to stimulate the body's own healing powers rather than to suppress particular symptoms. In some instances patients will discontinue conventional therapy in favour of alternate therapies.
Complementary therapy

Although complementary therapies are often the same as alternative therapies, the term complementary is more commonly used for therapies that are used in conjunction with conventional pharmacological treatments.

5.6.2 Types of CAMs

There are many different therapies under the banner of complementary and alternative medicines (CAMs), for ease of understanding they can be classified into one of the following:

- Nutritional
- Herbal/Botanical
- Physical
- Energy
- Psychological
- Biological

Nutritional therapies

This category includes all therapies that attempt to promote optimal health or eliminate disease through dietary modifications and/or the use of nutritional supplements. Some examples of nutritional therapies are:

- Vitamins, megavitamins, and minerals
- Macrobiotics
- Gerson therapy
- Swank diet
- Natural hygiene (ie raw foods)
- Enzymes

Herbal/Botanical therapies

This category includes the following:

- Traditional Chinese medicines
- Herbal remedies
- Homeopathy
- Environmental medicines
- Australian or other native healing methods
- Australian or other naturopathic medicines
- Ayurvedic medicines
- Tibetan medicines
- Iridology

Physical therapies

Physical therapies involve physical manipulation, touch, and/or exercise. They include:

- Acupressure
- Alexander technique
- Aromatherapy
- Chiropractic adjustments
- Colonic irrigation
- Craniosacral therapy
- Feldenkrais
- Hydrotherapy
- Hyperbaric Oxygen Therapy
- Lymphatic drainage
- Massage therapy
- Osteopathy
- Qi kong
- Reflexology
- Tai Chi
- Yoga

Energy therapies

Energy therapies (also known as life-force therapies) claim to optimise the flow of energy within the body. They include:

- Acupuncture
- Biodynamic massage
- Colour, light, and sound therapies
- Crystal healing
- Flower essences (Bach flower remedies)
- Reiki
- Polarity therapies
- Therapeutic touch
Psychological therapies

Psychological therapies (also known as mind/body control therapies) include:
• Art, dance, and music therapies
• Biofeedback
• Counselling
• Hypnosis
• Meditation
• Psychotherapy
• Relaxation
• Section prayer
• Support groups
• Visualisation

Biological treatments

Biological treatments include:
• Antioxidant agents
• Cell treatments
• Chelation therapy
• Metabolic therapy
• Oxidizing agents (eg ozone hydrogen peroxide)

5.6.3 Basic principles

There are differences in how natural therapies or CAMs approach health and disease, and how patients are assessed and treated from those of conventional medicine. This can vary with each type of therapy used by the natural therapist.

Some of the basic principles that natural therapists subscribe to (and many of these are applicable to all types of medicine) include:
• Do no harm, use safe and effective natural therapies
• Nature has healing powers and the therapist’s role is to work out what has gone wrong and how to assist the body in healing itself
• Identify and treat the cause and symptoms

• Use a holistic approach which includes evaluating and aiming intervention at the patient’s physical, mental, emotional and social aspects
• The therapist educates and motivates patients to take responsibility for their health
• Prevention is the best cure
• Given the right environment the body will heal itself, and the ability to do so is a basic property of every living organism. Illness can be seen as the body’s attempt to heal itself
• Each individual has a unique different system or constitution, and treatment needs to be specific
• The concept of an existence of an energy source or vital force. The human organism is perceived as a series of multi-dimensional energy fields. A life force exists that emanates from the body called the etheric or vital body which is a subtle overlay to our physical body

Variations on these basic principles

Many of the types of CAMs have some variations on these basic principles, and are understood by those who practise each type. Some of these are ancient practices such as the use of herbal medicines, whilst others are new philosophies and new ways of treatment.

Herbal medicine

A natural therapist uses plant products to prevent and treat illness. In Australia, guidelines on the use of herbs are taught in university courses on naturopathy. The Herbal Materia Medica is a catalogue used by students and practising therapists that lists over 150 herbal remedies, with brief details of the constituents, actions, indications, contraindications, side effects, and preparations and dosage. This is updated regularly. It is well recognised that plant substances can contain toxic materials that may be harmful to the body, and some herbs are banned in Australia.
Homeopathy

Homeopathy was developed in the 1800s by a German physician (Dr Samuel Hahnemann), and has become one of the most popular natural therapies used. Homeopathy uses a precise system of medicine, whereby minute doses of a substance are made very dilute but becomes high in energy through a special process. This energy and not its molecular structure, is used for healing benefits. The basic principle of homeopathy is a law of similarity or “like cures like”, where the same substance that caused the illness can in very diluted amounts heal the body.

A homeopath will also prescribe treatment on the basis of a person’s temperament or constitution, and physical, mental and emotional symptoms. This means that people suffering from the same disease often require different remedies.

Remedial therapy

Remedial therapists use massage, Reiki, aromatherapy, kinesiology, Alexander technique, reflexology and others to stimulate healing by treating the muscles, tendons and ligaments. This can also assist in removing blockages to energy flows.

Aromatherapy uses essential plant oils extracted by cold pressing or specialised distilling.

Traditional Chinese medicine

Practitioners of traditional Chinese medicine are often discussed separately from natural therapists. They use a combination of herbs, acupuncture and remedial therapy. Acupuncture follows energy lines throughout the body. This energy is called Qi (pronounced Chi) and when it doesn’t flow freely and becomes blocked the body becomes ill. Portal and entry flows of energy are located at specific areas, and there are acupuncture points to promote free flow of energy.

Osteopath and chiropractor

Osteopaths and chiropractors use principles of body mechanics and manipulative techniques to free the body. They focus on the spine and believe the structure greatly influences health. Osteopaths also emphasise the role of soft tissue on skeletal framework and general health.

Nutritional therapy

Most naturopaths use some sort of nutritional therapy such as vitamin supplements, dietary modification, mineral supplements, specific amino acids etc.

Iridology

Iridology is a diagnostic tool used by some naturopaths. Various parts of the body are reflected in the iris, and an iridology chart is used to identify where dysfunction or weakness is evident and then treated.

5.6.4 Regulation of CAMs

In Australia, there has been much discussion on the regulatory requirements of complementary therapies, and the legal status of the dispensing of these medicines. In 1996, the Commonwealth government began to acknowledge the need for tighter regulation of complementary therapies and medicines, and a review was initiated by the Therapeutic Goods and Administration (TGA). The Complementary Medicines Evaluation Committee and the Office of Complementary Medicine is now part of the TGA. In 2002, the National Herbalist’s Association (NHA) and the Federation of Natural and Traditional Therapists (FNTT) received a Commonwealth grant to review the process of establishing a uniform national registration scheme to practitioners of complementary therapies, and establish the Australian Council of Complementary Medicines as the registering authority. This process is still underway.
The current regulation governing the dispensing of herbal medicines in Australia is as follows. The Therapeutic Goods Act requires a medicine to be listed or registered if used in the prevention, cure or alleviation of a disease, defect or injury, or to influence, inhibit or modify a physiological process including any product dispensed by a naturopath. Many complementary therapies are listed at a lower risk category, which is defined as a medicine containing well known ingredients that have a long history of use.

The Goods Manufacturing Practice (GMP) Act applies to all manufactured goods including complementary therapies, however there is significant ambiguity and lack of clarification as to what are complementary medicines and in particular what is defined as a food or medicine.

A natural medicine practitioner is currently expected to register with the health department of the local council and covered under the Food Act. Those who practise Chinese medicine are expected to register with the Chinese Medicine Board of Registration under the Chinese Medicine Registration Act 2000.

The major professional bodies in Australia for CAMs are:
• Australian Traditional Medicine Society (represented on 2 Commonwealth statutory committees)
• Complementary Medicine Association (CMA)
• National Herbalist Association of Australia
• Federation of Natural and Traditional Therapists
• Australian Natural Therapists Association
• Australian Acupuncture and Chinese Medicine Association

There is no current legal or regulatory obligation for practicing natural therapists to become a member of any of the above professional bodies, although many are.

5.6.5 Role of the MS nurse

It is well recognised that the use of complementary therapies are not taught in western medicine and nursing courses. They are not well understood by many nurses and doctors, and may have not been scientifically researched to the same degree as pharmaceutical medicines. Increasingly some CAMs are being acknowledged as being of some benefit for some patients groups including cancer and MS patients. It is therefore not possible for nurses to comment on the safety and efficacy of these medicines. It is important that the MS nurse first ensures that the patient makes informed decisions regarding the use of CAMs. Ask yourself the following questions before assisting any of your patients:

1. Is it appropriate to provide information about CAMs?
   • Do I have the knowledge, skill, and judgment to assess the appropriateness of this therapy for this patient?
   • Do I have enough information about this therapy to answer the following questions:
     – what is the anticipated effect?
     – what are the potential benefits?
     – what are the potential risks?
     – what is the expected outcome?
   • Does the patient have access to relevant information regarding the risks and benefits of this therapy?
   • Has the therapy been recognised as an acceptable intervention within my agency/organisation?

2. Can I recommend agencies or practitioners who have the required knowledge, skills, and judgment to provide this therapy safely and effectively as well as provide ongoing assessment and evaluation?

3. Do I understand and can I deal with the possible outcomes?

Nurses who answer “no” to any of these questions should educate themselves more thoroughly about CAMs, or refer patients to healthcare professionals with the knowledge and skills needed to assist patients in making informed choices.

Nurses who answer “yes” to all of the above questions and who feel they are qualified to educate patients on CAMs should provide patients with access to reliable information.

All discussions about the potential and actual use of CAMs should be documented in the client’s record.
5.6.6 Points patients should consider

There are suggestions nurses can make to help patients when they are considering choosing a therapist or treatment eg:

• How reliable is the information I have about this CAM? Who provided me with this information, what qualifications did they have and is anyone else familiar with it?
• Have I gathered enough information about this therapy?
• What claims are being made about the treatment or product and what is it promising me? Can these claims be supported with real life evidence of success? (Nurses can recommend that it would be worthwhile to contact the TGA to see if the product is listed)
• What does this therapy or product involve? How much will it cost? How long will it take to have effect? How will this therapy interact with my current therapy? What time commitment is involved?
• How does the therapy or product work? What is the reason it is being prescribed?
• Can the therapist prescribing the treatment/product tell me about any risks or possible side effects? How will the effects be monitored and assessed?
• What will be the therapist’s corrective action if negative effects occur or there is no change in my health status?
• What are the natural therapist’s qualifications? Do they belong to any well known professional body or organisation? What areas of CAMs do they specialise in? How long have they been practising? What do they know about MS and its treatment?

Nurses should also instruct patients to:

• Consult an MS specialist to establish if they are aware of the CAM treatment or know of any possible side effects or drug interactions
• Discontinue the therapy/product if they have negative side effects and to notify the MS specialist nurse or doctor
• Inform the MS specialist nurse or doctor of the therapy and discuss if they are considering discontinuing any of the medication prescribed by their doctor
• Make sure that the patient carefully investigates all the ingredients of the product, and ensure that they do not contain toxic substances that may be harmful especially over the counter and/or self-prescribed products
• Ensure those who prescribe the treatment/product are qualified and have an understanding of MS and its management
• Use extreme caution with treatments, products or ingredients that suggest they “boost” or stimulate the immune system.

Although most natural medicines are accepted as having minimal side effects, it is important that care is taken with all things relating to the patient’s well being, and that patients are confident that the natural therapist they visit is trained appropriately and aware of the possible effects from particular remedies. The patient also needs to question the natural therapist’s knowledge of the conditions they are and are not allowed to treat.

Further reading

Website: www.ms-cam.org/ - This website provides accurate and unbiased information and conducts on line surveys to assess the effectiveness and safety of CAMs used by people with MS.
Introduction

Informal care, provided by family and friends, at no monetary cost including assistance with personal care activities, domestic chores, transport and childcare rises exponentially with the level of disability. An estimation of the value of informal care in Australia, based on the replacement valuation method, is approximately 15% of the total cost of MS equating to $90 million Australian dollars.53

5.7.1 Who cares for the carers?

Looking after a loved one with a disability is not an easy thing to do. Carers require financial, psychological and physical support so that their loved one can be cared for in the community.21,54 The burden of carers is likely to be exacerbated by the relatively young age of those who have MS, the unpredictable course of the disease, the absence of a cure, the episodic nature and potentially disabling neurological symptoms and the presence of depression and or cognitive issues.55

The role of the MS caregiver is as follows.56

• To keep people as functional as possible against the progression of the disease
• To prevent complications including skin breakdown, depression, infections, contractures and choking
• To assist with adaptation to change related the disease process and maximize independence at home
• To enhance the quality of life of people with MS and their families
• To prevent premature or inappropriate nursing home placement

Given the demanding role of access to regular respite, other supports for the caregiver are essential to prevent burnout.

LEARNING OBJECTIVES

After completing this section the reader will be able to:

• Understand the economic, social and emotional impact of caregiving
• Describe the stressors and rewards in being a primary caregiver
• Demonstrate an understanding of the issues faced by carers of people with MS and the services and supports that will be of benefit to them

This will ultimately enable persons with MS to continue living in the community. Promotion of self care is essential and time out to recuperate from the role of caregiver is beneficial. Health professionals and family members can encourage primary carers to access respite and help source and coordinate alternative care options in their absence.57

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. 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
Module 5 - Lifestyle Management

- 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 stressors involved in care giving include:

- Managing cognitive deficits and the associated problems they cause in daily life (e.g., memory problems, problems with judgment, initiation of activity, ability to process new information and behavioural issues)
- Ongoing daily provision of other aspects of physical care, especially managing incontinence of bladder and/or bowel
- Overwhelming sense of uncertainty and unpredictability
- Issues regarding sexuality
- Difficulty in accessing required level of care and support
- Financial concerns (insufficient income or high MS related medical costs)
- Disruption in usual roles
- Worry about possible nursing home placement
- Lack of own space and time for self
- Change in identity
- Lack of energy to do much else
- Loss of friends
- Altered socioeconomic status

However there are also significant personal rewards for being a caregiver including:

- Knowing you have made a real difference in the life of the person you love
- An enhanced feeling of self worth and achievement
- Having a clear conscience and no regrets through caring for your loved one
- Being recognised by others for your dedication
- Earning the gratitude of the person for whom they provide

In general, research into MS caregiving shows that avoidance coping leads to more distress when compared with meaning-based coping strategies such as positive reframing. Caregivers want and need as much accurate information as possible about MS, its various symptoms and how to manage them.

