Multiple sclerosis is the most common cause of neurological disability in young adults (Compston and Coles, 2002). It is a disease of the brain and spinal cord, and a lifelong condition that usually follows a relapsing or progressive course and results in a gradual accumulation of permanent disability (Scolding et al, 2015). MS causes a multitude of symptoms affecting physical and cognitive function as well as mood. The disease affects every aspect of people’s lives and is characterised by unpredictability and variability. This article provides an overview of the disease, its management and the holistic needs of people living with it.

**An overview of multiple sclerosis and its holistic management**

**Key points**

1. Approximately 108,000 people in the UK have multiple sclerosis, about three-quarters of whom are women.
2. Symptom management, disease-modifying drugs and neurorehabilitation form the basis of treatment.
3. Patients should contact their MS nurse or neurologist if they suspect they are having a relapse.
4. Infection tends to exacerbate other MS symptoms and may mimic relapse.
5. Symptoms of MS vary between individuals and for the same individual, from day to day and even hour to hour.

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**Abstract** Multiple sclerosis is the most common cause of neurological disability in young adults. It is a lifelong disease that generally results in a gradual accumulation of permanent disability. While much can be done to mitigate its impact, it causes a multitude of symptoms affecting physical and cognitive function as well as mood. The disease affects every aspect of people’s lives and is characterised by unpredictability and variability. This article provides an overview of the disease, its management and the holistic needs of people living with it.

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M ultiple sclerosis is the most common cause of neurological disability in young adults (Compston and Coles, 2002). It is a disease of the brain and spinal cord, and a lifelong condition that usually follows a relapsing or progressive course and results in a gradual accumulation of permanent disability (Scolding et al, 2015). MS causes a multitude of symptoms that affect physical and cognitive function as well as mood; symptoms vary between individuals and for the same individual. Although disease-modifying drugs (DMDs), which can change the disease course, are available for people with active relapsing disease, there is no cure. MS affects every aspect of people’s lives — work, family, social life — and is characterised by unpredictability and variability. This means a holistic approach to care is required to meet the needs of people living with the condition.

**Features of MS**

The cause of MS is still uncertain, but the disease is thought to result from a complex interplay between environmental and genetic factors that act on the immune system, causing an autoimmune, inflammatory response (Multiple Sclerosis Trust, 2011). Activated T cells cross the blood-brain barrier and enter the central nervous system, causing an inflammatory reaction that results in damage to myelin and myelin-forming cells called oligodendrocytes (this process is known as demyelination). Myelin is the insulating material that coats the axons of neurons in the CNS and ensures impulses along the axon are transmitted quickly and efficiently. When this coating is damaged, the transmission of impulses along the axon might be delayed or disrupted, or blocked altogether.

Another feature of MS is an ongoing loss of axons and degeneration of neurones, which results in a higher rate of cerebral atrophy than would be expected in the general population. Healthy adults lose 0.1-0.5% of their brain cells per year, while those with MS lose 0.5-1.35% per year (Giovannoni et al, 2015). This increased brain volume loss begins in the early stages of the disease (Giovannoni et al, 2015), often even before diagnosis, and continues throughout life unless the person is treated with an appropriate DMD; however, these drugs are only effective in active disease.
Risk factors

There are approximately 108,000 people in the UK with MS (Multiple Sclerosis Society, 2016; Mackenzie et al, 2013), roughly three times as many women as men (Harbo et al, 2013). Although the disease can be diagnosed at any age, most people are diagnosed between 20 and 40 years, while 2-5% of people are under 18 years old when diagnosed (Chitnis et al, 2009).

A genetic component to the risk of developing MS has been identified, with about 110 genes implicated so far. Different combinations of genes interact to influence risk, and no single gene is responsible. While the disease is therefore not considered hereditary, people who have a close relative with MS are at increased risk of developing it; for example, the child of a person with MS has a 1/67 chance of developing the disease, while the lifetime risk in the general population is approximately 1/330 (MS Trust, 2016).

