

Second edition
December 2009

A guide to MS

for GPs and primary care professionals

About this guide

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This guide is intended as a resource for GPs who plan to deliver the nGMS enhanced service for MS, and for the growing number of GPs with Special Interest (GPwSI) in MS as well as those primary care practitioners who may see only the occasional patient with MS.

The [resources](#) at www.mssociety.org.uk/professionals accompanying this guide include Read codes, toolkit and templates for use by GPs planning to take up the national enhanced service. Designed by primary care practitioners, they provide practical resources to help assessment and review of patients with MS.

The information here primarily reflects the legislative situation in England, though in many cases the situation will be similar in Wales, Scotland and Northern Ireland.

For queries specific to Wales, Scotland and Northern Ireland, contact our national offices, listed below:

MS National Centre (UK)
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www.mssociety.org.uk

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MS Society Northern Ireland
The Resource Centre
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Telephone 028 9080 2802
info@mssocietyni.co.uk
www.mssocietyni.co.uk

MS Society Cymru
Temple Court
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Cardiff CF11 9HA
Telephone 029 2078 6676
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www.mssociety.org.uk/wales

About the MS Society

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Multiple sclerosis (MS) is the most common disabling neurological disorder affecting young adults, and around 100,000 people in the UK have MS.

The MS Society is the UK's largest charity dedicated to supporting everyone whose life is affected by MS – personally or professionally. The MS Society works with health and social care professionals to improve services by:

- promoting good practice in MS treatment and care
- publishing newsletters, reports and educational materials
- organising networking opportunities and events
- funding health and social care posts in community, rehabilitation, primary and acute care settings, and in palliative care
- funding research into the cause, cure, and management of MS, as well as development of services, with an overall research commitment of £21m

The **MS Professional Network** has over 3,000 health and social care members, all with a common interest in improving services for people affected by MS. Membership is free and includes newsletters, conferences and learning events. To join, go to www.mssociety.org.uk/profs or call 020 8438 0810

National MS Helpline Freephone 0808 800 8000
helpline@mssociety.org.uk
www.mssociety.org.uk

The Multiple Sclerosis Society of Great Britain and Northern Ireland is a charity registered in England and Wales (207495) and Scotland (SC016433)

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1 MS, primary care and the MS Society

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The care of people affected by multiple sclerosis (MS) is higher on the primary care agenda than ever before. Policy developments – from the NICE *Clinical Guideline 8: Multiple sclerosis. Management of multiple sclerosis in primary and secondary care*¹ to the *National Service Framework for Long-term Conditions*² * – emphasise the important role played by primary care professionals in the lives of people with MS, their family and carers. Since 2004, MS has been included in the GMS contract as a [national enhanced service](#).

The National Service Framework (NSF) sets out 11 quality requirements which put the individual at the centre of care and aim to provide a service that is “efficient, supportive and appropriate at every stage from diagnosis to end of life.” It sees general practice as a key role in delivering high quality services along the entire care pathway.

People with MS consistently rate their GP as an important source of helpful information. A 2001 study³ reported a strong rating for the GP, with 87 per cent regarding contact with their GP as helpful. The GP was also found to be the professional with whom people with MS had most contact. This was confirmed in the more recent evaluation of the MS Society’s Nurse Fund Programme,⁴ which found that GPs were perceived to make a helpful contribution to the care of people with MS, with 72 per cent of people with MS reporting that they had seen their GP once or more in the last three months.

People with MS benefit from a holistic approach to care, with access to a wide range of professionals. The primary care team is therefore well placed to facilitate care across the entire care pathway.

Acknowledging the importance of primary care in the lives of people with MS, the MS Society has joined with other neurological organisations to form the Primary Care Neurology Society (www.p-cns.org.uk). Launched in 2005, this network organisation will offer information on new developments in clinical management and care across a range of neurological conditions.

*Note: The NICE Clinical Guideline 8 applies to England and Wales, and the NSF applies to England only. The [Self-management Strategy for Long Term Conditions in Scotland](#) (www.ltcas.org.uk) is a driver for change north of the border.

MS Society services and support

The MS Society is the UK's leading source of support and information for people living with MS. It is a membership organisation with more than 42,000 members, more than two thirds of whom have MS. This membership means the Society is the definitive voice of people living with MS in the UK.

The Society is the first port of call for support and information for most people with MS in the UK, whether via its website www.mssociety.org.uk and online community, its 300 plus local branches, or the free MS Helpline on 0808 800 8000.

The Society provides a range of services to all people affected by MS, not just to members. These services include a wide variety of publications for [people with MS](#), [carers](#) and [professionals](#); an [information service](#); a [specialist helpline](#); [financial grants](#); [support to access respite care](#); education and training events and local area teams.

The Society is committed to bringing high standards of quality health and social care within reach of everyone affected by MS and to promoting research into its cause and control. In 2008 alone, the MS Society committed £7.8 million pounds to different aspects of MS research, including searching for the cause and cure, symptom management and quality of life. Through partnership funding, the Society has also supported the appointment of more than 180 specialist practitioners in community, rehabilitation, primary and acute care settings, and in palliative care. The MS Society is the only charity in the UK funding this range of MS specialist practitioners.

The MS Society's vision is:

“To enable everyone affected by MS to live life to their full potential and secure the care and support they need, until we ultimately find a cure.”