Issues of particular importance are dealing with cognitive deficits caused by MS and managing incontinence of both bowel and bladder. Caregivers also require information regarding the services and support available to meet the needs of the person with MS as well as their own needs, the costs of those services and their accessibility. Finally, it is important to remember that most caregivers value the opportunity to share information on coping strategies that others have found useful. As new problems arise, so too will the need for new types of information. The literature shows that social support groups have a beneficial effect on the well-being of carers.

It is also important for caregivers to have someone to listen to their story and try to understand the things they have been experiencing. An empathic listener can validate their experience and show respect, honour and support for their commitment to caring for the person with MS.

Healthcare professionals should also support caregivers by having relevant information on available programs 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 the carers appraisal of their individual situation, support networks and coping processes as these shape positive and negative carer outcomes. Ideally information, training and support should be offered using a proactive approach rather than waiting until help is sought or a crisis occurs.

Caregiver stress is an internal experience that can result from the physical and/or emotional burden of caregiving. When a caregiver responds to that stress by inflicting harm on the person with MS they care for, it becomes abuse. The MS nurse should be familiar with different types of abuse including physical, sexual, psychological and emotional as well as neglect, exploitation and theft and understand their duty of care and reporting responsibilities.
5.7.2 To the future

Most people working in the MS care area should provide care and support that encompasses the health needs of the caregivers as well as those of the person with MS. Caregivers add value to Society and this should be recognised. The Carers Recognition Act of 2004 is legislation passed in WA that was developed in response to calls by carers for greater recognition and consideration by service providers.62

The WA Carers Charter provides guidelines for service providers in relation to:

- Treating carers with dignity and respect
- Including the carer in aspects of assessment, care planning and service delivery
- Including the views and needs of the carer in the decision making process
- Acknowledging and managing complaints made by carers in relation to service delivery.

It is essential that MS healthcare professionals project positive attitudes and hope through demonstrating caring, support, listening, educating, and advocacy.

Acknowledgment

In addition to the cited references, the author would like to acknowledge the clinical information provided by Judy Soderberg MSW, LISW, Director of the Multiple Sclerosis Achievement Center, Fairview University Medical Center, St. Paul, Minnesota.
Module 5 - Lifestyle Management

5.8 Family Issues

Introduction

Family issues are often overlooked during the nursing assessment as patients may find it difficult to discuss these issues. However, to achieve a full understanding of the burden of illness and implement appropriate interventions, it is important for nurses to determine the impact of MS on patients’ families. Furthermore, the 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. The information in sections 5.1 – 5.7 should be considered in supporting families living with MS.

Assessment

1. Assess family coping behaviours and problem-solving techniques
2. Assess family support system (eg spiritual practices)
3. Assess family activities and financial resources
4. Assess assumed and/or expected family roles and the impact MS has on these roles
5. Assess the perceived impact of MS on the family’s assumed and expected roles
6. Assess family interaction and communication patterns, including expressions of:
   • Anger
   • Fear
   • Despair
   • Affection
7. Assess family members’ level of understanding and knowledge of MS
8. Encourage the expression of feelings related to perceived or potential losses and determine the impact of these feelings on the family’s wellbeing

LEARNING OBJECTIVES

After completing this section the reader will be able to:
• Assess the family situation
• Follow a care plan for such difficulties

Desired outcome

Follow care plan for difficulties related to family issues
(see example in Table 5-7)
<table>
<thead>
<tr>
<th>Nursing diagnosis</th>
<th>Underlying causes</th>
<th>Intervention</th>
<th>Rationale</th>
<th>Expected patient and family outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grief</td>
<td>Loss of “normal” family unit</td>
<td>Encourage family to identify source of fear, Educate family on MS, Refer family to appropriate counselor and to family and community support groups, Assist patient and family in understanding the grieving process, Ensure patient and family understand that feelings of grief are “normal” under the circumstances</td>
<td>Identifying the source of fear reduces the likelihood that the nurse will implement ineffective interventions by making false assumptions about the source of fear, Education and support help the family cope with MS</td>
<td>Use supports to reduce fear, Communicate feelings of comfort and understanding, Develop or refine coping strategies that enable them to accommodate to the demands of the illness without destroying family balance</td>
</tr>
<tr>
<td>Anger</td>
<td>Diagnosis of a chronic illness</td>
<td>Provide family and patient with outlets for expressing anger, Educate family and patient on behaviours that restrict exaggerated emotional responses</td>
<td>Recognition of anger leads to the development of more positive coping strategies</td>
<td>Vent anger in a positive fashion</td>
</tr>
<tr>
<td>Fear</td>
<td>Related to the uncertainty of future events</td>
<td>Educate family on disease process</td>
<td>Improved knowledge reduces fears</td>
<td>Demonstrate an improved understanding of the disease process, Fear future events less</td>
</tr>
<tr>
<td>Guilt</td>
<td>Disease pathogenesis or process itself</td>
<td>Allow expression of guilt, Provide reassurance, Ensure patient and family understand that feelings of guilt are “normal” under the circumstances</td>
<td>Expression and alleviation of guilt help maintain healthy family dynamics</td>
<td>Demonstrate an increased understanding of the disease process, Acknowledge that guilt is an allowable emotion, Understand that the patient acquiring the disease was no one’s fault</td>
</tr>
<tr>
<td>Denial</td>
<td>Refusal to acknowledge disease process</td>
<td>Assess family’s knowledge of the disease and disease process, Educate the family on the diagnosis and the disease process, Provide family with the opportunity to express their interpretation of the patient’s situation, Acknowledge denial as a reasonable response to a potentially devastating diagnosis, Support patient through the disease process</td>
<td>Refusal may be due to lack of information, Understanding the family’s own interpretation of the patient’s situation reduces the possibility that the nurse will make erroneous assumptions when planning appropriate care, Acknowledging denial legitimises the family’s initial response as acceptable under the circumstances</td>
<td>Acknowledge disease, Increase level of trust in the nurse, Facilitate opportunity to revisit potential problematic response to denial and promote future acceptance of the disease</td>
</tr>
</tbody>
</table>
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6. The Diverse Roles in MS Nursing

MODULE OVERVIEW

This module contains three sections:

- **Section 1**: Remote Areas
- **Section 2**: Rehabilitation & MS
- **Section 3**: MS Nursing Research

Introduction

The list of needs for MS care is long and complex. Interventions range from instruction in the use of oral and injectable medications to bowel and bladder management strategies, and to the improvement of mobility. The dynamic nature of the disease and the psychosocial, economic, and physical implications of MS call for ongoing skill development and up-to-date information on the part of the nurse involved in MS care.\(^1\) The roles of the MS Nurse, MS Nurse Practitioner and MS Advanced Practice Nurse are well established in international settings. The education and skills of MS nurses are well suited to the complexity of issues facing individuals and families with MS. The nurse working in the field of MS is a care provider, facilitator, advocate, educator, counsellor, and researcher/innovator. The challenges of the disease require many creative interventions in a wide variety of settings.\(^1\)
Scope and role in MS nursing

With a greater understanding of the management of the disease and in particular the introduction of new disease-modifying treatments for MS, the goals of MS care have evolved from palliative care and alleviation of symptoms to include managing neurologic symptoms, reducing relapse rates, slowing disease progression, and preventing disability resulting from relapse and disease progression.3

MS nurse specialists are still a relatively young specialty, but they have become a dynamic group and have worked hard to ensure that high quality nursing care is achieved for patients with MS. With the pace of change in therapy options and the need for high quality services for people with MS, it is essential nurses working in this area have the knowledge, skills and competence to deliver effective and evidence-based care for their patients.4 Barnes et al5 within a European context note that it is “particularly encouraging” to see the development of the MS nurse (specialist) who are able to provide expert, specialist information and support, and that the MS nurse specialist is a key member of the multidisciplinary team.

D’Arcy6 provides an example of the role of an MS specialist nurse within a nurse led multidisciplinary clinic in the UK. This roles includes:

• Organising and developing the MS Clinic and community MS team. Coordinating referrals and follow up support services.

• Serving as a case manager and acting as the single point of contact between our group of MS patients and the multidisciplinary team. Knowledge of local and national services means that appropriate and timely referrals are made; and that services are co-ordinated to support continuity of care.

• Providing care support and co-ordination, including emotional and psychological support to patients while managing medical, therapeutic and social supports that underpin effective self-management.

These insights into European and UK roles are consistent with the evolution, described by Coleman et al7 of the role of MS Nurse Consultant in Australia that accompanied the introduction of disease-modifying therapies and the expansion of research into new MS therapies.

In the evaluation of the MS nurse specialist by Johnson et al8 “Specialists” in their study were very experienced nurses with an expressed commitment to empowering people with MS and their families to regain a feeling of control in living with the disease. MS specialist nurses provided information and ongoing emotional support from the time of diagnosis as well as multi-disciplinary coordination of care and advocacy. They formed a direct two-way link between the community, neurologists and the acute care team.

They further note that having a base in the acute sector and having the collaboration of a neurologist were important factors in facilitating the role. MS specialist nurses helped ward staff co-ordinate complex hospital discharges, often supporting patients in their management of immunomodulatory treatment. They were actively involved in local educational initiatives, and reported teaching as one of the most important aspects of their role. The opportunity to practice more holistically and autonomously as a nurse was highly valued.9

The MS specialist nurse can provide continuity of support through the spectrum of a person’s life with MS; from early presentation, when diagnosis is established, to the management of a different lifestyle when MS symptoms start imposing limitations.9

MS specialist nurses work in a holistic way and are often the fulcrum of the multi-disciplinary team in MS care. Their roles are diverse and they must exercise high levels of judgment, discretion and decision-making in clinical care. They monitor and improve standards of care both through supervision and audit. They provide skilled professional leadership and develop MS management through teaching, application of research and evidence-based practice, and support to colleagues in other disciplines.4
The MS specialist nurse’s role comprises a large number of different attributes, with psychosocial support, co-ordination of care, onward referral, provision of specialist advice and patient education being the most frequently identified. Data derived from self-reports of MS nurses provides evidence that the stated role of the MS nurse is consistent with what actually takes place in practice.\(^9\) In this data analysis a strong relationship is shown between the evidence for the MS nursing role in relation to the needs of people with MS. “Overall, there appeared to be a good fit between what patients want and what nurses do. The only dimensions where the link was weak were with the two very specific dimensions of stigma and autonomy. The strongest congruence related to ‘support in adjusting to the disease’ and the ‘provision of information about the disease’.”\(^{10}\)

The remainder of this module will examine three specific areas of MS Nursing that do not always receive the attention that acute care or “specialist” MS Nursing roles draw, but are vital services that support the continuum of care in MS Nursing (ie remote areas, rehabilitation and research). Many nurses working in these areas may not consider themselves “MS” nurses but their roles will often bring them in touch with the care of people with MS.
Introduction

This module was written with isolated nurses who work with people with MS and their families in mind. Isolated was taken to mean two distinct and different things. Firstly there are the geographically isolated nurses who practice in isolated usually rural communities. There are also professionally isolated nurses; those nurses working alone without regular peer contact or other health professionals input. Then there are nurses who fit into both groups; the truly alone. Just as nurses find themselves in a range of jobs and locations, isolated people with MS and their families also vary enormously. The authors of this module acknowledge this diversity and hope that you, the reader, find some of this information useful. The take home message is to build a professional network with other nurses and health professionals working with people with MS.

LEARNING OBJECTIVES

After completing this section the reader will be able to:

• Understand the challenges facing the nurse in remote areas
• Identify areas of support and how to minimise isolation
• Understand the importance of courses, training and further education
6.1.1 Relationships: Meeting the needs of people with MS and their families

MS nurses often find themselves working alone. This isolation can put particular strains on the nurse/patient relationship. The nurse feels that they are the only person that the individual with MS and their family can rely on for help. This pressure can result in the development of co-dependent relationships. A co-dependent relationship undermines the well being of the person with MS.

The characteristics attributed to co-dependent persons include; making themselves indispensable, martyr like work ethic, attempting to control others, overwork and being perfectionists and judgmental. These characteristics can lead to an undermining of the patient’s independence and the building of unnecessary ties with a patient.

The resultant redistribution of power results between the co-dependents for example the people with MS and carer, or people with MS and Nurse or Carer and Nurse and results in disempowerment of one person and promotes the development of resentment and anger further undermining the well being of all concerned.

The use of open communication to identify individual and family priorities and acknowledging limitations of service provision can help avoid the development of co-dependent relationships. Working with the people with MS and their families to optimise personal power and independence and the taking up of care options will help avoid co-dependent relationships.

6.1.2 Service utilisation issues

The health needs of people in rural areas have received increasing attention from researchers. Factors that impact on service utilisation for rural families include fatigue and expense of travel which limits a persons ability to visit service providers, the impact of symptoms on daily life and the need for clear communication with service providers.

In addition people with MS living in rural communities also reported a lack of convenient services and safety as issues. The example given is the lack of footpaths in many rural areas. If a person with MS has poor balance they are more likely to have difficulties walking on uneven dirt footpaths.

People in rural and isolated communities have been found to demonstrate characteristics that reduce the likelihood of them seeking out health promoting lifestyle strategies. Overall rural residents tend to be older, poorer and less well educated than their city counterparts. A reluctance to seek help for ‘mental health’ issues along with increased interpersonal isolation means that many rural and isolated people with MS do not have access to current health promoting strategies and ideas. A preference for relying on friends and family in times of needs also reduces contact with health professionals. Rural men whose wives have MS report less support from friends and religion, and an increased risk of illness brought on by stress.