Many studies have been undertaken to identify environmental risk factors associated with developing MS. It is known that low vitamin D levels correlate with an increased risk of developing MS: its prevalence across the world varies according to latitude, increasing in regions where exposure to sunlight is lower (Multiple Sclerosis International Federation, 2013). Studies have also clearly shown a season- and/or month-of-birth effect: in the northern hemisphere, there is an increase of MS births in spring and a decrease in autumn; in the southern hemisphere, the pattern is reversed, with an increase in November and a decrease in April (Torkildsen et al, 2012). Other environmental factors that are thought to be implicated include smoking, exposure to Epstein-Barr virus (Belbasis et al, 2015) and a high body mass index (Mokry et al, 2016).

Types of MS

MS is classified into different types according to the course of the disease (Box 1), but because there is no objective diagnostic test, it is often difficult to accurately determine the type. The transition between relapsing-remitting MS and secondary progressive MS can be particularly difficult to identify. Patients’ needs should thus be determined based on their clinical history, signs, symptoms and functional deficits, rather than on MS type.

Improved understanding of the pathophysiology of MS has recently led to a revision of the way MS is described, and neurologists are increasingly categorising the disease as either relapsing or progressive, and either active or inactive (Lublin et al, 2014). This is particularly relevant when considering treatment with DMDs. The prescription of DMDs should be based on the number of relapses experienced in a given period of time and on the indicators of disease activity shown by magnetic resonance imaging (NHS England, 2014).

Diagnosis

There is no single test that can be used to diagnose MS. Diagnosis is usually based on recent clinical history and confirmed by a neurological examination and an MRI scan of the brain and/or spinal cord. MS is confirmed if there are lesions (that is, scarring caused by inflammation) in the CNS that are spread out in time and location; for example, a patient may present with optic neuritis and the MRI scan may reveal older lesions elsewhere in the brain or spinal cord, as well as a new lesion on the optic nerve; this would be indicative of MS. In some instances, a lumbar puncture can be performed to examine the cerebrospinal fluid for evidence of a particular immunoglobulin – usually IgG – that indicates demyelination is occurring (Link and Huang, 2006).

Box 1. Types of MS

Clinically isolated syndrome (CIS)
This is the first clinical presentation of possible MS, characterised by evidence of lesion(s) spread out in terms of location, but not over time. A recent study estimated that approximately 60% of people diagnosed with CIS who have brain lesions evidenced by MRI will develop confirmed MS within five years, although estimates vary (Kuhle et al, 2015).

Relapsing-remitting MS
At diagnosis, 85% of people with MS have relapsing-remitting disease. This is characterised by periods of acute deterioration followed by periods of full or partial recovery.

Secondary progressive MS
This is characterised by progressive decline coming after a relapsing disease course; occasional relapses are possible during this second, more progressive phase of the disease. The majority of patients initially diagnosed with relapsing-remitting MS eventually transition to secondary progressive MS.

Primary progressive MS
In primary progressive MS, decline proceeds at a similar rate as in secondary progressive MS, but this occurs from disease onset. About 10-15% of people with MS have primary progressive MS at diagnosis.

Benign MS
Benign MS describes a disease pattern with very few symptoms and/or relapses and no accrual of disability over a period of many years; it can therefore only be diagnosed retrospectively. It is no longer good practice to give a diagnosis of benign MS, as the disease course can always change, but some people with MS may have been given this diagnosis in the past. People who have been diagnosed with benign MS in the past and continue to follow the same disease course are now likely to be classified as having inactive relapsing disease.

Patients need significant support at diagnosis. While there is plenty of high-quality information about MS, its treatment and how to cope with it, there is no substitute for a face-to-face appointment with a health professional who has specialist expertise. The MS specialist nurse will usually be able to offer that support to anyone diagnosed with MS, as recommended by the National Institute for Health and Care Excellence (2014).