The Society has a network of volunteer-run branches and regions across the UK, a National Centre in London and national offices in Northern Ireland, Scotland and Wales. Within each region in England, teams of service development staff and volunteers provide a range of support to branches.

Audit tool – *Measuring Success*

The MS Society has a proven audit tool called [Measuring Success](#) which allows PCTs, NHS Trusts, Commissioners and providers of rehabilitation to assess how they are complying with the NICE guidelines and the NSF. The tool was developed with input from

service users and has been used since 2004 successfully with many PCTs and NHS Trusts across England and Wales.

The tool can be supported by the MS Society via the provision of focus groups of service users to supplement and confirm or refute the finding of the self-assessment audit, and assist in the gap analysis and action planning for service improvement and development. Get the tool, free of charge from www.mssociety.org.uk/professionals. Support can be negotiated through your local MS Society Service Development Officer.

For more about MS Society support for primary care teams, visit www.mssociety.org.uk/professionals

MS Professional Network

The Society's MS Professional Network is a group of more than 3,000 multi-disciplinary professionals interested in improving local health and social care provision. Membership is free, and members gain access to local and national events, and receive a regular newsletter and an invitation to the annual conference. To find out more, to join, and to let us know what you need, go to www.mssociety.org.uk/profs or call 020 8438 0810.

2 The facts about MS

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- The pathophysiology of MS
- Symptoms
- Types of MS

MS is the most common disabling neurological disorder among young people, affecting around 100,000 people in the UK. Most commonly diagnosed between the ages of 20 and 40, the condition can affect people older and younger although only two to six per cent of patients show signs of MS [before the age of 16](#). Recent studies have suggested that the incidence and prevalence of MS may be increasing in many countries. However this is often attributed to better diagnostic tools and epidemiology. Studies from several countries including Canada⁵, Australia⁶, the USA⁷, and Japan⁸ have shown the female to male sex ratio of MS appears to be increasing, with a higher incidence of MS in women. The reason for these changes is unknown, though it is speculated that the rapid change must be due to environmental factors, even if it is associated with gene/ environment interaction. The age of onset tends to be a year or two later in men than in women. Men tend to present later and have greater disability.

Once present, the disease never goes: there is no cure and the person lives with the diagnosis for life. One of the hallmarks of MS is that it follows an uncertain and unpredictable course from person to person and even within the same individual over time.

The pathophysiology of MS

The MS Society has produced [Helping you explain MS](#), a visual aid on this topic, available at www.mssociety.org.uk/professionals

MS is an inflammatory demyelinating condition involving the immune system. When MS is active, activated T-cells cross the blood-brain barrier, setting up inflammation and causing demyelination. As a result, the transmission of messages along affected axons becomes distorted. Inflammation dies down in the plaque and healing mechanisms follow, forming a scar – gliosis. These resulting areas of damage – lesions or plaques – show up as white spots on MRI scans. A relapse is defined as the appearance of new neurological symptoms or the recurrence of old symptoms, lasting for more than 24 hours, in the absence of fever or infection.

As well as targeting myelin (and the oligodendrocytes which make myelin), the acute inflammatory process can damage axons and their cells, the neuron. Axonal and neuronal loss can be seen on MRI as black holes, even at the earliest stages of the disease.⁹

Later stages of the disease process are characterised by less inflammation and greater degeneration of neurones, causing progressive cerebral atrophy (which can be measured by MRI). This is probably the cause of the progressive accumulation of disability in MS.¹⁰

The type and number of symptoms experienced during a relapse vary from one individual to the next, depending on where in the CNS the myelin and axonal damage occurs. However, not all plaques result in functional deficit: those that do not are known as silent plaques.

Recovery occurs as inflammation dies down, the brain reorganises the traffic of impulses through unaffected pathways and remyelination occurs. Symptoms may improve or disappear. However, the new myelin is much thinner and may slow the conduction of nerve impulses.

Remyelination tends to occur only in the early stages of MS where the oligodendrocytes remain healthy enough to repair myelin damage. If the nerve fibre dies, repair cannot occur and this, as well as persistent demyelination, results in the permanent symptoms in MS. The brain can accommodate a certain amount of axon loss and demyelination without loss of function. But once a critical threshold of permanent structural damage is reached, deficits become persistent.

Most people with MS start with relapses and remission, but move in time to a phase of slowly progressive disability, with or without relapses (secondary progressive). It used to be thought that this phase simply represented the accumulation of relapses. Now, however, it is generally accepted that progression is due to the slow death of neurones in a process that does not depend upon inflammation but is more akin to the neurodegeneration of Alzheimer's or Parkinson's disease. Hence the lack of efficacy of anti-inflammatory drugs in the progressive phases of MS.

Symptoms

Primary symptoms appear as a result of demyelination or neuronal damage within the brain and spinal cord. They include weakness, fatigue, numbness, tingling, depression, bladder, bowel and sexual dysfunction, visual problems, pain, cognitive deficits and ataxia.

Secondary symptoms can arise at any time, and are similar to those of many neurologically disabling diseases: contractures, urinary tract infections, osteoporosis, muscle atrophy and skin breakdown.

Tertiary symptoms arise from the loss of mobility, income, status and social life with increasing disability. These include social isolation and depression.