Rural urban differences amongst people with MS were not supported by Long and Wienert. They found that people with MS reported the same difficulties with day-to-day life regardless of location. This was thought to reflect the nature of chronic illness, where the person affected and their family accommodate the impact of the illness and change their life expectations.

Logistical issues may impede the MS nurses responsiveness to the needs of the person and their family. Distance and lack of staff may mean that as an MS nurse with isolated clients you need to use a range of strategies to meet these families needs. Posting information and telephone calls may be the only alternative available. Rural people report a relatively low level of support compared to urban counterparts. Spouses are the most called in support person. With rural people frequently displaying characteristics of independence and self-reliance the MS nurse may need to take more time and sensitivity than expected to build a supportive relationship with the family.
6.1.3 Combating professional isolation

Professional isolation can lead people to feel they are unsupported and disconnected from essential services and personnel. The development of a support network can reduce this sense of isolation. A support person who understands your work, its challenges and rewards can be a good support. A support person who is not your in-line manager to whom you are accountable is also an important consideration. It is difficult to confide frustrations and uncertainties in your manager. In addition a support person who is not your source of funding is also important since conflict of interest may reduce the likelihood of expressing difficulties with the service. Making contact with other nurses in similar positions is a good start. Professional associations that make contact via the web, email or newsletters are another useful way to connect with nurses in similar positions.

Making contact face-to-face with other MS nurses may not be possible for a number of reasons; expense, distance, time and energy. The use of telecommunication strategies has been proposed as a cheap and effective way to access professional development and current information. Email in combination with the internet can link nurses with endless resources. Contacting support groups and service providers via email can mean that your query can be answered even if the person you wish to make contact with is not in their office. They can in turn reply to you while you are out in the community. If you are looking to make personal contact start by emailing local people or groups you think will be helpful. State what you are looking for and ask them to forward the email to someone they think could help if they cannot help you themselves.

Look to service providers for support. These are particularly important resources for nurses who care for people with MS but are not necessarily ‘MS’ nurses. The state and national MS Societies are an invaluable source of information. Check out their web sites. Make contact with staff directly, again email is a good start. Go interstate if you need to.

One MS Society may have more library resources than another. Look to government departments for assistance; Disability Services, Aged Care, Public Housing. These organisations have very specialised professionals that can assist you. For example the Department of Housing employs Occupational Therapists who help with home assessments and modifications. They have contacts that can help you.

While professional isolation is an often-raised issue for rural nurses, being known too well can also be an important issue. Rural nurses usually live in the community they work in. This can result in very particular professional issues. The nurses are visible and identifiable, known by and know of the clients. Their personal and professional boundaries are diminished. Rural doctors report having to live with their mistakes; they are not alone in this; rural nurses have to live with their professional decisions and actions too. The need to maintain professional confidentiality can increase feelings of professional isolation.

Professional issues for specialist nurse-led services

Registered nurses may be isolated by the nature of their position rather than by distance. While specialised nurses report satisfaction that they are making a difference they also report difficulties with the position. Difficulties reported include; adapting to the primary healthcare setting, difficulties meeting practice staff, and contending with a heavy workload.

Specific issues raised by Australian nurse practitioners have included; minimal professional support from employers, little legislative protection for the extended scope of practice expected, lack of educational preparation for the role, and lack of access to ongoing education and peer support. What is reassuring about this is that you are not alone when you experience difficulties as a sole practitioner.

Solutions for professional isolation suggested by Mills and colleagues include documenting and sharing your experiences and improved pre-service education prior to taking up the position.
The use of case re-enactments via telecommunication, cross professional case reviews, discussions and best practice discussions as part of professional association meetings or publications and newsletters all provide opportunities for review and practice development.20

6.1.4 Educational needs

Preparing for work as a sole or isolated practitioner

Leading a nurse-led specialist service or working alone can result in particular professional difficulties. Occupational health and safety issues such as support and personal safety need to be considered. The UK nurses’ registration body has proposed that all positions need defined standards and set specific training and preparation. There are key areas of knowledge that a nurse in this leadership position needs. The MS nurse needs current and thorough knowledge of MS, knowledge of community practice and experience working in the community prior to working alone.21 This gives you some idea of the professional development that would benefit MS nurses in the community if they did not have it before they were in post.

In-service education: keeping up to date

Doctors working in isolation (ie rural with distance), or professionally (ie working alone) demonstrate reduced competence over time. Aging and isolation from peers are recognised demographic risk factors for loss of competence.20 MS nurses working alone or in isolated communities run the same risks.

Professional association membership is one mechanism nurses use to keep up to date. Members and non-members of professional associations report that they value education, professionalism, improvement of my profession, maintenance of professional standards and self-improvements. Members of professional associations look to the association to promote these attributes. Non-members list cost; money and time as reasons they do not belong to a processional organisation.22

Resources to draw on

Resources nurses can draw on include professional associations. Other organisations also offer opportunities for self-improvement. Universities often have guest speakers. Contact the organiser and get on their mailing list. These sessions are often free and the focus is often current research. Universities offer a range of study options too. These are usually fee paying. Invite an academic to provide a staff in-service lecture on their area of specialisation. Academics need the exposure in industry and you want the in-service. This promotes links between rural and urban health professionals and benefits both.23 Nurses Unions also offer professional development sessions.

Using the web, how to and what to do if you can’t

The internet offers cheap, easy to access professional development opportunities too.20 Providing support and information to people with MS and their families via the internet is gaining momentum all the time. Telecommunications, computers and the internet means that isolated people with MS and MS nurses can build links and work more closely with their urban colleagues.24

It is important that research and best practice guidelines are incorporated into nursing practice. Where does the MS nurse look for such information? The process of undertaking research is addressed in the research module of this Manual. The purpose of this section is to explore opportunities to make contact with researchers.

When looking for published research add ‘Australia’ or ‘best practice’ to the search term. For example if you have entered ‘best practice guidelines and pain management’ search using ‘pain management and best practice guidelines’. If you then add ‘Australia’ to the search you will find research completed in Australia. Email the researcher, tell them of your clinical work and interest in the area. This can result in important links between clinicians and researchers and benefit both parties.
All this builds your professional network. Building a professional network helps promote professional development and promotes the incorporation of research and best practice into a practical context.25

Research/post graduate education opportunities

All universities have web sites outlining courses available. If you see an article you like contact the author directly asking if courses addressing the topic of interest are offered externally from their university. Remember post graduate courses particularly research based Masters and PhDs are an opportunity to research and study a topic of interest to you. While courses may address content in which you are not interested in, many post-graduate courses offer flexibility so that you can focus on which your interest.

Useful websites

www.msaustralia.org.au/
www.msra.org.au/
www.msnainc/
www.mssociety.org.uk/
www.nmss.org/
www.msif.org/en/
www.msnews.org/
www.mscare.com/
Introduction

Rehabilitation comes from the Latin *rehabilitare* meaning “to restore to a former rank” and *habilitare* meaning to “enable”.26 Classically, clinical medical management has been divided into cure and palliation. Glickman27 suggests that a recent paradigm shift has occurred allowing people with MS access to the “clinical benefits available through rehabilitation medicine”. The National Collaborating Centre for Chronic Conditions28 recommends that “specialist neurological and neurological rehabilitation services should be available for every person with MS when they need them”. The Royal College of Nursing defines rehabilitation as a “client centered, active and creative process which involves adaptation to changes in life circumstances. It is a shared activity between client, carer and professionals who recognise the individual contribution of all concerned. It is designed to enable the client to achieve optimum and/or acceptable levels of functioning. Its aim is to minimise handicap resulting from impairment and/or disability”.29

Rehabilitation utilises multidisciplinary teams to provide home, inpatient and outpatient services for people with complex and changing disabilities including MS. It is important to note that with all the focus today on the role of immunomodulatory treatments that Kraft30 and Glickman27 suggest that the use of disease-modifying therapies does not remove the need for rehabilitative strategies in the management of MS. Disease-modifying pharmacological treatments show an effect in relapse reduction and reduction and slowing down disease progression but do not improve the patient.31 "The only way to improve function in MS is rehabilitation”.31 Rehabilitation strategies can minimise disability and handicap including pharmacological, physical and psychological interventions.30

**LEARNING OBJECTIVES**

After completing this section the reader will be able to:

- Understand the role of rehabilitation in MS
- Have a greater knowledge of relevant theory
- Understand the role of the nurse in MS rehabilitation
- Appreciate the need to set goals and evaluate MS rehabilitation outcomes
6.2.1 Rehabilitation and MS

Ward et al\textsuperscript{32} state “rehabilitation programs aim to reduce risks of unwanted complications as well as to improve function in the short-term”. Prevention is an important component of rehabilitation. Further, they go on to note that a “rehabilitation approach is fundamental to the management of progressive diseases such as MS. Rehabilitation in progressive disease is never one-off”. Compston et al\textsuperscript{33} also highlight the importance of people with MS and their health care professionals realising the “dynamic role of rehabilitation services during the course of the illness.”

Brain plasticity is suggested as part of the explanation as to why people with MS can experience clinical recovery or improvement even when there is irreversible axonal loss.\textsuperscript{34} “The enhancements of any beneficial effects of this cortical adaptive plasticity by cognitive and physical rehabilitation and by pharmacological modulation are key target goals for the management of MS.”\textsuperscript{34}

The literature supports a place for rehabilitation medicine in the management of MS. According to the 2007 Cochrane review\textsuperscript{35} “there was ‘strong evidence’ that despite no change in the level of impairment, inpatient multidisciplinary rehabilitation can produce short-term gains at the level of activity (disability) and participation for patients with MS. For outpatient and home based rehabilitation programs there was ‘limited evidence’ for short-term improvements in symptoms and disability with high intensity programs, which translated into improvement in participation and quality of life. For low intensity programs conducted over a longer period of time there was ‘strong evidence’ for longer term gains in quality of life; and also ‘limited evidence’ for benefit to carers”.

Rehabilitation techniques “can actually improve MS patients by as much as 1.5 expanded disability status score (EDSS) points”.\textsuperscript{31} The "multiplicity and diversity of physical and cognitive problems point to a multidisciplinary approach".\textsuperscript{36} Grasso et al\textsuperscript{36} suggest an “intensive multidisciplinary rehabilitation approach be recommended in all MS patients, and that this treatment is to be started as early as possible to maximise functional recovery”.

Freeman et al\textsuperscript{37} research concluded “the benefits gained from rehabilitation were partly maintained after discharge despite worsening neurologic status. Carry-over of benefits, however, declined over time, reinforcing the need for continuity of care between the inpatient setting and the community”.

Complex diseases such as MS require comprehensive management using a team of experts providing frequent re-evaluations as the disease progresses.\textsuperscript{31} Haggerty et al\textsuperscript{38} review of the literature found continuity should be maintained in terms of information provided, management of complex clinical diseases and relational continuity to past care and including a link to future care. The National Collaborating Centre for Chronic Conditions\textsuperscript{28} strongly recommends that any person seen at the MS rehabilitation service “should be informed about how to make contact with the service when he or she is no longer under regular treatment or review”.

6.2.2 Rehabilitation and the role of the MS nurse

The client is the most important part of the rehabilitation team. Other members include physicians, nurses, physiotherapists, occupational therapists, speech therapists, recreational therapists, social workers, case managers, dieticians, vocational therapists and psychologists. The role of the nurse in this context includes teacher, facilitator, client advocate, change agent, care giver, coordinator and liaison with all relevant services, counsellor, consultant and researcher,\textsuperscript{39} as well as providing expertise in areas such as assessment, education, medication management as required by the person with MS.

“The priority of rehabilitation nursing is to provide assistance to those who have chronic conditions or disabilities for the purpose of helping them attaining or maintaining the highest level of functioning possible, optimal health and wellbeing, and effective adaptation to alterations in their lifestyles”.\textsuperscript{39}
The MS nurse is often the first port of call for people with MS and their carers, and is often in the position to identify and advocate for those people with MS who may benefit with some rehabilitation. When the MS nurse is assessing rehabilitation needs one needs to consider physical, psychological, vocational and social needs. It is important to promote realistic expectations when discussing the benefits of rehabilitation.

Assessment

Good assessment is integral to the provision of rehabilitation to maximise an individual’s function. “Identifying functional capabilities is essential to successful rehabilitation”. Assessment of MS clients should thus include a detailed evaluation of physical, psychological, vocational, and social functioning. Hoeman states “Assessment should encompass caregiver role adaptation, distress, and impact on siblings and other family members”. Holistic health assessments should ascertain information in a logical and comprehensive manner including physical and mental health, psychological status, social circumstances, and beliefs.

Teamwork

Bakheit’s review of the literature suggests that the effectiveness of a rehabilitation team is influenced by the team’s structure, the style of leadership and the rehabilitation process itself. Effective teams are composed of professionals with well-defined roles and with skills that match the needs of their patients. The MS nurse can be an active and valuable part of the rehabilitation team bringing expertise in MS, an understanding of services available in the community for people with MS and importantly provides continuity for the person with MS after rehabilitation via acute and/or community roles.

The following elements were linked to effective teamwork:

• commitment to the same philosophy of team work
• leadership with a vision supported by senior staff

• patient led focus
• a high level of role understanding including joint planning and goal setting
• sharing knowledge within the team developing team knowledge

The benefit of implementing the above elements that influence patient progress include continuity, consistency, reduction of ambiguity, appropriate referrals, holistic information and problem solving.

6.2.3 Goal setting and evaluating MS rehabilitation outcomes

Goal setting

“Goal-setting, that is the process of agreeing on desirable and achievable future state, has recently been described as one of the skills that specifically characterises professionals involved in rehabilitation”. “People with differing disease courses have different needs; this may need to be reflected in different approaches to goal setting. Goal-setting programs must maintain the patient’s autonomy and acknowledge the patients role and goals.” The National Collaborating Centre for Chronic Conditions (2004) recommends when several other professionals are involved in work with the person with MS they should “work towards common agreed goals using a common therapeutic approach”. Rehabilitation goals should aim to improve quality of life rather than a deficit/deficiency or disability.