Newly diagnosed patients often ask about their prognosis, but it is rarely possible to give accurate information at an individual level. Some patients will follow a relatively mild course of disease and a small number will experience a rapid decline and significant disability, while most will be somewhere between these two extremes. Various prognostic indicators (Box 2) can be used to give patients a general sense of whether a better or poorer outcome over time is likely. Learning to live with this prognostic uncertainty is one of the many challenges of coping with MS, which is a life-changing disease. Specialist nurses can offer expert support and advice to patients and families at all stages.

Management of relapse

Most people with MS (85%) have relapsing-remitting disease at diagnosis (Lublin and...
Reingold, 1996), so most will experience at least one relapse and many will have recurring relapses. Since relapses indicate increased or ongoing disease activity, they should always be reported to the MS nurse or neurologist.

A relapse is an onset of new symptoms or a worsening of existing symptoms that lasts for more than 24 hours. It follows a period of improving or stable neurological status of at least 30 days since the start of the previous relapse; the worsening should occur in the absence of infection, fever or significant metabolic disturbance (NHS England, 2014). Relapses can be difficult to diagnose; symptoms will depend to some extent on the area of the CNS in which the increased inflammatory activity is occurring. Recovery, which can be full or partial, will take place over time regardless of whether treatment is given.

Treatment with high-dose methylprednisolone is recommended if the relapse is affecting a patient's ability to undertake his or her usual activities (NICE, 2014); a short course of high-dose steroids will help speed up recovery, but make no difference to long-term outcomes. Treatment should begin within two weeks of initial patient contact to maximise benefit (NICE, 2016), although alternative causes that might explain the acute deterioration in symptoms, such as infection, must be ruled out first (treatment with high-dose steroids is contraindicated in the presence of active infection). Patients who suspect they may have a relapse are advised to contact their MS nurse or neurologist (Roberts et al, 2016) to ensure correct and timely management and optimal DMD therapy.

Disease-modifying drugs

Over the last 20 years, increasing numbers of DMDs have become available, all of which reduce the frequency and severity of relapses and the amount of scarring (lesions) shown by MRI. Some have also been shown to reduce the rate of disability progression and brain volume loss (Scolding et al, 2015).

DMDs must be prescribed by a specialist neurologist with support from an MS nurse, and may be given orally, by self-injection or via infusion. Some are more effective than others, but can potentially have more serious side-effects. The neurologist or MS nurse should clearly explain the benefits and risks of different drugs when discussing treatment.

Starting treatment early in the disease course and keeping disease activity as low as possible both help optimise long-term outcomes (Giovannoni et al, 2015). Disease activity should be regularly monitored by MRI (Scolding et al, 2015) and relapses should be reported and recorded: any increase in disease activity may signal that DMD treatment needs to be changed.

Monitoring depends on the DMD taken but usually requires regular blood tests to check lymphocytes, liver enzymes and sometimes thyroid levels. Nurses caring for patients taking DMDs for MS must be aware of the potential side-effects, which can include lymphopenia, elevated liver enzymes and immunosuppression, as well as many others specific to each drug. Table 1 lists common side-effects of DMDs.

### Symptom management

MS is associated with a wide variety of symptoms (Fig 1) and most patients need a blend of symptom management and neurorehabilitation, while some also benefit from DMD therapy. Symptoms often occur concurrently and affect each other; for example, fatigue may exacerbate other symptoms, which in turn may exacerbate fatigue (Coyne et al, 2015). To ensure effective symptom management, diagnosing the main issue(s) is key, but not always straightforward. Unpicking the relationship between the different symptoms often requires specialist expertise.

