Multiple sclerosis: understanding a complex neurological condition


Summary
This article provides a brief overview of the pathophysiology of multiple sclerosis (MS). The symptoms experienced, including their management and treatment by members of the multidisciplinary team, are discussed, with a particular focus on the role of the nurse. Promoting and/or enabling self-management is an integral part of the nurse’s role. Although there is no cure for MS, good management can enable all people affected by the condition to come to terms with their diagnosis and have a positive outlook for the future.

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Aims and intended learning outcomes
The aim of this article is to increase the reader’s knowledge and understanding of multiple sclerosis (MS) and how it may affect individuals, as well as appreciating the variability of all aspects of the disease and its management. After reading this article and completing the time out activities you should be able to:

- Describe the pathophysiology of MS.
- Recognise the signs and symptoms of MS.
- Consider the implications of a diagnosis of MS and possible changes to lifestyle.
- Appreciate the variability of all aspects of the disease.
- Promote self-management in patients with MS.

Introduction
MS is one of the most common disabling neurological conditions affecting young adults, with an estimated 100,000 people diagnosed with the disease in the UK (MS Society 2009a). MS is variable in presentation, symptoms and disease course. At present, there is no cure for MS, but good management can prevent complications and help patients come to terms and live with their diagnosis. Management of the condition can be described in terms of partnerships – self-management alongside multidisciplinary team management, and complementary and alternative medicines (CAMs) in association with ‘conventional’ therapy.

Pathophysiology
MS has been described as a ‘mysterious disease’ (MacLean and Freedman 2009), a ‘progressive neurological disorder affecting the central nervous system’ (Ward-Abel and Burgoyne 2008) and as a ‘primarily and inflammatory disorder of the brain and spinal cord’ (Compston and Coles 2008). By examining what is known about the pathophysiology of MS, one can understand why all of these descriptions are correct.

Epidemiological studies, including possible genetic, environmental and geographical contributions, have provided insight into possible causal factors in MS. It is accepted that...
environmental and genetic factors are involved, although the timing and exact role of each remains unclear (Noseworthy et al 2000, Compston and Coles 2008, Goodin 2009). Factors currently being studied include Epstein-Barr virus, sunlight and vitamin D (Compston and Coles 2008).

Once the currently unknown environmental and genetic triggers for the development of MS are activated, disease processes commence that are often relentless. It is important to remember that the rate of progression of the disease can vary from rapid to slow. The pathological processes that are a feature of MS occur in the central nervous system (CNS), but the symptoms that result can be experienced throughout the body.

There is a consensus that MS is a multifactorial disease, caused by complex interactions that include exposure to environmental factors, probably in early childhood, triggering the disease process some years later in a genetically predisposed person. The disease process includes the triggering of an autoimmune response, the breakdown of the usually intact blood-brain barrier and an inflammatory process occurring in the CNS as a result of damage to the myelin sheath (demyelination) by activated immune cells.

The myelin sheath is produced by oligodendrocytes, which protect the axons and aid nerve conduction. Demyelination leads to nerve conduction being interrupted or lost, and symptoms such as pain and loss of function. If the oligodendrocytes are undamaged, new myelin can be made through a process known as remyelination. Function may, however, be compromised. If the axon itself is damaged, disease progression and disability result (Compston and Coles 2008). Axonal damage can occur at any time in the disease process.

**TABLE 1**

<table>
<thead>
<tr>
<th>Main types of multiple sclerosis (MS)</th>
<th>Relapsing-remitting</th>
<th>Secondary progressive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage of people diagnosed with MS</td>
<td>15</td>
<td>85</td>
</tr>
<tr>
<td>Description</td>
<td>Symptoms appear (relapse) then resolve, partially or fully (remission). Relapses last for at least 24 hours, but commonly last for weeks or months. Remissions can last for weeks or even years. A relapse is an episode of neurological disturbance, caused by inflammation or demyelination, which occurs at least 30 days after any previous episode began, lasts at least 24 hours and is not caused by infection or any other known cause (McDonald et al 2001).</td>
<td></td>
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<tr>
<td></td>
<td>More than 65% of people who are initially diagnosed with relapsing-remitting MS will enter this phase within 15 years of being diagnosed (Koch et al 2008). Secondary progression occurs when someone has a sustained progression of MS without any relapses having taken place. Some people may continue to have relapses.</td>
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**Diagnosis, types of MS and prognosis**

MS is usually diagnosed by a neurologist using guidelines known as the ‘McDonald criteria’, written in 2001 and revised in 2005 (McDonald et al 2001, Polman et al 2005). The guidelines advise that a diagnosis of MS is made using a combination of clinical history, neurological examination and supporting paraclinical tests, including evoked potentials – tests that produce electrical potentials following sensory stimulation along a sensory pathway – and magnetic resonance imaging (MRI).