The National Collaborating Centre for Chronic Conditions state goals set should:

• be agreed as relevant and important by the person with MS
• cover both short-term specific actions and longer term outcomes
• be challenging or ambitious but achievable
• be set both at the level of individuals and at the level of the team as a whole
• be formulated in such a way as to leave no doubt as to when they have been met.

“Rehabilitation is determined by goals that are set, based on the clinician’s ability to predict what potential for improvement the patient has.” The goals of rehabilitation include maximising potential, learning, ability, quality of life, family-centered care, wellness, culturally competent care and community reintegration. The goals should involve promoting independence, maximising potential, and restoring optimal functioning. Treatment goals for MS should include enhancing recovery from acute exacerbations, slowing the natural course of the disease, and management of the symptoms.

Flannery et al suggest the following goals for rehabilitation in degenerative conditions:
• management of symptoms
• education of the patient and family
• maintenance of function
• slowing of progression or prevention of complications
• assisting the patient and family to cope
• support to help the patient accept the effects of the disorder realistically
• enhancing the patients quality of life
• linking to resources.

Outcome measures
Storr et al state there is limited evidence of the efficacy of rehabilitation in MS, however it must be acknowledged that “outcome measures represent a special challenge: it is impossible to define a single measure that would be relevant to all patients because of the inter-individual variation in functional deficits and rehabilitation needs”. A quality partnership between the client, their family/carer and the health professionals involved in the rehabilitation process is imperative.

The following considerations should be made by the MS nurse when choosing outcome measures:
• when assessing the clinical effect of therapeutic interventions on the functional capacity of patients, a disability/activity limitation, handicap/participation restriction, or a health related or quality of life measure would be more desirable
• generic health status outcome measures may not be sensitive enough to detect change in moderately to severely disabled MS patients.

Many outcome measures are reported in MS literature including those which focus on impairment; focus on goals at the limitation in activity; focus on goals at the level of participation and/or personal context and other outcomes. The MS nurse may be involved in clinical research evaluating the efficacy of rehabilitation interventions at an individual and/or service level.

Integrated care pathways
Rossiter et al acknowledge the time and associated costs of providing rehabilitation to degenerative neurological conditions such as MS and suggest implementation of ‘integrated care pathways’ to improve the auditing process including goal attainment and outcome measures. A care/clinical/critical pathway is designed to be a clinical resource to support the delivery of timely, coordinated evidence-based care. There are both positives and negatives associated with the use of clinical pathways in the literature. The use of clinical pathways in MS rehabilitation would need to be flexible enough to meet the diverse range of disease and person specific factors seen in clinical practice.
Introduction

The nursing profession has undertaken research since the times of Florence Nightingale, developing a ‘scientific’ body of knowledge to support its practice. Not all nurses will engage in research but there is an ever increasing expectation that all nurses will be able to read, understand and (critically) appraise research literature, and then use this knowledge/evidence to guide and support clinical decision making.50

The mere mention of nursing research will often send nurses running in the opposite direction; it is seen as the domain of academics and postgraduate students. But all jokes aside, while not all MS nurses will identify themselves as “researchers” all of us use (nursing) research and evidence to guide our knowledge, practice and teaching with our patients/clients. Our body of knowledge is guided and driven by the acquisition of evidence from research in all its forms.

Recent times have seen an explosion of the use of the terms evidence-based medicine/nursing/practice. “Evidence-based clinical practice is an approach to decision making in which the clinician uses the best evidence available, in consultation with the patient, to decide upon the option which suits that patient best”.51 Evidence-based Practice (EBP) allows an individual clinician to examine “evidence” on treatments or therapies with an individual patient/client, and with them decide if this is appropriate to undertake. The biggest limitation in the implementation of EBP lies in its evaluation, defining the levels of evidence, how even experienced clinicians are expected to critique an individual paper, clinical practice guidelines, systematic reviews and meta-analysis studies – in the context of individual patient circumstances.

As an example in MS ‘management’, various research methodologies are weighted more heavily within the hierarchy of evidence utilised.

LEARNING OBJECTIVES

After completing this section the reader will be able to:

• Appreciate the importance of research
• Discuss the role of evidence-based medicine
• Understand more about the Australian MS Longitudinal Study

A systematic review of randomised controlled trials (RCTs) is on top of the ladder – as an example it tells us that a drug works – and this is the pinnacle of ranking evidence. A qualitative quality of life (QoL) study of people taking that same drug shows that a percentage of people taking it have an improvement in symptoms, however the side effects and their management actually decrease QoL – much lower down on the scale of evidence evaluation.

MS nurses can and do add to the body of knowledge (evidence) about MS management and care every day. By supporting formal MS nursing research, such as:

• conducting qualitative QoL studies in the community
• encouraging people with MS to register with the Australian MS Longitudinal Study
• documenting and reporting adverse events to therapy
• publishing – everything from case reports to nurse initiated research projects
• keeping up to date with advances in MS care, and using that knowledge and evidence to shape the care we provide to people with MS

The Australian MS Longitudinal Study (AMSLS, also known as the MS Life Study) is a nationwide research database for people with multiple sclerosis. It is owned and operated by MS Australia and its research arm, MS Research Australia, funded by specific educational grants from pharmaceutical companies and other corporate and private donors. In 2007, there were about 2,700 volunteers with MS participating in the study, representing all states and territories. Thus the AMSLS employs a large national sample of Australians with MS. The study is interdisciplinary in scope and uses scientific survey methodology to investigate issues important to people currently living with MS and their families, including clinical, therapeutic, socio-economic and quality-of-life aspects of the disease. Results from this work have been used to lobby governments for a better deal for Australians with MS, to improve services by agencies such as the MS Societies, and to alert physicians and MS nurses on issues related to patient consultation and care.

Any Australian resident diagnosed with MS after June 2002 is eligible to participate in the Australian MS Longitudinal Study. Volunteers receive several surveys each year, relating to different topics, and with the potential to improve their life situation (see above). Participants can opt in or out of particularly surveys, as they wish. The AMSLS is guided by a Supervisory Committee provided by MS Australia, and is ethically approved and monitored by an NHMRC-constituted Human Research Ethics Committee in Canberra. More information on participation in AMSLS research can be obtained from MS Research Australia (www.msaustralia.org.au/msra).

Module 7 provides a more detailed examination of research processes, types and ethical considerations for anyone who is interested in pursuing MS research.

Reflecting on personal practice: an author’s notes

There are many definitions of evidence. Most of them focus on the individual clinician and the individuality of the patient. The implication therefore is that the clinicians – as experts – assimilate the information about best practice and use their expertise in applying it to the patient. However, expert opinion/experience is often regarded as low-level evidence (e.g. Level IV for NHMRC if based on a case series with no control group) whereas the highest level of evidence is based on results obtained from RCTs. In MS, where there are few RCTs, it is a challenge to practice best evidence-based medicine where much of it is based on expert opinion.

It is even a bigger challenge for our patients/clients to understand evidence. MS is a chronic, incurable, unpredictable and progressive disease. We have some therapies that are partially effectve for some patients. For many others, we have symptomatic management at best. People with MS will look far and wide for better treatments and cures, and they often bring in copious amounts of information that they have sourced.

The internet is fantastic in allowing rapid access to knowledge from around the world. A problem for research and academia is that the “best” information is often restricted by passwords, user accounts and fees for papers etc. Unfortunately the “worst” information is in full reach of anyone who types the right question into a search engine, for example Google “MS Cures”.

Module 6 - The Diverse Roles in MS Nursing
Further reading


References


4. United Kingdom Multiple Sclerosis Specialist Nurses Association (Multiple Contributors). Specialist nursing in MS - the way forward: the key elements for developing MS specialist nurse services in the UK. Multiple Sclerosis (Research) Charitable Trust Letchworth, Herts. 2001. www.mstrust.org.uk/


Introduction

The role of the MS nurse is very important in all aspects of MS research as has been described in Module 6. This module seeks to provide the novice or the experienced MS research nurse with information, guidelines and references in this area of MS nursing practice.

Broadly, the word research refers to any action that is undertaken to answer a question. Everyday, nurses conduct research as part of routine clinical practice; the nursing process in itself is a form of research: identification of the issue, development of a plan, implementing the plan and then evaluating the outcomes of that action. However, more formal methods of research are also necessary so that nursing and medical practice can be based on best (and where possible) evidence-based practice.

For definitions and more information about evidence-based practice please refer to the following website: www.joannabriggs.edu.au/about/eb_nursing.php
7.1 Nursing Driven Research

7.1.1 Overview of nursing driven research

An understanding of research and the development of research ‘skills’ are emerging as an essential, not optional, role for the nurse with the increased development of a body of nursing knowledge to underpin practice. This body of knowledge may be derived from a number of sources, such as tradition, authority, experience and intuition, trial and error, logical reasoning and the scientific method – the most advanced method of acquiring knowledge.¹

The purposes of research can be defined as:
- Identification
- Description
- Exploration
- Explanation
- Prediction and control which describes how, why and what we do as nurses.

The outcomes of research that fulfil these purposes enable a body of knowledge to evolve that is current, accurate, and scientifically valid which is a crucial part of the professionalism, accountability and social relevance of nursing practice.¹

In this section, two ways of approaching research will be discussed, namely quantitative and qualitative methodologies, although in practice these may be used in conjunction with each other.

Many texts are dedicated exclusively to medical and/or nursing research using qualitative and quantitative methods, therefore a brief overview will only be provided for this module and the reader is encouraged to utilise the materials referenced at the end of this module for more information.

LEARNING OBJECTIVES

After completing this section the reader will be able to:
- Appreciate the importance of research
- Understand how research contributes to the body of knowledge
- Describe the differences between quantitative and qualitative research
- Follow the process for undertaking research
- Investigate sources of research funding

7.1.2 Quantitative research

This research methodology is strongly associated with scientific approaches to research. Research questions (often called hypotheses) are asked by the researcher and then tested in a formal, objective and systematic way.

Evidence is gathered throughout the research process, most often in the form of numerical data based on a formal measurement and then statistically analysed. The data resulting from quantitative methods aim to be reproducible and able to be generalised. Constraints or controls are placed on the study as part of this design.
The purpose is to minimise biases or preconceptions in the study and maximise the accuracy of the study results.1

7.1.3 Qualitative research

Qualitative research methods add value to nursing practice, as the human experience of health and illness does not always fit within the scientific research approach.

This methodology uses a reasoning process to ultimately produce meaning. Many different meanings are possible because of variations between individuals within a given social context. Qualitative research can capture these complexities; this enables nurses to deconstruct traditional knowledge and understanding, and develop new ideas and meanings.

Qualitative research methodologies, unlike quantitative methodologies are frequently subjective, inductive, do not seek to be generalisable, and tend to involve narrative rather than numbers. It involves research methods such as interviews, observations in the field, and document reviews.2

Unlike the quantitative approach, which aims to ultimately answer a pre-determined question, the qualitative approach can often lead to more ‘new’ questions being asked throughout the research process. This facilitates the development of a theory or framework about the human experience.1

7.1.4 The process of research

For the nurse wishing to undertake formal research for the first time, the research process can often be a daunting experience. A brief overview of the process of research is provided here to help demystify this very achievable nursing role.1,3,4

1. Formulate a research problem or question
   • Become aware of your own observations in your area of practice
   • Look for weaknesses, deficiencies, limitations
   • Follow your interests3

2. Review the literature (look at what research has already been done in the area and the findings, if any)
   • Go to medical and nursing research search engines such as PubMed www.ncbi.nlm.nih.gov/sites/entrez
   • Go to your hospital/health service library and request assistance if required from the librarian in order to become familiar with the online search options and how to find and access research material and other publications
   • Review clinical research databases
     - Clinical Evidence
     www.clinicalevidence.bmj.com
     - Cochrane Collaboration
     www.cochrane.org/index.htm

3. Develop a framework for how you will answer the research question
   • Review nursing research text books for information on the best method for answering your research question
   • Review successful proposals developed by other nurses
   • Speak to a peer who has experience in research

4. Development of the proposal or protocol
   • Refer to the local Health Service Ethics Committee’s publications (on the internet) for the required inclusions in a study protocol

5. Submit proposal to Institutional Ethics Committee
   • Refer to the local Health Service Ethics Committee’s publications (on the internet) for the required process and submission dates

6. Commence study as per proposal/ protocol

7. Collect data
   • Please refer to recommended texts for methods of data collection
   • A tip: For qualitative research a research journal can be useful to record the process of research and your experiences (these may come in handy later!)

8. Analyse data
   • If data is numerical you may need the assistance of a statistician or statistical software package
   • If the data is descriptive there are many recommended methods in the literature that will help to collate the data. The referenced texts at the end of this module provide information on analysing the often-large volumes of qualitative data
7.1.5 Funding projects

Often unrecognised by nurses considering setting up a research study, is the notion of seeking financial support. There are many local, national and international organisations, which provide support for nurses wishing to undertake research in key areas. In large teaching hospitals there may be a person assigned to support researchers with searching for sources of funding. Please refer to your local ethics committee for more information.

Examples of local and national organisations and groups that may be able to provide support:

• Australian Government
• Pharmaceutical companies associated with MS
• Local health services
• Nurses Boards in each state, for example the Nurses Board of Victoria offer grants for research. See the following link for information on the conditions of the grants www.nbv.org.au/media/42404/conditions standard for grants 2008.pdf
• MS Nurses Australia Inc (National Organisation)
• MS Health Professionals Network (in Victoria)
• Australian Neuroscience Nurses Association (ANNA)

When seeking funding for projects consider all potential sponsorship opportunities. For example, if the research involves a device or therapy, the company that developed the device may be able to offer support with the study (either by provision of the device or financial support).