Factors most commonly associated with a good prognosis include female gender, sensory symptoms at onset, optic neuritis at onset, mild disability five years from onset, and long intervals between attacks. Factors having a worse prognosis include male gender, pyramidal or cerebellar signs at onset, multi-symptom onset, frequent attacks in the first two years and moderate to severe impairment five years from onset.¹¹ However, although true epidemiologically, these associations are not sufficiently strong to be used to counsel patients.

The life expectancy of someone with MS is reduced on average by around 10 years compared to the general population.¹² Death only rarely occurs directly as a result of MS (through a brainstem relapse compromising respiration for instance, which occurs less than once a year in the UK). However, as with other disabling conditions, skin, urinary and chest infections can take their toll on those very severely affected.

To the person recently diagnosed, perhaps more significant than death is the frightening prospect of many years with significant disability.

Patient information

[What is MS?](#)

Types of MS

Relapsing remitting MS is characterised by clearly defined disease relapses with partial or full recovery, and periods between relapses characterised by a lack of disease progression. It affects around 85 per cent of people at the outset. On average, relapses (varying from mild to severe) last for about four to six weeks and occur slightly less than once a year. At their worst, acute relapses may require hospital treatment.

Secondary progressive MS follows on from relapsing remitting MS when people experience gradually more or worsening symptoms. To confirm that someone has moved from relapsing remitting to secondary progressive MS, there has to be clear evidence of sustained deterioration for at least six months which is completely independent of the effect of relapses. Typically, 65 per cent of people with relapsing remitting MS will have developed secondary progressive MS after 15 years.

Primary progressive MS is characterised by a slow progression of disability from the outset, without any relapses or remissions. Commonly, it is diagnosed later than relapsing remitting MS, and affects men and women equally. Problems tend to occur in one main area, and often relate to walking. The likely explanation is that the

*lesions are more apparent in the spinal cord than the brain, which also means that bowel, bladder and sexual function may be involved. People with this form of MS are less likely to experience severe cognitive problems. Primary progressive MS occurs in 10 per cent to 15 per cent of people diagnosed with MS.*¹³

‘Benign’ MS is a term that can only be used with confidence in retrospect – and is an area of potential misunderstanding. If, after 10 to 20 years, a person’s MS has not worsened and they have very little or no disability, they might then be said to have ‘benign’ MS. Perhaps 10 to 30 per cent of people with MS fit this rather broad description and have had many years without major disability. But there are inherent dangers in using the word ‘benign’. Rarely, if ever, is MS completely problem free as the word might suggest; and a relapse can occur after many years of inactive disease. In addition, it’s still difficult to predict future MS symptoms, by looking at current ones.

Malignant MS, (also know as ***Marburg's disease*** or ***acute MS***) is a rare form of MS. It has a rapidly progressing course, leading to severe disability or death within a year.

Patient information

What is relapsing remitting MS?

What is secondary progressive MS?

What is primary progressive MS?

3 Patients' frequently asked questions

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Can MS be treated?

While there is no cure for MS, much can be done to help. There are three approaches to managing the condition:

- Disease modifying drugs which can reduce the number and severity of relapses in some people. If given early, they *may* reduce the rate at which people accumulate disability.
- Symptom management – various treatments to help reduce MS symptoms such as spasticity, bladder problems, pain and fatigue. These can have a major impact on improving people's quality of life.
- Relapse management – when someone with MS presents with an acute episode of symptomatic deterioration in the absence of infection, treatment with a short course of high-dose steroids may help to resolve the symptoms more quickly.¹⁴ The importance of ongoing support, intervention from other members of the multi-disciplinary team and the provision of equipment and adaptations, if required, cannot be overstated.
- In the near future, there may also be trials of drugs to promote repair of previously damaged areas.

Will MS affect my life span?

The life expectancy of someone with MS is reduced on average by around 10 years compared to the general population.¹² Death only rarely occurs directly as a result of MS but over a typical 30 to 40 year course of the disease, the accumulation of disability can become significant. In some cases, people who are immobile late in their illness may acquire infections that can be fatal. Although we have no clear explanation, there is evidence to show that the rate of suicide is higher among people with MS than the general population (some estimate by as much as seven times). This could be because depression is a common though often undetected symptom – a factor which all health professionals working with people with MS should be aware of and which GPs are particularly well-placed to detect and treat.

Will I have to use a wheelchair?

The belief that MS is a progressive disease that inevitably leads to a wheelchair does not fit the experience of the majority of people with the condition. A minority of people with MS become disabled to the extent that they need a wheelchair, and it can take many years for them to reach this stage. The wheelchair should be regarded as a tool that

makes mobility easier and enables the individual to participate in activities from which they might otherwise be excluded.

Is it safe to get pregnant?

MS does not affect a woman's fertility. Women attempting to become pregnant are advised to discuss this with their neurologist: it is also important to discuss any medication they may be taking with their neurologist and GP, as potential risks versus the benefits need to be assessed before conception.

Anyone taking the disease modifying therapies should be advised to stop before conception since the risks to the growing foetus are not known. MS symptoms usually stabilise or improve during pregnancy. There is also some evidence that relapses occur more commonly in the first three months following delivery, so it can help if women make prior provision for more rest and assistance during this time. But overall, the relapse rate is unchanged by pregnancy.

Can I still drive?