When an individual has a first episode, also called an attack or event, it is referred to as a clinically isolated syndrome. Only after the second episode, with evidence of dissemination in time (happening at different times, with a period of recovery in between) and space (at least two different areas involved), is the term ‘multiple’ used, as in MS. MRI can provide evidence that an episode occurred without clinical signs or symptoms of neurological activity. In this situation, a diagnosis of MS can be made even if the person had only been aware of having had one episode.

The disease course is variable and different patterns or types of MS can be identified (Table 1). Once a diagnosis of MS has been made, the number of attacks and the rate of progression of
the disease can be variable. Some people will have a 'benign' course with relatively few episodes and little disability as a result, while others can have a rapidly progressive 'malignant' disease, resulting in disability and possibly early death (Noseworthy et al 2000, Vollmer 2007). Most patients will have a disease course between these two extremes (Confavreux and Vukusic 2006a).

Individuals may find it difficult to come to terms with a diagnosis of MS. This is a time of uncertainty and confusion and people need support, time and understanding, as emotions can be mixed (Johnson 2003, Vitali 2004). An MS specialist nurse is often the person who provides this support and information. Relationships developed at this time, between the person who has been diagnosed, his or her family and the team of healthcare professionals, can enable the individual to come to terms with the diagnosis and cope better with future uncertainty (Porter and Keenan 2003).

This uncertainty can extend to questions about prognosis, for which there are few direct answers. Natural history studies give some insight into patterns of MS and it has been shown that prognosis is related to age rather than the type of MS at onset (Confavreux and Vukusic 2006b), but it remains difficult to predict the disease course for each individual.

In general, the disease is likely to progress more slowly in people who are diagnosed with MS early in their adult lives than in those diagnosed at a later age, but those diagnosed as young adults are more likely to acquire disability at an earlier age (Vollmer 2007). Research shows that the ratio of women to men being diagnosed with MS is 3:1 (Orton et al 2006).

**Symptoms and management**

Variability is a commonly used description of the many aspects of MS, including symptoms that can vary in location and severity. As previously mentioned, demyelination can affect any part of the CNS, thus affecting the individual’s function. It is not possible to determine from MRI which particular symptom relates to a specific area of demyelination. McDonald and Compston (2006) discussed the difficulty in compiling accurate reports of symptoms of a first episode of MS (Table 2). McDonald and Compston (2006) also identified symptoms occurring during the course of the disease, which are summarised in Box 1.

Symptoms of MS can be categorised and described in different ways, which can be confusing for many people, particularly for individuals who have just been diagnosed. Symptoms may be described as silent or hidden because they are experienced by the individual, but cannot be seen. These include fatigue, pain, sensory disturbances, cognitive problems and mood disturbance. Symptoms may also be termed primary, when they result from the episode of demyelination, for example bladder dysfunction; secondary, when they are a complication of the primary symptom, for example urinary tract infection; or tertiary, when they result from coping with a long-term chronic condition, for example depression. Symptoms can have an effect on each other and medications used to treat one symptom may adversely affect another. It is important to remember that symptoms may not be the result of MS, but another disease process or even infection (Leary et al 2005).

In 2003 the National Institute for Clinical Excellence (NICE) produced the document *Multiple Sclerosis: Management of Multiple Sclerosis in Primary and Secondary Care* for people working with, and affected by, MS. These evidence-based guidelines cover all aspects of care by the multidisciplinary team. As well as

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**Table 2**

Common symptoms of a first episode of multiple sclerosis

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Incidence</th>
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<tbody>
<tr>
<td>Weakness in one or more limb</td>
<td>35%</td>
</tr>
<tr>
<td>Optic neuritis</td>
<td>20%</td>
</tr>
<tr>
<td>Paraesthesiae</td>
<td>20%</td>
</tr>
<tr>
<td>Diplopia</td>
<td>10%</td>
</tr>
<tr>
<td>Vertigo</td>
<td>5%</td>
</tr>
<tr>
<td>Disturbance of micturition</td>
<td>5%</td>
</tr>
<tr>
<td>Other</td>
<td>&lt;5%</td>
</tr>
</tbody>
</table>

(McDonald and Compston 2006)
for ways of alleviating symptoms or managing their lives. CAMs are used by many people with MS (Yadav et al 2006), but few individuals discuss their use with professionals involved in their care for fear of disapproval (Pucci et al 2004, Doskoch 2006).