Financial support together with all stakeholders of the research must be disclosed to the ethics committee. This is to avoid possible conflict of interest issues.
7.2 Medical Research

7.2.1 Overview of interventions and therapies
(clinical and non clinical trials)

Clinical trials fall broadly into two categories:
- Pharmaceutical company sponsored drug/device trials and
- Investigator initiated clinical trials.

The size and scope may vary from international multicentre trials enrolling over 1000 participants to a nursing research study looking at immunotherapy compliance in 10 participants. Whatever the size and scope, there are characteristics that are common in all trials involving human participants.

7.2.2 Phases of clinical trials

Before a medicine is registered for approval it must undergo several phases of investigation. At each stage there must be enough evidence to support the medicine’s advancement.

The compound tested undergoes studies involving cell cultures, isolated tissues and laboratory animals. These different testing stages provide the researcher/research group with a reasonably good indication of what to expect of the compound/drug in human studies.

On average only one medicine in a thousand (1/1000) will make it to human testing.

Phase 1

Phase 1 clinical trials are the first investigations in humans. They primarily observe the drug’s safety profile at various doses.

Phase 2

Phase 2 clinical trials consist of closely monitored well controlled testing in a larger group (usually 100-300 participants) who have the condition being targeted by the drug (in this case people with MS). In this phase:
- The optimal dose of the drug is established
- End points are established that represent favourable outcomes for the study
In MS, endpoints may include but are not limited to:
• A decrease in the relapse rate
• Reducing brain lesions on MRI
• Slowing disease progression as measured by EDSS (see Module 2, Section 5 for further information)

Phase 3

Phase 3 clinical trials are designed to confirm the efficacy of the drug in the condition it targets (MS) based on the statistical endpoints established in the phase 2 studies.

These studies continue to monitor and build the safety profile of the drug and record possible side effects and adverse events resulting from long-term use.

Phase 3 studies are controlled (with placebo or comparator being used), double blind (neither the participant nor the investigator are aware of who is receiving active drug) with a sample size of around 1000 participants.

If the Phase 3 trial is successful, marketing approval is sought from regulatory authorities, for example the Food and Drug Administration (FDA) in the USA, and Therapeutic Goods Administration (TGA) in Australia.

Pharmaceutical companies may trial drugs in one disease that are already approved and ‘on the market’ for another disease. This is called ‘off label’ use of the drug. If these trials are successful, further clinical trials in this new indication are initiated.

7.2.3 What does a trial protocol involve?

Clinical trials can vary in size and complexity depending on the study question being asked. For example, a trial of a new drug in a new indication requires detailed and complex protocols and procedures with many participants in comparison to a qualitative study looking at education techniques with a small number of people. Notwithstanding these differences there are factors that are common to most study protocols and are outlined in detail by regulatory organisations.

* The TGA provides an overview of the minimum essential requirements of an investigators brochure for a clinical trial
* Health Service Ethics Committees publish (on the internet) their recommended inclusions for study protocols. It would be useful for the reader to source these documents at their local site.

7.2.4 Regulatory processes

Health care products purchased by consumers worldwide are expected to be safe, effective and of high quality. Countries have varying regulatory processes in place to ensure that acceptable standards are met. Examples are the Therapeutic Goods Administration (TGA) in Australia, the Food and Drug Administration (FDA) in the United States, and the European Medicine Evaluation Agency (EMEA) in the European Union.

Therapeutic Goods Administration

The TGA has an important role to monitor and assess therapeutic goods for safety and also ensure timely access for Australians to therapeutic advances. Its role also extends to post marketing pharmacovigilance where products are investigated and tested to ensure ongoing compliance.
All therapeutic goods intended for use in, or export from Australia must be registered on the Australian Register of Therapeutic Goods (ARTG), which is a database of information about these products.

The following website has more information: www.tga.gov.au/docs/html/artg.htm

**The cost of medicines once approved**

The Pharmaceutical Benefits Scheme (PBS) is an Australian Federal Government initiative that has been operating since 1948 and is governed by the National Health Act 1953 (Commonwealth). The principle of the scheme is to offer people living in Australia with reliable, timely and affordable access to medicines.

The scheme provides a system whereby the Government pays a large proportion of the cost (a subsidy) for medicines, which may cost hundreds or thousands of dollars. The consumer can receive this benefit when filling their prescription (provided the prescription is filled under the PBS).

The PBS is one of the world leaders in drug subsidy systems. Close to 80% of dispensed prescriptions are subsidised under the PBS in Australia. In 2007, the PBS cost to the Commonwealth Government was almost $7 billion.


**Access programs**

Often pharmaceutical companies offer ‘access programs’ for patients requiring access to new therapies.

The following access programs are available after TGA approval but prior to PBS listing or reimbursement:

**Product Familiarisation Programs (PFP):** these programs are run by a company with the aim of allowing the medical profession to evaluate and become familiar with product.

In accordance with Medicines Australia’s Code of Conduct, they should be initiated only in the first 12 months following first supply of the product approved for registration. The medicine will be provided under a PFP for a fixed period, after which it may only be available on a private prescription if it is not reimbursed under the PBS.

**Expanded access:** For patients who may benefit from the drug use but don’t qualify for the clinical trials, sponsors of the investigational new drugs may provide for “expanded access” use of the drug. In addition, expanded access can describe providing access to a medicine after regulatory approval but prior to the medicine being listed on the PBS or otherwise reimbursed.

**Compassionate use:** Provision of a medicine containing active ingredients that have not been registered for that use, outside the scope of a company-sponsored clinical trial. The patient is usually suffering from a serious or life-threatening condition where there is no alternative effective medicine available to treat the condition.

An access program is also available prior to TGA approval. This scheme is known as the Special Access Scheme (SAS). The SAS refers to arrangements which provide for the import and/or supply of an unapproved therapeutic good for a single patient, on a case-by-case basis. Applications are made by registered medical practitioners to the TGA.
7.3 Ethical Guidelines to Research

7.3.1 History of ethics

The history of human research although outwardly a noble pursuit in the quest for disease eradication and increased knowledge, has a history of physical abuse, non-disclosure, putting the benefit of society over the safety of the participant and misuse of disadvantaged populations.

Examples through history have been recorded as far back as 6th century BC where meat and vegetable experiments were conducted on young Jewish prisoners in the Book of Daniel. In 4th century AD "Primum non nocere" ("First do no harm"), became an obligatory oath for physicians prior to practicing medicine (attributed to Hippocrates). However, there have been a number of documented cases after this time. In particular, there was a case which involved 22 elderly patients receiving the injection of live cancer cells at the Jewish Chronic Disease Hospital in Brooklyn (1962). This incident provided the impetus for the formation of institutional review boards (IRBs) in the USA.

Hospitals in Australia formed (although sporadically) institutional ethics committees (IECs) in 1965 at various hospitals and universities following the release of the "Declaration of Helsinki".

7.3.2 Declaration of Helsinki

The Declaration of Helsinki is a set of ethical principles for medical research involving human subjects which was developed for the worldwide medical community by the World Medical Association (WMA). The document is considered to be the cornerstone of human research ethics and has been amended seven times since its development in Helsinki, Finland in 1964.

7.3.3 Ethical principles

A number of ethical principles threaten to compete with each other when considering medical research involving humans. Consider the following definitions:

- Autonomy: treat subjects as independent individuals, respecting their welfare and rights
- Beneficence: do good
- Non-maleficence: do no harm
- Justice: prioritise the most needy individuals, potentially at the cost of the welfare of society
7.3.4 Competing interests

Other considerations when reviewing the ethics of research involving humans is the competing interests which may be involved in the studies and their outcomes.

Consider the following issues that represent competing interests:
1. Pharmaceutical companies who conduct the research studies are businesses that ultimately need to make money for their shareholders
2. Physicians who are Principal Investigators of studies receive authorship on publications increasing their status in the scientific field
3. Societies’ desire to find a cure for diseases
4. Individual desires to access treatments.

Consideration must then be given to the principles of good clinical practice which should underpin nursing and medical practice.

7.3.5 Good clinical practice

Good clinical practice (GCP) is a responsibility that must be shared between all stakeholders of the research: sponsors, investigators, site staff, contract research organisations (CRO), ethics committees, regulatory authorities and the research subjects.

It is a process that encompasses well established ethical and scientific quality standards for the design, conduct, recording and reporting of research involving humans.

Refer to the TGA website for more information and to view the clinical trials handbook: http://www.tga.gov.au/ct/cthandbook.pdf

7.3.6 Regulating good clinical practice

NHMRC

The National Health and Medical Research Council (NHMRC) in Australia upholds the guidelines of good clinical practice by pursuing the following activities:
- Raise the standard of public health
- Support consistent state and territory health standards
- Foster medical and public health research and training
- Support consideration of health related ethical issues

Refer to the NHMRC website for more information: www.nhmrc.gov.au/

Individual hospital sites also have a regulatory group, the Institutional Ethics Committee, to ensure that the principles of good clinical practice are upheld.

Institutional Ethics Committees

The Institutional Ethics Committee (IEC) system began its formal development in 1976 when the first NHMRC Statement on Human Experimentation was amended making it a condition of NHMRC funding that applicants for grants be granted ethical approval by an institutional medical ethics review committee. The requirements of IECs by the NHMRC include:

1. Conform with the NHMRC Statement on Human Experimentation and Supplementary Notes as published from time to time
2. While promoting the advance of knowledge by research, ensure that the rights of the subjects of research take precedence over the expected benefits to human knowledge
3. Ensure that, in all projects involving human subjects and relating to health, the free and informed consent of the subjects will be obtained
4. Ensure that no member of the committee adjudicates on projects in which they may be personally involved
5. Ensure that research projects take into consideration local cultural and social attitudes
6. Give its own consideration to projects that involve research in more than one institution
7. Require the principal investigator to disclose any previous decisions regarding the project made by another IEC and whether the protocol is presently before another IEC
8. Determine the method of monitoring appropriate to each project.

Membership of the Ethics Committee

The NHMRC establishes the following minimum membership for a properly constituted IEC in Australia:
• laywoman not associated with the institution
• layman not associated with the institution (a layperson is defined as one who is not closely involved in medical, scientific or legal work)
• minister of religion (of any faith)
• lawyer
• medical graduate with research experience.

It requires an IEC to be composed of men and women of different age groups and those members are appointed as individuals for their expertise and not in a representative capacity.

Further reading


Useful websites

www39.homepage.villanova.edu/rosemary.schiller/01Introduction%20to%20course/
Australian Radiation Protection and Nuclear Safety Agency (ARPANSA) Guidelines
www.arpansa.gov.au/


Guidelines Approved Under Section 95A of the Privacy Act 1988 (2001)


Guidelines Under Section 95 of the Privacy Act 1988 (2000)

National Statement on Ethical Conduct in Research Involving Humans (1999)

Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (2003)
References


**8. Glossary**

**Acute** - a term used to describe a symptom, sign or disease in which the attack is sudden, severe and of short duration.

**Afferent pupillary defect** - see Marcus Gunn pupil.

**Alopecia** - loss of hair.

**Anomia** - form of aphasia characterised by the inability to name objects, caused by a lesion in the temporal lobe of the brain.

**Arrhythmia** - variation in the normal heart rhythm.

**Asphyxia** - deficiency of oxygen and an increase in carbon dioxide in the blood and tissues. Symptoms include irregular and disturbed respirations, or a complete absence of breathing, and pallor or cyanosis.

**Ataxia** - failure of muscle coordination resulting in irregular and jerky movements.

- **Cerebellar ataxia** - caused by a lesion in the cerebellum area.
- **Sensory ataxia** - results from dysfunction to position sensing nerve inputs, eg Romberg’s sign where patient sways or falls on closing their eyes.
- **Vestibular ataxia** - caused by a lesion to brain stem and the vestibular nuclei.

**Auditory agnosia** - inability to hear because the auditory stimulus cannot be interpreted, in spite of the presence of a normal sense organ (can hear sounds but not interpret).

**Cataract** - opacity of the eye lens.

**Causalgia** - severe sensation of burning pain, often in an extremity, sometimes with local erythema of the skin.

**Chronic** - term used to describe a symptom or disease in which the attack is slow, worsens with time and is long in duration.

**Clonus** - muscle rigidity and relaxation that occurs spasmodically.

**Cognition** - mental process characterised by knowing, thinking, learning and judging.

**Coordination** - harmony of movement between several muscles or groups of muscle so that complicated manoeuvres can be made.

**Cycloplegia** - paralysis of the eye ciliary muscle.

**Cytokines** - generic term for nonantibody proteins released by one cell population on contact with a specific antigen. These act as intercellular mediators in the generation of an immune response.

**Decubitus ulceration** - an inflammation, sore, or ulcer in the skin over a bony prominence. It results from ischaemic hypoxia of the tissues caused by prolonged pressure.

**Demyelination** - process of destruction or removal of the myelin sheath from a nerve or nerve fibre.

**Diplopia** - double vision due to lack of coordination of the external muscles of the eye. May be vertical or horizontal.

**Disability** - loss, absence, or impairment of physical or mental fitness.

**Disease-modifying therapy** - treatment that influences the course of the disease.
Dysarthria - problems with the clarity or rhythm of speech resulting from damage to the central or peripheral nervous system.
- Ataxic dysarthria - excess and equal speech stress, irregular articulation and distorted vowels.
- Flaccid dysarthria - hyper-nasally, breathing voice and weak consonant strength.
- Spastic dysarthria - harsh voice, low pitch imprecise articulation and decreased rate of speech.

Dysdiadochokinesia - inability to perform rapidly alternating movements, such as rhythmically tapping the fingers on the knee.

Dysgraphia - impairment of the ability to write.

Dyskinesia - impairment of voluntary movement.

Dysmetria - unable to accurately measure distances associated with muscular actions.

Dysphonia - any abnormality in the speaking voice, such as hoarseness.

Dyspnoea - difficult or laboured breathing.