The vast majority of people with MS are able to continue driving. However, drivers are legally obliged to inform the Driver & Vehicle Licensing Agency ([DVLA](#)) and their motor insurance company of their diagnosis. GPs are also obliged to tell the DVLA if they think their patient has not done so. The DVLA sends the person Form PK1 (Application for Driving Licence /Notification of Driving Licence Holder's State of Health) to complete and return, and will usually write to the GP. Even where a person is able to drive, it is common for a one, two or three year licence to be granted for someone with MS, as it is with other variable conditions.

If there are concerns about an individual's ability to drive, the DVLA may refer them for an assessment of driving skills – judgement, decision making and problem solving – as well as a test drive. People can also refer themselves if they are concerned about their ability to drive. The DVLA can then recommend specific adaptations to cars and record this on the licence or issue a short period licence or, in cases where symptoms are severe, withdraw the licence. If there are no medical problems affecting their ability to drive, the DVLA will write back and confirm their licence.

It can be helpful to use an insurance company that specialises in covering drivers with disabilities (such a list is available from www.radar.org.uk).

People receiving the higher rate mobility component of Disability Living Allowance can claim exemption from vehicle excise duty (road tax) on one vehicle and access the [Motability scheme](#), which offers new and good used cars through hire purchase or allows people to hire cars

through the scheme. The [Forum of Mobility Centres](#) offers practical advice on driving, vehicle adaptation and suitable vehicle types for disabled drivers and passengers.

People with MS who are still driving have an obligation to notify the DVLA if their condition significantly deteriorates – if there are ‘significant or persisting changes’ in their condition.

Patient information on vehicle adaptations

[Motoring with MS](#)

Are my children at risk from MS?

Although the cause of MS is not completely understood, researchers believe that people can have a genetic predisposition to the condition. The approximate risk of developing MS for the general population is around 1:600 although this figure varies depending on geographical location (in Scotland, the figure is around 1:500). The risk of developing MS is increased to around 1:50 for children where one parent has MS, and about 1:33 for those with a brother or sister who has MS. This means that for a patient with MS, the risk of children developing the condition is greater than the general population but still very low. People should be reassured that while MS can occur more than once in a family, it is much more likely it will not happen.

When MS does run in families, people frequently ask whether the course and severity of the condition are predictable. Studies looking for genetic similarities in families where MS is present in several family members have shown that there is very little similarity in the type of MS¹⁵ (which has prompted the idea that there may be two types of genetic factors at work: one group that predisposes a person to develop MS and another set that determines the ultimate course of the disease).

Patient information

[Women’s health – pregnancy, menstruation, contraception and menopause](#)

[Living with the effects of MS](#)

[Annie and Dan talk about MS](#) – a film for children under ten who have a parent with MS

Will I need to give up my job?

Since December 2005, everybody diagnosed with MS is covered by the [Disability Discrimination Act](#) (DDA) from the point of diagnosis. The DDA prohibits unlawful discrimination in all aspects of employment – in

recruitment, selection, training, promotion, redundancy and dismissal – and places a duty on employers to make reasonable adjustments to the workplace or working arrangements to enable someone to continue working.

Although there is no legal requirement to disclose MS to the employer*, people are best advised to disclose their condition if they want to take advantage of the law. A key provision of the DDA is that employers are expected to consider reasonable adjustments where they will facilitate employment.

*There are exceptions. For example, where health and safety necessitates disclosure, or for combat roles in the armed forces.

Reasonable adjustments include:

- adjustments to working hours or work objectives
- enabling an employee to take more regular breaks
- moving the work station away from a source of heat or nearer a lavatory
- designating a car park space near the work entrance to minimise walking
- providing handrails, a ramp or specialised equipment such as an adapted computer screen or keyboard, voice-recognition software or special seating

The Government's [Access to Work scheme](#) can help with such adjustments and with grants for physical adaptations to the building. The scheme is accessed through Disability Employment Advisers at local Jobcentre Plus offices.

Patient information

[Working with MS](#)

Will a general anaesthetic affect my MS?

There have been a small number of studies investigating the effects of anaesthesia in people with MS. The results have been inconclusive, but there does not appear to be any established link between being given an anaesthetic and the worsening of MS symptoms. If surgery is required to tackle a medical condition, it is usually better to go ahead and have it, although it is important to talk through concerns with the surgeon or neurologist.

Should I have a flu jab or travel vaccination?

Many people with MS wish to avoid flu as there is evidence that having an increased body temperature associated with fevers can temporarily worsen MS symptoms, and that people are more likely to suffer a relapse after flu.¹⁶ There is no reason why people with MS should not receive a flu jab or most travel vaccinations. Evidence from a number of randomised controlled trials shows that people with MS are not at increased risk of MS exacerbations after having a flu vaccination.¹⁷

There is no indication that people receiving disease modifying drugs – beta interferon, glatiramer acetate or natalizumab – should not receive the flu vaccine. However, care is needed for people receiving immune suppressants such as azathioprine or mitoxantrone as these people may be immunosuppressed. The safety of administering live attenuated vaccines is unknown in this situation.

Will the menopause affect my MS?

Menopause appears to have no effect on MS symptoms, although there has been little research in this area.

Patient information

[Women's health – pregnancy, menstruation, contraception and menopause](#)

Can I carry an organ donor card if I have MS?

The Department of Health issued the new version of the [Microbiological Safety of Blood & Tissues for Transplantation \(MSBT\) Guidelines](#) in August 2000, which takes into account the risks of disease transmission to the recipient of an organ. The only absolute contraindications for donation are HIV and transmissible spongiform encephalopathies (CJD). MS falls into a group of “diseases of unknown aetiology” and the person’s suitability is decided by medical teams when they are identified as a potential donor.