The MS Society, in conjunction with the Motor Neurone Disease Association, Alzheimer's Society and Parkinson’s Disease Society, has collaborated with the charitable trust Sense About Science to produce a guide highlighting the importance of evidence-based information on new treatments and therapies (Sense about Science 2008).

Managing relapses

There is always a possibility that new or heightened symptoms may be the result of a relapse, and a thorough assessment should be carried out to identify the cause. This should include screening for infection, which can trigger a relapse or make existing symptoms worse (NICE 2003). Recommended management of a relapse, when it affects the individual’s function, should involve treatment with high-dose corticosteroids (NICE 2003). Corticosteroids will hopefully reduce the severity and duration of the relapse. Their use is usually contraindicated if infection is present, highlighting the need to screen for infection as part of the assessment. Rehabilitation may also be considered, if the person’s function is reduced or his or her level of dependence increases. The nurse has a major role in the care of someone having a relapse, from providing information on side effects of the corticosteroids to preventing complications or offering support and reassurance.

Although there is no cure for MS, there are treatments that can help to relieve symptoms and/or modify the disease course. Members of the multidisciplinary team should be involved and nurses are often identified as the key worker, concerned mainly with patient assessment and co-ordination of services. The MS specialist nurse plays a pivotal role in initiating, monitoring and titrating treatments. People with MS will search
the residual deficits resulting from incomplete recovery (O’Connor et al 2005, Halper 2007, Kalb 2007, Lublin 2007). It is therefore important that people with MS are given the opportunity to discuss and consider treatment options, as well as possibly making changes to their lifestyle. Having access to accurate, evidence-based information and being supported in decision making can empower individuals to make the right choices for themselves, in their own time (MacLean and Russell 2005).

**Disease-modifying therapies**

The term ‘disease-modifying therapies’ (DMTs) is used to describe a group of medications, including interferon-beta 1a, interferon-beta 1b and glatiramer acetate, all licensed for use in people who have a relapsing pattern of MS – either relapsing-remitting MS or secondary progressive MS with relapses (Department of Health (DH) 2002). Although they are not meant as a treatment for symptoms, there is evidence that they reduce the number of relapses (Rice et al 2001, Munari et al 2003, Clerico et al 2008).

There has been much controversy about the use of these therapies, including a NICE (2002) technology appraisal that stated: ‘On the balance of their clinical and cost effectiveness neither beta interferon nor glatiramer acetate is recommended for the treatment of multiple sclerosis (MS) in the NHS in England and Wales.’ However, these therapies are now available under the first ‘risk-sharing scheme’ in the UK (DH 2002).

People with MS who are eligible for these therapies have to decide whether to commence treatment. They need a lot of information and support to help them make their decisions. The MS specialist nurse usually co-ordinates the decision-making process, providing patients with information and demonstrating the constitution and administration of the different therapies. To aid decision-making, an independent website funded by the DH has been created – www.msdecisions.org.uk – providing information, advice and a decision aid. The website has information on natalizumab, which is only recommended as a treatment in rapidly evolving relapsing-remitting MS (NICE 2007).

There are other treatments, currently unlicensed for use in MS, which are used in some centres for rapidly progressive MS. An example is mitoxantrone, an immunosuppressive agent that is licensed in the United States for use in MS, but not in the UK. Mitoxantrone has a cumulative cardiac effect, limiting the amount that can be given. Glatiramer acetate may be used as a maintenance therapy following a course of treatment with mitoxantrone (Ramtahal et al 2006).

**Time out 6**

Access the MS decision aid at www.msdecisions.org.uk.

What do you think of the level of information it contains? Would it help you to make a decision about the use of particular therapies? Would you recommend it to someone diagnosed with relapsing-remitting MS?