EDSS - (Expanded Disability Status Scale) used in MS research to measure disability levels in a variety of functional systems, such as balance, touch, vision, bowel and bladder control, or mood.

Erythema - redness of the skin caused by congestion of the capillaries in its lower layers. It occurs with any skin injury.

Exacerbation - increase in the seriousness of a disease or disorder, as marked by a greater intensity in the signs and symptoms of the patient being treated.

Fatigue - state of exhaustion or loss of strength or endurance. It limits activities and quality of life.
- Acute fatigue - a new or significant increase in feelings in the previous 6 weeks.
- Chronic fatigue - present for any amount of time on 50% of the days for more than 6 weeks.

Flatulence - excessive formation of gases in the stomach or intestine.

Gastrocolic reflex - mass peristaltic movement of the colon that often occurs 15 to 20 minutes after food enters the stomach.

Hyponatraemia - sodium deficiency in the blood.

Hypotonic - solution with a lower osmotic pressure.

Immune system - biochemical complex protecting the body against pathogenic organisms and other foreign bodies.

Impotence - inability in a man to carry out sexual intercourse from either psychological or physical causes.

Inflammation - tissue response to injury. Inflammation is characterised by mobilisation of white blood cells and antibodies, swelling and fluid accumulation.

Insomnia - inability to sleep.

Interferons - group of immune system proteins, produced and released by cells infected by a virus. These inhibit viral multiplication and modify the body’s immune response.

Internuclear ophthalmoplegia - paralysis of the eye medical rectus muscle on lateral gaze.

Intravenous pyelogram (IVP) - a series of x-rays of the kidney, ureters, and bladder with the injection of a contrast dye into the vein to detect tumours, abnormalities, kidney stones, or any obstructions, and to assess renal blood flow.

Leucocyte - white blood cell such as a neutrophil, eosinophil or basophil.

Lhermitte’s sign - electric sensation running down the spine or into the limbs when flexing the neck forward suddenly.

Lymphocyte - white blood cell of crucial importance to the adaptive part of the body’s immune system eg B lymphocytes originate in the bone marrow and produce antibodies, and T lymphocytes are produced in the bone marrow and mature in the thymus.
Magnetic resonance imaging (MRI) - important diagnostic procedure in MS that produces visual images of different body parts without the use of x-rays. It is possible to visualise and count lesions in the white matter of the brain and spinal cord.

Marcus Gunn pupil - diminished direct-light reaction in one eye with preservation of the consensual reaction. Demonstrates retinal or optic nerve disease. Also known as afferent pupillary defect or APD.

Multiple sclerosis (MS) - progressive disease characterised by disseminated demyelination of nerve fibres of the brain and spinal cord.

Muscle tone - state of balanced muscle tension.
- Atonic muscle tone - weak, lacking normal tone.

Myalgia - diffuse muscle pain, usually accompanied by malaise.

Mydriasis - abnormal dilatation of the pupil of the eye. Usually caused by injury to the pupil sphincter or by the use of mydriatic drugs.

Myelin - soft white coating of CNS nerve fibres. It insulates and aids nerve fibre conduction. When the myelin is damaged in MS, nerve fibre conduction is faulty or absent.

Myelotomy - surgical incision/section of nerve tracts within the spinal cord, usually for the relief of intractable pain.

Necrosis - localised death of tissue in response to disease or injury.

Neuralgia - characterised by severe stabbing pain, caused by a variety or disorders affecting the nervous system.

Neuromyelitis optica - See Devic’s disease.

Neuropathy - nerve degeneration and loss of function.

Nocturia - production of large amount of urine during the night.

Nystagmus - involuntary rapid movement of the eyeball. It may be hereditary or result from disease of the semicircular canals or of the central nervous.

Optic atrophy - failing or wasting of the optic nerve.

Optic neuritis - inflammatory optic neuropathy, usually an acute disease of the optic nerve caused by focal inflammation associated with demyelination.

Pain - often present in MS.
- Acute pain - sharp, intermittent spasms that are sudden and spontaneous in nature.
- Chronic pain - persists for longer than 1 month, without resolution, and characterised as neuropathic or dysaesthetic extremity pain.
- Dysaesthetic - when pain is not normally present eg on touching.
- Subacute pain - can vary from days to weeks, it can be as a result of an acute inflammatory demyelinating episode.

Palpitations - rapid and forceful contractions of the heart.

Paraesthesia - any subjective sensation experienced as numbness, tingling or ‘pins and needles’.

Partial or complete cordotomies - operation on the spinal cord to divide the anterolateral nerve pathways for relief of intractable pain.

Patulous urethra - opening to a small tubular structure that drains urine from the bladder.

Plaque - flat, often raised, patch on the skin or other organ; in blood vessels signifies evidence of atherosclerosis.

Primary-progressive MS - clinical course of MS characterised from the beginning by progressive disease, with no plateaus or remissions, or an occasional plateau and very short lived, reversal of symptoms.

Pubococygeal spasticity - marked rigidity of muscles belonging to the pubis and coccyx.
Reflex - backward or return flow of energy or of an image, as a reflection.

Relapse - return of symptoms from which a patient appears to have recovered.

Relapsing-remitting MS - clinical course of MS that is characterised by clearly defined acute attacks with full or partial recovery and no disease progression between attacks.

Retention - resistance to movement or displacement.

Rhizotomy - cutting of a nerve root, a posterior (or sensory) root for the relief of intractable pain, or anterior root for relief of persistent spasm or involuntary movement.

Romberg's sign - indication of loss of the sense of position in which the patient loses balance when standing erect, feet together and eyes closed.

Saccades - jerky movement of the eye in response to "follow" commands. It is seen in demyelination of the descending supranuclear occipital pathway.

Sclerosis - condition characterised by hardening of tissue resulting from any of several causes, including inflammation, the deposit of mineral salts and infiltration of connective tissue fibres.

Scotoma - defect of vision in a defined area in one or both eyes.

Secondary-progressive MS - clinical course of MS that initially is relapsing-remitting and then becomes progressive at a variable rate, possibly with an occasional relapse and minor remission.

Seizures - hyperexcitation of neurons in the brain leading to a sudden violent involuntary series of contractions of a group of muscles.

Somnolence - abnormal drowsiness, inclination to sleep.

Spasticity - form of muscular hypertonicity with increased resistance to stretch. The hypertonicity is often associated with weakness, increased deep reflexes and diminished superficial reflexes.

Thalamotomy - stereotaxic surgical technique for the discrete destruction of specific groups of cells within the thalamus, as for the relief of pain or for relief of tremor and rigidity in Parkinson's disease.

Tremor - involuntary muscular quivering that may be due to fatigue, emotion or disease.

- Action tremor - also known as intention, goal directed or hyperkinetic tremor which is associated with voluntary movement and may range from mild to severe in nature.

- Postural tremor - present while voluntarily maintaining a position against gravity and sometimes appears or is exaggerated during specific postures.

- Rest tremor - occurs when the patient is relaxed or at rest and is completely against gravity.

Trigeminal neuralgia - acute neuropathic pain affecting the face, cheek and jaw (areas served by the trigeminal, or 5th cranial nerve).

Uhthoff’s symptom - reduction in visual acuity caused by a small increase in body temperature (exercise, hot bath etc), present in MS patients with optic neuropathy.

Urticaria - acute or chronic irritating skin condition characterised by the recurrent appearance of an eruption of weals.

Vertigo - instability characterised by a feeling of rotating or falling.

VEP testing - visual evoked potential is a sensitive tool in diagnosing MS, it is a test for optic neuritis or other demyelinating events. The test involves watching a black and white checkered pattern on a TV screen in a darkened room.

Xerophthalmia - cornea and conjunctiva become horny and necrosed owing to a deficiency of vitamin A.
Module 9
Appendices
9. Appendices

MODULE OVERVIEW

This module contains eight sections:

Appendix A  Kurtzke Functional System (FS) Rating Scale for Neurological Assessment
Kurtzke Expanded Disability Status Scale (EDSS) *

Appendix B  Modified Fatigue Impact Scale (MFIS) **

Appendix C  Bladder Control Scale (BLCS) **

Appendix D  Urolog

Appendix E  Bowel Control Scale (BWCS) **

Appendix F  Spasticity, Ashworth Scale, Spasm Frequency 100 Metre Walk

Appendix G  Berg Balance Scale ***

Appendix H  Sexual Function & Multiple Sclerosis


*** As referenced on the last page of Appendix G.
# Kurtzke Functional System (FS) Rating Scale for Neurologic Assessment

## 1. Pyramidal Functions

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Normal</td>
</tr>
<tr>
<td>1</td>
<td>Abnormal signs without disability</td>
</tr>
<tr>
<td>2</td>
<td>Minimal disability</td>
</tr>
<tr>
<td>3</td>
<td>Mild to moderate paraparesis or hemiparesis (detectable weakness but most function sustained for short periods, fatigue a problem); severe monoparesis (almost no function)</td>
</tr>
<tr>
<td>4</td>
<td>Marked paraparesis or hemiparesis (function is difficult), moderate quadriparesis (function is decreased but can be sustained for short periods) or monoplegia</td>
</tr>
<tr>
<td>5</td>
<td>Paraplegia, hemiplegia, or marked quadriparesis</td>
</tr>
<tr>
<td>6</td>
<td>Quadriplegia</td>
</tr>
<tr>
<td>V</td>
<td>Unknown</td>
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## 2. Cerebellar Functions

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Normal</td>
</tr>
<tr>
<td>1</td>
<td>Abnormal signs without disability</td>
</tr>
<tr>
<td>2</td>
<td>Mild ataxia tremor or clumsy movements easily seen, minor interference with function</td>
</tr>
<tr>
<td>3</td>
<td>Moderate truncal or limb ataxia (tremor or clumsy movements interfere with functions in all spheres)</td>
</tr>
<tr>
<td>4</td>
<td>Severe ataxia in all limbs (most function is very difficult)</td>
</tr>
<tr>
<td>5</td>
<td>Unable to perform coordinated movements due to ataxia</td>
</tr>
<tr>
<td>V</td>
<td>Weakness (grade 3 or worse on pyramidal) interferes with testing</td>
</tr>
</tbody>
</table>
### 3. Brainstem Functions

<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Normal</td>
</tr>
<tr>
<td>1</td>
<td>Signs only</td>
</tr>
<tr>
<td>2</td>
<td>Moderate nystagmus or other mild disability</td>
</tr>
<tr>
<td>3</td>
<td>Severe nystagmus, marked extraocular weakness, or moderate disability of other cranial nerves</td>
</tr>
<tr>
<td>4</td>
<td>Marked dysarthria or other marked disability</td>
</tr>
<tr>
<td>5</td>
<td>Inability to swallow or speak</td>
</tr>
<tr>
<td>V</td>
<td>Unknown</td>
</tr>
</tbody>
</table>

### 4. Sensory Functions

<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Normal</td>
</tr>
<tr>
<td>1</td>
<td>Vibration or figure-writing decrease only in one or two limbs</td>
</tr>
<tr>
<td>2</td>
<td>Mild decrease in touch or pain or position sense, and/or moderate decrease in vibration in one or two limbs; or vibratory (c/s figure writing) decrease alone in three or four limbs</td>
</tr>
<tr>
<td>3</td>
<td>Moderate decrease in touch or pain or position sense, and/or essentially lost vibration in one or two limbs; or mild decrease in touch or pain and/or moderate decrease in all proprioceptive tests in three or four limbs</td>
</tr>
<tr>
<td>4</td>
<td>Marked decrease in touch or pain or loss of proprioceptive, alone or combined, in one or two limbs; or moderate decrease in touch or pain and/or severe proprioceptive decrease in more than two limbs</td>
</tr>
<tr>
<td>5</td>
<td>Loss (essentially) of sensation in one or two limbs; or moderate decrease in touch or pain and/or loss of proprioceptive for most of the body below the head</td>
</tr>
<tr>
<td>6</td>
<td>Sensation essentially lost below the head</td>
</tr>
<tr>
<td>V</td>
<td>Unknown</td>
</tr>
</tbody>
</table>
5. **Bowel And Bladder Functions**

(Rate on the basis of the worse function, either bowel or bladder.)