Can I give blood?

The National Blood Service’s donor selection guidelines currently state that people with MS cannot give blood.

It may be worth noting that in April 2008 the American Red Cross lifted the ban for people with MS in the USA allowing them to become blood donors.

4 Answering the “Why me?” question

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- Patient information and support
- Genetics
- Environmental factors

Patient information and support

The [MS Society MS Helpline](#) offers confidential emotional support and information to anyone affected by MS (including family, friends and carers). Information is available in over 150 languages via an interpreter. Call freephone 0808 800 8000 (weekdays 9am-9pm) or email helpline@mssociety.org.uk

Two MS Society booklets in particular might be helpful:

[*Just diagnosed – an introduction to MS*](#)

[*Living with the effects of MS*](#)

As with all complex conditions, people with MS want to know what has made them susceptible to the disease. It can therefore be helpful for GPs and others working in primary care to understand the current theories of causation. While the precise cause remains uncertain, research suggests that a combination of genetic and environmental factors may play a role.

Genetics

MS is not directly inherited and, unlike some conditions, there is no single gene that causes it. It is possible that a combination of genes make some people more susceptible to developing the condition; however, these genes are also common in the general population.¹⁸

There is no genetic test for MS. Because there is no single gene which causes it, knowing whether a particular gene had been inherited would not be informative. It is thought there may be between 50 and 100 genes which contribute to MS and, while these genes are also found in the general population, they can contribute to the likelihood that someone might develop MS.

The approximate risk of developing MS for the general population is around 1:600 although this figure varies depending on geographical location (in Scotland the figure is around 1:500). The risk of developing MS is increased to around 1:50 for children where one parent has MS.

About 20 twin studies have shown that if one twin has MS there is around a 30 per cent chance that an identical twin will also be affected, but only a 4 per cent chance that a non-identical twin will be affected.

The fact that identical twins are not always “concordant” for MS clearly indicates that other non-genetic factors contribute to determining susceptibility.

Environmental factors

Studies indicate that the environment has a significant influence on the development of MS. It is more common in areas further away from the equator and virtually unheard of in places like Malaysia and Ecuador but relatively common in Britain, North America, Canada and Scandinavia.¹⁹ It is not clear why, but it is possible that something in the environment, perhaps bacteria or a virus, plays a role. No single virus has been identified as contributing to MS but some researchers think that a common childhood virus may act as a trigger.²⁰ Migration studies indicate that exposure to environmental factors in early adolescence is associated with development of MS. Individuals who migrate from one area of the globe to another at some stage before adolescence are essentially exposed to a level of risk of developing MS equivalent to that of the area to which they migrate. In contrast, those who migrate after adolescence carry the risk of the area they migrated from.²¹

In the last two decades, nearly 20 infectious agents have been proposed in MS, with prime suspects including Epstein-Barr virus, HHV-6, herpes viruses 1 and 2, varicella zoster virus, measles virus, and several retroviruses, including Multiple Sclerosis Associated Retrovirus (MSRV) and chlamydia. To date, no infectious agent has been isolated consistently from MS tissue and research continues. Many people who do not have MS would have also been exposed to these viruses, and the combination of genotype and exposure to an as yet uncertain environmental factor is likely to be key in determining who develops MS.

Two factors which have been recognised as potentially accounting for the link between geography and incidence of MS are sunlight exposure and vitamin D status.

Some studies suggest that high levels of vitamin D decrease the risk of MS.^{22, 23} It is thought exposure to sunlight might bring about protection against autoimmune diseases such as MS by any number of immunosuppressive mechanisms such as vitamin D production. One recent study involved examining the history of sun exposure in 70 pairs of identical twins in which one twin had MS while the other did not. A connection between a lack of sun exposure and development of MS was proposed.²⁴

A study published in 2009 showed that conditions in the environment may influence how genes behave which could in turn impact on the risk of developing MS.²⁵

In conclusion, there is no straightforward answer to the question: “Why me?” but people should be reassured that there is nothing we know of that they or anyone else could have done, or not done, that would have altered the outcome; and the focus should be on helping them and their families to live with MS.

Patient information

[Information about vitamin D](http://www.mssociety.org.uk) from www.mssociety.org.uk

5 The diagnosis

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- Symptoms
- Referral to a neurologist
- Primary progressive MS
- Uhthoff's phenomenon
- Supporting the person with MS
- Additional tests
- A note about optic neuritis

The incidence of MS is low, at about three to seven per 100,000 population.¹ So, over the course of a full-time career, the average GP is likely to be involved in five patients being diagnosed with MS. Depending upon their index of suspicion, the average GP may have referred the same number again with symptoms suggestive of MS that turn out to be due to other causes. Since everyone with MS experiences the disease differently, it is difficult for GPs to build up any sort of expertise in diagnosing the symptoms.

Symptoms

While neurologists are usually responsible for making the diagnosis, the GP is the first to see anyone with 'vague' neurological symptoms, and has the difficult task of identifying who needs referring for investigations. The peculiar nature of MS complicates the diagnostic process. MS presents in many different ways depending on the site of plaque formation in the CNS. Symptoms vary in severity and can be transitory in nature. Such elusive symptoms indicate any number of potential diagnoses. MS symptoms are often so nebulous that patients themselves may attribute their symptoms to stress, or perhaps a trapped nerve, and delay going to their GP until the symptom becomes more troublesome.