Once the main issue(s) has been determined, a holistic approach to symptom management should be sought, with different members of the multidisciplinary team involved. Advice on lifestyle changes, the provision of information and, if appropriate, the prescription of symptom-specific medication should be underpinned by a personalised care plan. Care should be coordinated by an MS nurse or a specialist allied health professional (Croft et al, 2016). The management of MS symptoms clearly requires an integrated MDT approach, but this is not always seen in

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**Box 2. Prognostic indicators**

Factors indicative of a better outcome over time:
- Female sex
- Low rate of relapses per year
- Full recovery from first relapse
- Long interval between first and second relapse
- Symptoms predominantly sensory
- Age of onset less than 35 years
- Mild disability at five years from onset

Factors indicative of a poorer outcome over time:
- Male sex
- High rate of relapses per year
- Incomplete recovery from first relapse
- Short interval between first and second relapse
- Symptoms predominantly of motor involvement; for example, poor balance, weakness, ataxia
- Age of onset 35 years or over
- Significant disability at five years from onset

Source: MS Trust (2017)

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**Table 1. Common side-effects of DMDs**

<table>
<thead>
<tr>
<th>Generic drug</th>
<th>Common side-effects (affecting ≥1 in 100 people)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beta interferons</td>
<td>Flu-like symptoms, Injection-site reactions, Headache</td>
</tr>
<tr>
<td>Glatiramer acetate</td>
<td>Injection-site reactions, Lipatrophy, Headache, Depression, anxiety, Nausea, Feeling weak, Chest pain, Swollen lymph nodes, Gastrointestinal changes</td>
</tr>
<tr>
<td>Dimethyl fumarate</td>
<td>Nausea, Diarrhoea, Hair thinning and loss, Increased liver enzyme levels</td>
</tr>
<tr>
<td>Teriflunomide</td>
<td>Flushing and feeling hot, Gastrointestinal upset, Decreased white blood cells, Rash, Increased liver enzyme levels, Ketones and protein in urine</td>
</tr>
<tr>
<td>Fingolimod</td>
<td>Cough, Headache, Back pain, Diarrhoea, Increased risk of infection, Increased liver enzyme levels, Decreased white blood cells</td>
</tr>
<tr>
<td>Natalizumab</td>
<td>Headache, Dizziness, Itchy skin rash, Increased risk of infection</td>
</tr>
<tr>
<td>Alemtuzumab</td>
<td>Infusion-related reactions, Increased risk of infection, Thyroid disorders (affecting ≥3 in 10 people), Idiopathic thrombocytopenic purpura (affecting ≤1 in 100 people)</td>
</tr>
</tbody>
</table>

Source: MS Trust (2015)
practice. It is beyond the scope of this article to describe all symptoms in detail, but three common ones – fatigue, cognitive dysfunction and mood disorders – are dealt with below.

**Fatigue**
Fatigue affects 90% of MS patients at some point, and most of them experience fatigue most of the time (Nagaraj et al, 2013). People with MS cite fatigue as one of the most disabling symptoms of the disease (Giovanonni, 2012), and it often has a significant impact on physical and cognitive function. It can be described as tiredness out of all proportion to the activities undertaken, and is one of the key reasons why MS patients may need to retire early (Coyne et al, 2015). In some patients, medication helps alleviate the worst effects of fatigue; however, a multidisciplinary approach to management is usually more effective. Patients can help themselves: many MS services run self-management courses that have been shown to help, such as the Fatigue: Applying Cognitive behavioural and Energy effectiveness Techniques to lifeStyle (FACETS) programme (Thomas et al, 2015).

**Cognitive dysfunction**
Cognitive dysfunction is experienced by 40-65% of patients with MS; this often invisible symptom usually presents as difficulties with problem-solving, short-term memory, and concentration and attention span, although other aspects of cognition can be affected as well (Amato et al, 2008). Cognitive problems are another key factor in people with MS needing to retire early (Coyne et al, 2015).

**Mood disorders**
MS can negatively affect mood: approximately half of MS patients experience at least one clinically significant episode of depression during their lifetime; this usually occurs in response to the difficulties of living with MS but may be idiopathic in nature (Siegert and Abernethy, 2009). While it is unlikely to resolve spontaneously, depression in MS responds well to both antidepressant medication and psychological interventions such as cognitive-behavioural therapy (NICE, 2014).