<table>
<thead>
<tr>
<th>Grade</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Normal</td>
</tr>
<tr>
<td>1</td>
<td>Mild urinary hesitancy, urgency, or retention</td>
</tr>
<tr>
<td>2</td>
<td>Moderate hesitancy, urgency, retention of bowel or bladder or rare urinary incontinence (intermittent self-catheterisation, manual, compression to evacuate bladder, or finger evacuation of stool)</td>
</tr>
<tr>
<td>3</td>
<td>Frequent urinary incontinence</td>
</tr>
<tr>
<td>4</td>
<td>In need of almost constant catheterisation (and constant use of measures to evacuate stool)</td>
</tr>
<tr>
<td>5</td>
<td>Loss of bladder function</td>
</tr>
<tr>
<td>6</td>
<td>Loss of bowel and bladder function</td>
</tr>
<tr>
<td>V</td>
<td>Unknown</td>
</tr>
</tbody>
</table>

6. **Visual (Or Optic) Functions**

<table>
<thead>
<tr>
<th>Grade</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Normal</td>
</tr>
<tr>
<td>1</td>
<td>Scotoma with visual acuity (corrected) better than 20/30</td>
</tr>
<tr>
<td>2</td>
<td>Worse eye with scotoma with maximal visual acuity (corrected) of 20/30 to 20/59</td>
</tr>
<tr>
<td>3</td>
<td>Worse eye with large scotoma, or moderate decrease in fields, but with maximal visual acuity (corrected) of 20/60 to 20/99</td>
</tr>
<tr>
<td>4</td>
<td>Worse eye with marked decrease of fields and maximal visual acuity (corrected) of 20/100 to 20/200; grade 3 plus maximal acuity of better eye of 20/60 or less</td>
</tr>
<tr>
<td>5</td>
<td>Worse eye with maximal visual acuity (corrected) less than 20/200; grade 4 plus maximal acuity of better eye of 20/60 or less</td>
</tr>
<tr>
<td>6</td>
<td>Grade 5 plus maximal visual acuity of better eye of 20/60 or less</td>
</tr>
<tr>
<td>V</td>
<td>Unknown</td>
</tr>
</tbody>
</table>


7. Cerebral Or Mental Functions

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>0</td>
<td>Normal</td>
</tr>
<tr>
<td>1</td>
<td>Mood attention only (does not affect DSS score)</td>
</tr>
<tr>
<td>2</td>
<td>Mild decrease in mentation</td>
</tr>
<tr>
<td>3</td>
<td>Moderate decrease in mentation</td>
</tr>
<tr>
<td>4</td>
<td>Marked decrease in mentation (chronic brain syndrome—moderate)</td>
</tr>
<tr>
<td>5</td>
<td>Dementia or chronic brain syndrome - severe or incompetent</td>
</tr>
<tr>
<td>V</td>
<td>Unknown</td>
</tr>
</tbody>
</table>

8. Other Functions

(Any other neurological findings attributable to MS)

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<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td></td>
<td>Spasticity</td>
</tr>
<tr>
<td>0</td>
<td>None</td>
</tr>
<tr>
<td>1</td>
<td>Mild (detectable only)</td>
</tr>
<tr>
<td>2</td>
<td>Moderate (minor interference with function)</td>
</tr>
<tr>
<td>3</td>
<td>Severe (major interference with function)</td>
</tr>
<tr>
<td>V</td>
<td>Unknown</td>
</tr>
</tbody>
</table>

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Others</td>
</tr>
<tr>
<td>0</td>
<td>None</td>
</tr>
<tr>
<td>1</td>
<td>Any other neurological findings attributed to MS</td>
</tr>
<tr>
<td></td>
<td>Specify:</td>
</tr>
<tr>
<td>V</td>
<td>Unknown</td>
</tr>
</tbody>
</table>
## Kurtzke Expanded Disability Status Scale

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.0</td>
<td>Normal neurologic exam</td>
</tr>
<tr>
<td>1.0</td>
<td>No disability, minimal symptoms</td>
</tr>
<tr>
<td>1.5</td>
<td>No disability, minimal signs in more than one functional system</td>
</tr>
<tr>
<td>2.0</td>
<td>Slightly more disability in one functional system</td>
</tr>
<tr>
<td>2.5</td>
<td>Slightly greater disability in two functional systems</td>
</tr>
<tr>
<td>3.0</td>
<td>Moderate disability in one functional system; fully ambulatory</td>
</tr>
<tr>
<td>3.5</td>
<td>Fully ambulatory but with moderate disability in one functional system and more than minimal</td>
</tr>
<tr>
<td>4.0</td>
<td>Fully ambulatory without aid, self-sufficient, up and about some 12 hours a day despite relatively severe disability; able to walk without aid or rest some 500 meters</td>
</tr>
<tr>
<td>4.5</td>
<td>Fully ambulatory without aid, up and about much of the day, able to work a full day, may otherwise have some limitation of full activity or require minimal assistance; characterised by relatively severe disability; able to walk without aid or rest some 300 meters</td>
</tr>
<tr>
<td>5.0</td>
<td>Ambulatory without aid or rest for about 200 meters; disability severe enough to impair full daily activities (work a full day without special provisions)</td>
</tr>
<tr>
<td>5.5</td>
<td>Ambulatory without aid or rest for about 100 meters; disability severe enough to preclude full daily activities</td>
</tr>
<tr>
<td>6.0</td>
<td>Intermittent or unilateral constant assistance (cane, crutch, brace) required to walk about 100 meters with or without resting</td>
</tr>
<tr>
<td>6.5</td>
<td>Constant bilateral assistance (canes, crutches, braces) required to walk about 20 meters without resting</td>
</tr>
<tr>
<td>7.0</td>
<td>Unable to walk beyond approximately five meters even with aid, essentially restricted to wheelchair; wheels self in standard wheelchair and transfers alone; up and about in wheelchair some 12 hours a day</td>
</tr>
<tr>
<td>7.5</td>
<td>Unable to take more than a few steps; restricted to wheelchair; may need aid in transfer; wheels self but cannot carry on in standard wheelchair a full day; may require motorized wheelchair</td>
</tr>
<tr>
<td>8.0</td>
<td>Essentially restricted to bed or chair or perambulated in wheelchair, but may be out of bed itself much of the day; retains many self-care functions; generally has effective use of arms</td>
</tr>
<tr>
<td>8.5</td>
<td>Essentially restricted to bed much of day; has some effective use of arms retains some self care-functions disability in several others</td>
</tr>
<tr>
<td>9.0</td>
<td>Helpless bed patient; can communicate and eat</td>
</tr>
<tr>
<td>9.5</td>
<td>Totally helpless bed patient; unable to communicate effectively or eat/swallow</td>
</tr>
<tr>
<td>10.0</td>
<td>Death due to MS</td>
</tr>
</tbody>
</table>
Appendix B

Modified Fatigue Impact Scale (MFIS)

Patient’s Name: _______________________________ Date: _____ / _____ / _____

ID#: ________________________________________ Test#: 1 2 3 4

day month year

Following is a list of statements that describe how fatigue may affect a person. Fatigue is a feeling of physical
tiredness and lack of energy that many people experience from time to time. In medical conditions like MS, feelings
of fatigue can occur more often and have a greater impact than usual. Please read each statement carefully, and then
circle the one number that best indicates how often fatigue has affected you in this way during the past 4 weeks.
(If you need help in marking your responses, tell the interviewer the number of the best response.) Please answer
every question. If you are not sure which answer to select, please choose the one answer that comes closest to
describing you. The interviewer can explain any words or phrases that you do not understand.

Because of my fatigue during the past 4 weeks …

<table>
<thead>
<tr>
<th>Number</th>
<th>Statement</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I have been less alert.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2.</td>
<td>I have had difficulty paying attention for long periods of time.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3.</td>
<td>I have been unable to think clearly.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4.</td>
<td>I have been clumsy and uncoordinated.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5.</td>
<td>I have been forgetful.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6.</td>
<td>I have had to pace myself in my physical activities.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7.</td>
<td>I have been less motivated to do anything that requires physical effort.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8.</td>
<td>I have been less motivated to participate in social activities.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Continued on the next page...
Because of my fatigue during the past 4 weeks...

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>I have been limited in any ability to do things away from home.</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>10</td>
<td>I have had trouble maintaining physical effort for long periods.</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>11</td>
<td>I have had difficulty making decisions.</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>12</td>
<td>I have been less motivated to do anything that requires thinking.</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>13</td>
<td>My muscles have felt weak.</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>14</td>
<td>I have been physically uncomfortable.</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>15</td>
<td>I have had trouble finishing tasks that require thinking.</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>16</td>
<td>I have had difficulty organising my thoughts when doing things at home or work.</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>17</td>
<td>I have been less able to complete tasks that require physical effort.</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>18</td>
<td>My thinking has been slowed down.</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>19</td>
<td>I have had trouble concentrating.</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>20</td>
<td>I have limited my physical activities.</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>21</td>
<td>I have needed to rest more often for longer periods.</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
Modified Fatigue Impact Scale -5-Item (MFIS-5)

Patient’s Name:_________________________________________  Date:   ______ /_____ /_____

ID#: _________________________________________________  Test#:      1         2         3        4

Following is a list of statements that describe how fatigue may affect a person. Fatigue is a feeling of physical
tiredness and lack of energy that many people experience from time to time. In medical conditions like MS, feelings
of fatigue can occur more often and have a greater impact than usual. Please read each statement carefully, and
then circle the one number that best indicates how often fatigue has affected you in this way during the past 4
weeks. (If you need help in marking your responses, tell the interviewer the number of the best response). Please
answer every question. If you are not sure which answer to select, please choose the one answer that comes
closest to describing you. The interviewer can explain any words or phrases that you do not understand.

Because of my fatigue during the past 4 weeks …

<table>
<thead>
<tr>
<th>Statement</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I have been less alert.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. I have been limited in my ability to do things away from home.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. I have had trouble maintaining physical effort for long periods.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. I have been less able to complete tasks that require physical effort.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. I have had trouble concentrating.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Bladder Control Scale (BLCS)

Patient’s Name: ________________________________ Date: ______ / _____ / ______

ID#: _________________________________________ Test#: 1 2 3 4

Instructions
These questions concern bladder problems that can occur in MS. Many of these questions are very personal, but this is an important topic to cover. If you are marking your own answers, please circle the appropriate response (0, 1, 2, ...) based on your bladder function during the past 4 weeks. If you need help in marking your responses, tell the interviewer the number of the best response. Please answer every question. If you are not sure which answer to select, please choose the one answer that comes closest to describing you. The interviewer can explain any words or phrases that you do not understand.

During the past 4 weeks, how often have you...

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>Once</th>
<th>Two to four times</th>
<th>More than weekly but not daily</th>
<th>Daily</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Lost control of your bladder or had an accident?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Almost lost control of your bladder or had an accident?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Altered your activities because of bladder problems?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. During the past 4 weeks, how much have bladder problems restricted your overall lifestyle? (Please circle one number).</td>
<td>Not at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
# Appendix D

## Urolog

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Pill</th>
<th>Amount Voided (ml)</th>
<th>Catheter Drainage (ml)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Pill</th>
<th>Amount Voided (ml)</th>
<th>Catheter Drainage (ml)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

FHH #: __________________________

Catheterise ____________________________________  Medication __________________________________________
Appendix E

Bowel Control Scale (BWCS)

Patient’s Name: ___________________________________________  Date: ______ /_____/_____
day    month      year

ID#: _________________________________________________  Test#: 1 2 3 4

Instructions

These questions concern bowel problems that can occur in MS. Many of these questions are very personal, but this is an important topic to cover. If you are marking your own answers, please circle the appropriate response (0, 1, 2, …) based on your bowel function during the past 4 weeks. If you need help in marking your responses, tell the interviewer the number of the best response. Please answer every question. If you are not sure which answer to select, please choose the one answer that comes closest to describing you. The interviewer can explain any words or phrases that you do not understand.

During the past 4 weeks, how often have you...

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>Once</th>
<th>Two to four times</th>
<th>More than weekly but not daily</th>
<th>Daily</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Been constipated?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Lost control of your bowels or had an accident?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Almost lost control of your bowels or almost had an accident?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Altered your activities because of bowel control problems?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. During the past 4 weeks, how much have bowel problems restricted your overall lifestyle? (Please circle one number.)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Not at all</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Appendix F

### Spasticity

<table>
<thead>
<tr>
<th>UE Flexors</th>
<th>R</th>
<th>L</th>
<th>LE Flexors</th>
<th>R</th>
<th>L</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elbow</td>
<td></td>
<td></td>
<td>Hip Extensors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elbow</td>
<td></td>
<td></td>
<td>Hip Extensors</td>
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<tr>
<td>Pronators</td>
<td></td>
<td></td>
<td>Hip Adductors</td>
<td></td>
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</tr>
<tr>
<td>Wrist</td>
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<td>Knee Extensors</td>
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<td></td>
<td>Knee Flexors</td>
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<td>Totals</td>
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</tbody>
</table>

### Ashworth Scale

0  No increase in tone
1  Slight increase in tone, giving a "catch" when affected part moved in flex or ext.
2  More marked increase in tone but affected part easily flexed
3  Considerable increase in tone; passive movement difficult
4  Affected part rigid in flex or ext.

### Spasm Frequency

Score ________________

Scoring

0  No spasms
1  Mild induced by stimulation
2  Infrequent full spasms occurring <1/hour
3  Spasms occurring >1/hour
4  Spasms occurring >10/hour

### 100 Metre Walk

_____ _____ _____ . _____ _____ (secs.)

Aids used list below:

____________________________________________________________

____________________________________________________________

Circle:  UN = Unable
        NA = Not Attempted
## Berg Balance Scale

Name _____________________________________________________________ Date: _____ / ____ / _____

Location ___________________________________________________________ Rater ____________________

<table>
<thead>
<tr>
<th>ITEM</th>
<th>DESCRIPTION</th>
<th>SCORE (0-4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Sitting to standing</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>Standing unsupported</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>Sitting unsupported</td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>Standing to sitting</td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>Transfers</td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>Standing with eyes closed</td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>Standing with feet together</td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>Reaching forward with outstretched arm</td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>Retrieving object from floor</td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>Turning to look behind</td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>Turning 360 degrees</td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>Placing alternate foot on stool</td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td>Standing with one foot in front</td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>Standing on one foot</td>
<td></td>
</tr>
</tbody>
</table>

**TOTAL**

### General Instructions

Please demonstrate each task and/or give instructions as written. When scoring, please record the lowest response category that applies for each item.

In most items, the subject is asked to maintain a given position for specific time. Progressively more points are deducted if the time or distance requirements are not met, if the subject’s performance warrants supervision, or if the subject touches an external support or receives assistance from the examiner. Subjects should understand that they must maintain their balance while attempting the tasks. The choices of which leg to stand on or how far to reach are left to the subject. Poor judgment will adversely influence the performance and the scoring.

Equipment required for testing are a stopwatch or watch with a second hand, and a ruler or other indicator of 2, 5 and 10 inches (5, 12.5 and 25 cm). Chairs used during testing should be of reasonable height. Either a step or a stool (of average step height) may be used for item #12.
1. Sitting To Standing

INSTRUCTIONS: Please stand up. Try not to use your hands for support.

( ) 4   able to stand without using hands and stabilise independently
( ) 3   able to stand independently using hands
( ) 2   able to stand using hands after several tries
( ) 1   needs minimal aid to stand or to stabilise
( ) 0   needs moderate or maximal assist to stand

2. Standing Unsupported

INSTRUCTIONS: Please stand for two minutes without holding.