Nonetheless, GPs should suspect MS in any young adult with symptoms such as:

- double or blurred vision
- poor balance and coordination
- muscle weakness (often in legs)
- stiffness or spasticity in muscles
- altered sensation (numbness, tingling or a burning feeling)
- slurred speech
- fatigue inappropriate to activity
- bladder and bowel problems
- impotence
- forgetfulness and poor concentration

It is unusual, but possible, to make the diagnosis of MS in children, or in adults over the age of 50. Should the GP mention the possible diagnosis to the patient before referral?

This is a test of pastoral skills, common to many other conditions. No firm recommendations can be made. NICE says an individual should be informed “as soon as a diagnosis of MS is considered reasonably likely, unless there are overwhelming patient-centred reasons for not doing so.”¹ Just over half of people referred for investigation of MS turn out not to have the disease.

So, if a GP systematically broaches the diagnosis early, unnecessary distress may be caused. Many GPs choose to talk in couched terms, about a suspicion of a neurological condition, and that they wish to get an expert view. NICE adds that throughout the process of investigating and making the diagnosis, the health care professional should find out what and how much information the patient wants to receive. And this should be reviewed on each occasion.

Immediately following diagnosis, those who already have documented evidence of two clinically significant relapses in the last two years, may be eligible for assessment for disease modifying drugs (see chapter 7). Others will need to wait for a further relapse to meet the criteria.

Referral to a neurologist

The difficulty in diagnosing MS is that no single specific diagnostic test is available, so diagnosis is made on the basis of:

- a history indicating the probability of disease
- neurological examination with findings consistent with MS
- positive paraclinical evidence from MRI scans and, occasionally, evoked potential tests

In cases where the diagnosis is difficult, it may be necessary to do a lumbar puncture.

NICE states that the diagnosis of MS should be made clinically by a doctor with specialist neurological experience, on the basis of evidence of CNS lesions separated in space and time, primarily on the basis of the history and examination.¹

The 2001 McDonald criteria for diagnosing MS²⁶ stress the importance of diagnosing MS on the basis of objective signs of the spread of lesions or plaques over time and space.

A 2005 revision of the McDonald criteria include, as evidence of dissemination in time, the appearance of a new T₂ non-enhancing

lesion any time after a reference scan that was carried out at least 30 days after the initial clinical event.²⁷ This revision to the criteria should allow an even earlier diagnosis of MS without any loss of diagnostic accuracy.

The McDonald criteria also simplify the diagnostic classification, with only three possible outcomes from a diagnostic evaluation: MS, possible MS or not MS. If a “possible MS” diagnosis is given, the person should be followed up at the neurology clinic. The GP and primary care team might be contacted to assess new symptoms and provide reassurance and support as required.

The incentive for making the diagnosis of MS earlier, by using these MRI criteria, is that earlier use of disease modifying drugs may have greater impact on the subsequent accumulation of disability.

Several clinical trials such as the BENEFIT, CHAMPS and ETOMS^{28, 29, 30} studies, looking at the disease modifying drug beta interferon, have shown that it delays progression from a single neurological event to confirmed MS. However, the actual benefits to patients appear to be marginal, and whether beta interferon delays disability in the long term is unclear.

Primary progressive MS

Primary progressive MS is particularly difficult to diagnose because people do not experience the characteristic relapses of MS. People with primary progressive MS also tend to be older, making brain MRI less valuable for diagnosis since, after the age of 50, vascular and age-related changes start to produce white-matter lesions. In addition, MRI scans of primary progressive MS are more difficult to interpret because there are fewer lesions on the brain: a lumbar puncture may be useful for diagnosis. Oligoclonal bands (IgG antibodies) are seen in the CSF of over 95 per cent of people with MS.

Uhthoff's phenomenon

There is one characteristic feature of MS that may alert professionals to the diagnosis: Uhthoff's phenomenon. This describes the situation where people get symptoms of neurological dysfunction when their body temperature is raised (with pyrexia, after a hot bath, after exercise or in a hot climate). This can only be seen in demyelinating conditions such as MS and is never seen in diseases where axons or neurons are lost.

After the diagnosis, according to the NICE guidelines, the individual should be:

- offered at least one more appointment in the near future to see, wherever possible, the doctor who gave the original diagnosis

- put in touch with an MS nurse or other professional with specialist knowledge of MS or other neurological conditions and counselling experience
- offered written information about [local](#) and [national](#) disease-specific support groups, including details of local rehabilitation services
- offered information about the disease, preferably in the form of an information pack, specific to the newly-diagnosed (a [Just diagnosed pack](#) is available from the MS Society)
- within six months of diagnosis, offered the opportunity to participate in an educational programme that covers all aspects of MS
MS nurses generally offer a comprehensive service to people newly-diagnosed with MS and will work with the primary health care team to ensure the above needs are met

Supporting the person with MS

As with many long-term conditions, diagnosis is a time of anxious waiting, with delayed test results an all too frequent complaint. Receiving a diagnosis can be helpful because it provides an explanation for puzzling neurological problems.

When a fuller explanation is provided at the time of diagnosis, studies have shown that patient satisfaction and outcomes are improved.³¹ The authors concluded that addressing people's concerns is likely to reduce distress and disability, and that providing continuity – seeing the same doctor on each visit – increases patient satisfaction and may also improve medical outcomes.