Recently, the results of two placebo-controlled trials into the use of two oral preparations, cladribine and fingolimod, have been reported. (Giovannoni et al 2010, Kappos et al 2010). People taking cladribine were 55% less likely to experience a relapse, compared to those taking placebo, during the course of the trial (Giovannoni et al 2010). In the fingolimod trial, rate of relapse was reduced by 54-60% over the two-year trial period, compared with people who were taking placebo (Kappos et al 2010). A trial comparing fingolimod to interferon-beta 1a was also carried out and reported that the relapse rate of people who took fingolimod was reduced by 53% compared with that of people taking interferon-beta 1a. (Cohen et al 2010).

The manufacturers of both cladribine and fingolimod have applied for licenses for their use in people with MS. It is hoped that the drugs will be available in 2011, although it is important to remember that both drugs have significant side effects and care must be taken with their use. However, this signals a major change in the method of administration of DMTs for people with MS, especially for those who have a phobia of needles.

These therapies usually commence under the supervision of an MS specialist nurse. There are many considerations to make before starting treatment, including possible side effects. Nurses are able to advise and support patients to understand the various treatments, possible side effects and the importance of adhering to treatment (Keenan and Porter 2003, Denis et al 2004).

The disease-modifying therapies are licensed for use in adults. There have been some small studies into their safety and tolerability in children with MS with good results, demonstrating a reduction in relapse rate, which may reduce possible future disability (Banwell et al 2007).

**Self-management and independent living**

Individuals diagnosed with MS will encounter many challenges and possible changes to their life.
on a personal, social and work level. They will have to make many decisions, including whether or not to try a particular treatment. Ensuring that people have access to information and are able to make decisions that are ‘right’ for them is important. The nurse should be involved in helping the person to take control of his or her life and decision making, as recommended by NICE (2003). This may also involve supporting individuals in their decisions, even if the nurse does not agree with their choices. It is important that nurses are aware of the Mental Capacity Act 2005 and their responsibilities for ensuring that the underlying principles are upheld.

**Time out 7**

What is your understanding of the principles that underpin the Mental Capacity Act 2005? What do you see as your possible role with a person who has MS and problems with memory and decision making?

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**References**

Baker GA, Young CA (2006) Learning and understanding, especially if the person with MS explained a number of times to ensure that the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves’. This has been reiterated in the white paper Our Health, Our Care, Our Say: A New Direction for Community Services (DH 2006). Information may need to be provided in different formats, such as paper or online, and may need to be discussed and explained a number of times to ensure understanding, especially if the person with MS experiences fatigue or cognitive problems.

There is a variety of ways in which nurses can promote self-management and independent living. These include self-management education programmes, which are often organised by the local MS specialist nurse, possibly in conjunction with the local branch of the MS Society (Embrey 2005, MS Society 2009b), wellness programmes (Ennis et al 2004) Long-term treatment options for people with MS and management of acute relapses. Postgraduate Medical Journal 81, 955, 302-308.


learning zone neurological disorders

and availability of the Expert Patient Programme. Involving people with MS in the design and delivery of any service provision will empower them, as well as ensuring the service meets their needs. This will also help in meeting the vision of the NHS as a user-led service (DH 2008).

To self-manage, people with MS need to be signposted to sources of advice, information and support, which they can then choose to access. Self-management can enable independent living by providing individuals with the information to make informed decisions. It is important to understand that independent living and living independently, for example in one’s own home, are two different things. Independent living for people with MS has been defined as ‘The right of every person to have the information, advice and support to make informed decisions and live the lifestyle of their choice’ (personal communication from Brenda Joyce, strategic lead, MS Society, London, April 8 2009). This is what underpins the personalisation agenda, which aims to ensure that people have choice and control over the support and services they receive, irrespective of where they are provided and whether they self-fund or receive statutory services. This is the vision and way forward for the social care sector (DH 2007).

Conclusion

There is still much that remains unknown about MS. This leads to uncertainty and fear about the future for many people with the condition, as well as family members. Providing individuals with the support and tools to help them self-manage their condition is important to enable them to take control of their lives. The MS specialist nurse is pivotal in this process, providing information and support to all people affected by MS including professionals, as well as signposting to other services as required. All members of the multidisciplinary team have an important role in supporting and enabling independent living in people with MS.

Time out 8

Now that you have completed the article you might like to write a practice profile. Guidelines to help you are on page 60.

Robinson I, Hunter M, Neilsen S (1996) A Dispatch from the Front-Line: The Views of People with Multiple Sclerosis about their Needs; Brunel MS Research Unit, Uxbridge.