**Long-term impact**
The quality of life of people with MS almost inevitably declines over time. Health utility scores measure individuals’ perspectives on their state of health: people with MS report that their health utility declines rapidly from disease onset and continues to decline as the disease progresses; MS patients aged 18-25 have a lower health utility score than people aged 80 and over in the general population (Giovanonni et al, 2015). However, there are exceptions and it is important to remember that every MS patient is different and will experience a different disease course.

Lifespan is not significantly affected by MS: the average reduction is 5-10 years (Marrie et al, 2015). This means that many people with MS live with a significant and increasing degree of disability for many years; about a third of them need some degree of support in their daily lives, which is mostly provided by informal carers – usually spouses or partners (Hillman, 2013). The needs of informal carers and families must also be addressed. Support from neurorehabilitation and palliative care services becomes increasingly important as disease progresses and the care of people with increasing disability should be coordinated by an MS specialist nurse or a therapist with specialist expertise in MS (Croft et al, 2016).

**Implications for nursing care**
There is much that non-specialist nurses and health professionals can do to support people with MS and their families.
Although it is a complex condition and meeting people’s needs can be challenging, there is a great deal of excellent information available online, both for patients and professionals (for example, on the MS Trust and MS Society websites). All patients should be in contact with an MS nurse and/or neurologist, who should also be the first point of contact for health professionals needing advice. Local services can be identified using the MS Trust map of services (Bit.ly/MSTrustServiceMap).

It is important to remember that symptoms and symptom intensity vary between patients and for the same individual, from day to day and even hour to hour. In addition to understanding the problems MS can cause and appreciating its impact on people’s quality of life, nurses should be aware of the issues described below.

**Infection**

Infection can cause an acute deterioration in symptoms and decline in wellbeing; it tends to exacerbate other symptoms and may mimic relapse. Urine infections are particularly common in people with MS, typically as a result of bladder dysfunction. Infection should be considered as a possibility in patients experiencing an acute deterioration in their symptoms, and treated promptly if diagnosed.

**Fatigue**

Fatigue can be overwhelming and it negatively affects cognitive function as well as physical ability. The extent of fatigue will vary over time for the same person, which means that what they are able to do will vary too – a patient may be able to dress independently one day but not the next. Support needs should thus be assessed just before delivery and not based solely on a baseline assessment that may relate to the patient’s ability days or weeks earlier.

**Effect of heat**

Heat can cause a temporary worsening of symptoms. This is known as Uhthoff’s syndrome (Rae-Grant, 2013). Typically, heat exacerbates weakness and increases fatigue. Encouraging patients to cool down – with a cold drink, a fan or cooler clothing – can be helpful.

**Cognitive dysfunction**

Over half of patients with MS experience some form of cognitive dysfunction (das Nair et al, 2016) at some stage. This often presents as poor short-term memory and difficulties with problem-solving, decision-making and concentration. When discussing treatment options, it may be necessary to repeat information and allow plenty of time for questions. It is also good practice to back up any discussion with written information that patients can refer to and share with their family. Patients experiencing cognitive dysfunction often find it more difficult to remember appointments or medication: suggesting simple strategies, such as setting up mobile phone alerts, can help them.

**Summary**

MS can affect anyone, although it is more likely to be diagnosed in young women. It is characterised by increasing disability over time and associated with a decline in quality of life. However, there is much that can be done to mitigate its impact, such as prescribing DMD therapy in active disease and using a holistic approach to symptom management throughout the disease.

Nurses and other health and social care professionals caring for people with MS should be aware of its signs and symptoms and of their variability over time, both between people and within one individual. Care should be provided by an integrated MDT and underpinned by a personalised care plan. All patients should be in contact with an MS nurse and/or neurologist, who should also be the first point of contact for health professionals needing advice.

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