High levels of anxiety and distress are experienced in the period following diagnosis. One study showed that on average, eight months after diagnosis, 34 per cent of patients and 40 per cent of their partners had high levels of anxiety and 36 per cent of patients and 24 per cent of partners had significant levels of distress.³²

Such findings indicate careful monitoring is needed by primary health professionals to identify those who require further psychological support. Other key times of anxiety for people with MS are when their symptoms suddenly deteriorate. One US study found that uncertainty was a key factor in causing depression in people with MS, and that the worsening MS symptoms increased people's feelings of uncertainty.³³ The authors concluded that health professionals need to recognise these periods of uncertainty and proactively provide support.

Patient information

[Living with the effects of MS](#)

[Just diagnosed – an introduction to MS](#)

Additional tests

Magnetic resonance imaging (MRI) is a non-invasive technique using a strong magnetic field to visualise damage in the brain and spinal cord in MS. Many people find the experience claustrophobic and unpleasant and most do not expect the loud banging noises that accompany an MRI scan. MRI scans reflect differences in the water content of tissue; in MS the myelin lost from MS lesions is replaced by an increased water content that can be visualised on the scan. MRI can pinpoint the location and size of lesions and can be used to provide an objective measure of MS-related damage. MRI scans are abnormal in over 90 per cent of people with MS. Although very useful in making a diagnosis of MS, MRIs are not conclusive and scan results should always be viewed together with the history and clinical findings.

Evoked potentials (EP) are occasionally used as part of the diagnostic process. With visual evoked potentials, a stimulus is used to evaluate the rate of conduction along the optic nerve from the retina to the occipital cortex. Less often, brainstem and sensory evoked potentials may be used. Evoked potentials are typically delayed but may be attenuated, dispersed or blocked by areas of demyelination and axonal loss. Hence they can be used to detect 'clinically silent' lesions in afferent pathways, and contribute to a diagnosis of MS.

Lumbar punctures are not always necessary for a diagnosis of MS, but are often used in cases where the diagnosis is unclear. They can also help to rule out other conditions. A white blood cell count of 5-35 white blood cells per mm³ can be indicative of MS. If IgG has entered the CSF, this indicates that the blood brain barrier has been breached and oligoclonal bands will be present. Oligoclonal bands are found in the CSF of 95 per cent of people with MS and are highly indicative of MS.³⁴

A note about optic neuritis

Optic neuritis is the presenting symptom in about 20 per cent of patients with MS.³⁵

NICE states that every individual presenting with an acute decline in visual acuity, with or without associated pain, should be seen by an ophthalmologist for diagnosis. In the past, there has been a reluctance to discuss the link between optic neuritis and MS because of the anxiety this may cause and the fact that many people will not develop MS. However, a diagnosis of optic neuritis can affect insurance policy applications and many people have only discovered that they are at risk of developing MS when they have had an insurance application refused. NICE guidelines state that if the diagnosis of optic neuritis is confirmed, without any other specific cause, the ophthalmologist should discuss the potential diagnosis with the individual and refer them to a neurologist for additional assessment.

Data obtained from the Optic Neuritis Study Group (2003)³⁶ shows that the risk of developing MS within 10 years of an episode of optic neuritis is significantly higher in people who have one or more lesions on brain MRI. Ten year risk of MS if no lesions on brain MRI was 22 per cent; if one or more lesion was present, risk was 56 per cent. However, it should be noted that even if lesions are present on brain MRI, over 40 per cent of people will not develop MS within 10 years.

6 NICE guideline for MS

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NICE (2003) *Clinical Guideline 8: Management of multiple sclerosis in primary and secondary care*¹ provides a benchmark for good professional practice and gives people affected by MS a clear idea of what to expect. Its overriding aim is to enable people affected by MS to have faster and easier access to services. It lists six key priorities for implementation and offers recommended treatments for symptoms and relapse management.

Professionals may wish to consider their own practice against the NICE guidelines, perhaps considering the following:

- agreeing the most appropriate referral points and pathways into each service
- models of care that reduce the wait from referral to being seen in a specialist neurology clinic or being seen again once investigations are complete
- development of shared protocols for liaison between services to ensure a shared approach to symptom management
- protocols that might be developed to ensure seamless services for people with MS
- improved support for patient self-management
- complaints or feedback that reflect a lack of responsiveness, and remedies to deal with this

Six key priorities

NICE (2003) *Clinical Guideline 8: Management of multiple sclerosis in primary and secondary care* identifies six key priorities:

Specialised services

Specialist neurological and neurological rehabilitation services should be available to everyone with MS when they need them. This is usually when they develop any new symptom, sign, limitation on activities or other problem.

Rapid diagnosis

People suspected of having MS should be seen promptly by a specialist neurology service and seen rapidly within an audited time.

Seamless services

All organisations in a local health area should set up effective ways to share and transfer responsibility for, and information about, people with MS to ensure a seamless service from the individual's perspective.

Responsive services

People with MS should be involved actively in all decisions and actions to do with their care. Services should recognise and respond to the varying and unique needs and expectations of each person with MS.

Thorough assessment

Health professionals should consider in a systematic way whether any “hidden” difficulties such as fatigue, depression, cognitive impairment, impaired sexual function or reduced bladder control might be contributing to their clinical situation.