( ) 4   able to stand safely 2 minutes
( ) 3   able to stand 2 minutes with supervision
( ) 2   able to stand 30 seconds unsupported
( ) 1   needs several tries to stand 30 seconds unsupported
( ) 0   unable to stand 30 seconds unassisted

*If a subject is able to stand 2 minutes unsupported, score full points for sitting unsupported. Proceed to item #4.*

3. Sitting With Back Unsupported But Feet Supported On Floor Or On A Stool

INSTRUCTIONS: Please sit with arms folded for 2 minutes.

( ) 4   able to sit safely and securely 2 minutes
( ) 3   able to sit 2 minutes under supervision
( ) 2   able to sit 30 seconds
( ) 1   able to sit 10 seconds
( ) 0   unable to sit without support 10 seconds

4. Standing To Sitting

INSTRUCTIONS: Please sit down.

( ) 4   sits safely with minimal use of hands
( ) 3   controls descent by using hands
( ) 2   uses back of legs against chair to control descent
( ) 1   sits independently but has uncontrolled descent
( ) 0   needs assistance to sit

5. Transfers

INSTRUCTIONS: Arrange chairs(s) for a pivot transfer. Ask subject to transfer one way toward a seat with armrests and one way toward a seat without armrests. You may use two chairs (one with and one without armrests) or a bed and a chair.

( ) 4   able to transfer safely with minor use of hands
( ) 3   able to transfer safely definite need of hands
( ) 2   able to transfer with verbal cueing and/or supervision
( ) 1   needs one person to assist
( ) 0   needs two people to assist or supervise to be safe
6. Standing Unsupported With Eyes Closed

INSTRUCTIONS: Please close your eyes and stand still for 10 seconds.

- [ ] 4   able to stand 10 seconds safely
- [ ] 3   able to stand 10 seconds with supervision
- [ ] 2   able to stand 3 seconds
- [ ] 1   unable to keep eyes closed 3 seconds but stays steady
- [ ] 0   needs help to keep from falling

7. Standing Unsupported With Feet Together

INSTRUCTIONS: Place your feet together and stand without holding.

- [ ] 4   able to place feet together independently and stand 1 minute safely
- [ ] 3   able to place feet together independently and stand for 1 minute with supervision
- [ ] 2   able to place feet together independently and to hold for 30 seconds
- [ ] 1   needs help to attain position but able to stand 15 seconds feet together
- [ ] 0   needs help to attain position and unable to hold for 15 seconds

8. Reaching Forward With Outstretched Arm While Standing

INSTRUCTIONS: Lift arm to 90 degrees. Stretch out your fingers and reach forward as far as you can. (Examiner places a ruler at end of fingertips when arm is at 90 degrees. Fingers should not touch the ruler while reaching forward. The recorded measure is the distance forward that the finger reach while the subject is in the most forward lean position. When possible, ask subject to use both arms when reaching to avoid rotation of the trunk.)

- [ ] 4   can reach forward confidently >25 cm (10 inches)
- [ ] 3   can reach forward >12.5 cm safely (5 inches)
- [ ] 2   can reach forward >5 cm safely (2 inches)
- [ ] 1   reaches forward but needs supervision
- [ ] 0   loses balance while trying/ requires external support

9. Pick Up Object From The Floor From A Standing Position

INSTRUCTIONS: Pick up the shoe/slipper which is placed in front of your feet.

- [ ] 4   able to pick up slipper safely and easily
- [ ] 3   able to pick up slipper but needs supervision
- [ ] 2   unable to pick up but reaches 2-5cm (1-2 inches) from slipper and keeps balance independently
- [ ] 1   unable to pick up and needs supervision while trying
- [ ] 0   unable to try/needs assist to keep from losing balance or falling

10. Turning To Look Behind Over Left And Right Shoulders While Standing

INSTRUCTIONS: Turn to look directly behind you over toward left shoulder. Repeat to the right. Examiner may pick an object to look at directly behind the subject to encourage a better twist turn.

- [ ] 4   looks behind from both sides and weight shifts well
- [ ] 3   looks behind one side only other side shows less weight shift
- [ ] 2   turns sideways only but maintains balance
- [ ] 1   needs supervision when turning
- [ ] 0   needs assist to keep from losing balance or falling
11. Turn 360 Degrees

INSTRUCTIONS: Turn completely around in a full circle. Pause. Then turn a full circle in the other direction.

( ) 4 able to turn 360 degrees safely in 4 seconds or less
( ) 3 able to turn 360 degrees safely one side only in 4 seconds or less
( ) 2 able to turn 360 degrees safely but slowly
( ) 1 needs close supervision or verbal cueing
( ) 0 needs assistance while turning

12. Placing Alternate Foot On Step Or Stool While Standing Unsupported

INSTRUCTIONS: Place each foot alternately on the step/stool. Continue until each foot has touched the step/stool four times.

( ) 4 able to stand independently and safely and complete 8 steps in 20 seconds
( ) 3 able to stand independently and complete 8 steps >20 seconds
( ) 2 able to complete 4 steps without aid with supervision
( ) 1 able to complete >2 steps needs minimal assist
( ) 0 needs assistance to keep from falling/unable to try

13. Standing Unsupported One Foot In Front

INSTRUCTIONS: (DEMONSTRATE TO SUBJECT)
Place one foot directly in front of the other. If you feel that you cannot place your foot directly in front, try to step far enough ahead that the heel of your forward foot is ahead of the toes of the other foot. (To score 3 points, the length of the step should exceed the length of the other foot and the width of the stance should approximate the subject’s normal stride width)

( ) 4 able to place foot tandem independently and hold 30 seconds
( ) 3 able to place foot ahead of other independently and hold 30 seconds
( ) 2 able to take small step independently and hold 30 seconds
( ) 1 needs help to step but can hold 15 seconds
( ) 0 loses balance while stepping or standing

14. Standing On One Leg

INSTRUCTIONS: Stand on one leg as long as you can without holding.

( ) 4 able to lift leg independently and hold >10 seconds
( ) 3 able to lift leg independently and hold 5-10 seconds
( ) 2 able to lift leg independently and hold = or >=3 seconds
( ) 1 tries to lift leg unable to hold 3 seconds but remains standing independently
( ) 0 unable to try or needs assist to prevent fall

( ) TOTAL SCORE (Maximum = 56)

*References
Appendix H

Sexual Function and Multiple Sclerosis

The following information has been provided by Jenny Richards – MS Australia, MS Society of Western Australia.

Introduction

Problems with sexual function

In men, the most common concerns are those surrounding issues of erection and difficulty in achieving orgasm. For women these are changes to libido, diminished orgasm, changes in vaginal moisture and irritation, and the appearance of uncomfortable sensory changes in the genitals.

Mechanisms of sexual response

The central nervous system controls sexual responses with the integration of many different areas of the brain. These areas are responsible for the following responses – libido, movement, perception of pleasure, sexual stimuli, sensation, cognition and concentration.

The sexual response cycle involves impulses or sexual messages being relayed from the genitals, the spinal cord, (sacral, lumbar, and thoracic spine) and the brain. The impulse along the nerve pathways can be affected by demyelination; however there are many pathways involved in the mediation of sexual stimuli that are not affected by demyelinated nerves.

Sexual dysfunction in women with multiple sclerosis

During the sexual response in women two basic physiological processes occur:

1. Vasocongestion: the accumulation of blood into the blood vessels and tissues of the genitals;

2. Myotonia: also referred to as neuromuscular tension. This is an increase of energy in the nerves and muscles which occurs throughout the body during sexual activity, particularly in the breast and chest wall.

Sexual dysfunction in men with multiple sclerosis

Between the brain, spinal cord and penis there is a complex series of nerve pathways which initiate and maintain an erection. When these pathways receive a signal they set in motion a series of changes, these are:

1. An increase in arterial blood flow to the corpus cavernosa which causes the tissues to expand in the penis;

2. Then this arterial inflow of blood is associated with the relaxation of muscle in the penis which compresses the many small veins in the penis trapping the blood and causing an erection.

When the nerve impulse to the penis is impaired due to demyelination, the man’s ability to achieve and maintain an erection can be affected.
Primary sexual dysfunction in women

This occurs as a result of the physiological processes that are occurring in the central nervous system due to MS disease activity. These processes directly affect sexual response and/or sexual feelings.

Symptoms can include:

- Altered sensations in the genital area
- Decreased vaginal lubrication
- Reduced or diminished pleasure
- Changes in the ability to achieve orgasm or the intensity of the orgasm.

Generally these symptoms can be managed using various products that are easily available including lubricants, medications and by exploring mutually acceptable alternative positions or strategies.

Primary sexual dysfunction in men

This occurs as a result of myelin destruction in the spinal cord or the brain (neurological changes) resulting in interference with sexual response. Importantly, men can achieve reflex erections (these are not under the influence of the brain or upper spinal cord) due to the presence of nerve pathways in the sacral area of the spinal cord that travel to and from the male genitals.

A reflex erection can be caused by vigorously stimulating the penis and scrotum with a vibrator, as well as from inserting the flaccid penis into the vagina in a procedure called “stuffing”. This must be done carefully with the vagina well lubricated so the penis does not fold back onto itself causing injury (particularly if there is already a diminished sensation as injury to the penis will not be detected as easily).

Management of erectile dysfunction

1. The use of a vacuum erection device draws blood into the penis resulting in engorgement and erection. Once the penis is erect a rubber band is fitted around the base to restrict the venous blood return. The user determines the safety of the device; the band must only remain around the engorged penis for 30 minutes or less to prevent complications. Other potential side effects are skin irritation and bruising.

   To use the device correctly hand dexterity is required for positioning and removing the rubber band.

2. Pharmacological treatments are listed below and vary from injectables to oral treatments. It is interesting to note that very little, if any, pain is commonly reported from penile injections. It must be noted that these drugs can have side effects.

   Medications that may be prescribed in Australia to treat erectile dysfunction

<table>
<thead>
<tr>
<th>Drug name</th>
<th>Route of administration</th>
<th>Common side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alprostadil (Caverject)</td>
<td>Injection</td>
<td>Penile discomfort, priapism</td>
</tr>
<tr>
<td>Papaverine</td>
<td>Injection</td>
<td>Scarring at injection site, greater risk of priapism</td>
</tr>
<tr>
<td>Sildenafil (Viagra)</td>
<td>Tablet</td>
<td>Headache, dizziness, flushing, abnormal vision, back pain, muscle aches, nausea</td>
</tr>
<tr>
<td>Tadalafil (Cialis)</td>
<td>Tablet</td>
<td></td>
</tr>
<tr>
<td>Vardenafil (Levitra)</td>
<td>Tablet</td>
<td></td>
</tr>
</tbody>
</table>

Please refer to approved product information before any drug is prescribed. This list is meant to be representative rather than exhaustive.
Sensory changes

There may be altered sensations during sex such as burning, tingling and pain. Unfortunately the medications commonly prescribed for these symptoms can also have the side effect of reducing sexual desire. These are listed in the table above:

Other treatment options that can be useful include:

- Vigorous stimulation of the penis or the scrotum to overcome decreased sensation in this area;
- The use of vibrators and other sexual aides to stimulate the area, as well as manual stimulation.

The use of a sexual aid should be discussed with a GP, urologist or sexual therapist.

Developing a “sensory body map” is a useful strategy to identify the locations of pleasant sensations.

Secondary sexual dysfunction

This relates to physical changes that indirectly alter sexual response and enjoyment:

- Fatigue
- Bladder and bowel problems
- Muscle spasm, pain, burning and positional discomfort

Fatigue

Various fatigue management strategies can be used effectively. General Practitioners can discuss medication options and outline potential side effects.

Bladder dysfunction

This can be managed through:

- Administration of anticholinergics, but these can also cause dryness of the vagina;
- Emptying the bladder and bowel prior to planned sexual activity, and restricting fluid intake for a few hours before to reduce the risk of accidents;
- Taping urethral urinary catheters out of the way.

Fear of the loss of bladder or bowel control during intercourse, accompanied by anxiety, feelings of loss of attractiveness and feeling vulnerable can all impact on the ability to enjoy the sexual experience.

Cognitive problems

Changes in memory, concentration and attention affect many people with MS and result in ‘cognitive drift’. Partners may interpret this as a sign of disinterest or may feel they are no longer attractive or desirable. Open discussion between partners assists understanding that this change can be a symptom of MS. Effective management of such symptoms may reduce their impact on sexuality, and a GP or other appropriate health professional should be consulted for information, assessment, and strategies to reduce the impact of these symptoms.

<table>
<thead>
<tr>
<th>Drug name</th>
<th>Route of administration</th>
<th>Common side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carbamazepine (Tegretol)</td>
<td>Oral</td>
<td>Dry mouth, headache, abdominal upsets and decreased sexual desire</td>
</tr>
<tr>
<td>Phenytoin (Epilepsin)</td>
<td>Oral</td>
<td>Decreased sexual desire</td>
</tr>
</tbody>
</table>

Please refer to approved product information before any drug is prescribed. This list is meant to be representative rather than exhaustive.

See Table 4-2 in Module 4 - Signs and Symptoms for a list of pharmacological options that may be used in Australia for treating fatigue.

Altered sensations such as pain, burning in the vaginal area, muscle stiffness, tingling and also discomfort caused by certain positions all impact sexual satisfaction.

Drug name Route of administration Common side effects
Carbamazepine (Tegretol) Oral Dry mouth, headache, abdominal upsets and decreased sexual desire
Phenytoin (Epilepsin) Oral Decreased sexual desire

Please refer to approved product information before any drug is prescribed. This list is meant to be representative rather than exhaustive.
Tertiary sexual dysfunction

This includes problems that arise from social, cultural and psychological issues. Self-image, sexual desire, mood and communication can all be affected by MS and can lead to altered sexual functioning. Traditional perceptions of gender roles, commonly affected by MS, can impact adversely on sexual function.

It is important to dedicate time and effort to maintaining intimacy and nurturing relationships in the context of the challenges to sexual functioning which are caused by MS.
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