Self-referral

People with MS should be informed how to make contact with their specialist neurological or neurological rehabilitation services when they are no longer under treatment or review.

7 Current drug therapies

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- Steroids
- Disease modifying drugs
 - Risk sharing scheme
 - ABN guidance for starting and stopping beta interferon and glatiramer acetate
 - Beta interferon
 - Glatiramer acetate
 - Natalizumab (Tysabri)

Steroids

MS relapses are treated with corticosteroids which have been shown to shorten the duration and severity of the relapse and accelerate recovery, although the overall degree of recovery is not improved and the long-term course of the disease is not altered.³⁷

Putative mechanisms for symptomatic recovery resulting from corticosteroid use include resolution of oedema, an effect on the permeability of the blood-brain barrier, and alterations in immunological abnormalities (systemic and within the CNS) that underlie the inflammatory process.³⁸

NICE says that individuals experiencing acute episodes (including optic neuritis) sufficient to cause distressing symptoms or an increased limitation of their activities should be offered a course of high-dose corticosteroids. The course should be started as soon as possible after onset of the relapse. NICE recommends this should be either:

- intravenous methylprednisolone, 500mg-1g daily, for three to five days (each infusion taking an hour or so)
or
- high dose oral methylprednisolone, 500mg-2g daily for three to five days (NICE, 2003¹)

Studies have shown no significant differences between oral or intravenous steroids in terms of outcomes such as reduction in disability.³⁹ The decision whether to prescribe oral or IV steroids should be made depending upon individual needs and on resources available locally.

Oral steroids can be prescribed by the GP and taken with minimal disruption to the individual's life. However, patients who present with more debilitating symptoms, or who may have particularly stressful home circumstances, may gain more benefit from intravenous steroids given in hospital. A hospital stay will also normally ensure that the patient can be reviewed by the multi-disciplinary team.

An alternative option, available in some areas, is a day case admission for three to five consecutive days to enable the patient to be given IV methylprednisolone and be reviewed by the MDT. Each of the locally available options should be discussed with the patient to determine the most appropriate option for their needs.

The MS nurse can be helpful in monitoring for any side effects during treatment and in evaluating the effectiveness of the steroids.

NICE states that frequent (more than three times a year) or prolonged (longer than three weeks) use of corticosteroids should be avoided. It is well recognised that treatment with steroids should not be prolonged, since complications of long-term treatment include side effects related to bone softening, aseptic necrosis of bone, cataracts, hypertension and adrenal insufficiency.

Patient information

[Managing a relapse](#)

[What is relapsing remitting MS?](#)

Disease modifying drugs

In people with relapsing remitting MS who experience relapses, there is evidence that beta interferon and glatiramer acetate impact on relapse rate and severity. In drawing up guidelines for their use, the Association of British Neurologists (ABN) considered that the different beta interferon and glatiramer acetate drugs each offer around a 33 per cent reduction in the number of relapses experienced over two years (compared to no treatment).⁴⁰

Beta interferon and glatiramer acetate are administered by self-injection. MS nurses attached to the centre where the drug is prescribed provide training and support to patients.

For certain groups of people with relapsing remitting multiple sclerosis, natalizumab (Tysabri) has now also been approved and has been shown to impact on relapse rate (around 67 per cent) and disability progression.^{41, 42} Tysabri is given once a month as an intravenous infusion over a one-hour period in a hospital or clinic setting. Observation for an hour is required following the infusion. See page 33 for more details about natalizumab.

Risk sharing scheme

Since 2002, when the Department of Health launched the risk sharing scheme, people with MS who meet the Association of British Neurologists' eligibility guidance (see below) may be prescribed beta interferon (Avonex, Betaferon, Extavia and Rebif) and glatiramer acetate (Copaxone).

The scheme does not cover the use of natalizumab, which has its own [NICE guideline](#) for use.

Under the risk sharing scheme for beta interferon and glatiramer acetate, around 5,500 patients are being monitored for 10 years, whether they remain on therapy or not, undergoing annual disability assessments using the Expanded Disability Status Scale (EDSS).⁴³ Some of the data is centrally collected and compared with what is known about the natural history of MS. Under the scheme, if the drugs are ultimately found to have long-term benefit for people with MS, the NHS will continue to pay the same price for them, but if the drugs do not perform as predicted, the price will be lowered (hence the 'risk share').

ABN guidance for starting and stopping beta interferon and glatiramer acetate

Guidelines drawn up by the Association of British Neurologists for the use of beta interferon and glatiramer acetate recommend that they should be offered to people who are ambulant (maximum EDSS 6.5) and have a diagnosis of relapsing MS established by the McDonald criteria. Eligible people will normally be 18 or older and fulfil the following criteria.^{40*}

* Note: recent studies suggest these drugs are safe in those under 18 years old.^{44, 45, 46}

Relapsing remitting MS:

At least two clinically significant relapses in the last two years.

The guidance also notes that there may be other circumstances under which a neurologist might consider prescribing. This includes for those under 18 years old and where only a single relapse has occurred in the previous two years but MRI evidence shows continuing disease activity.

Secondary progressive MS:

Treatment is not recommended in secondary progressive MS where there are no relapses. Treatment is only recommended in relapsing secondary progressive MS where relapses are the predominant cause of increasing disability.

Stopping treatment:

The ABN does not have mandatory stopping criteria that apply in all cases. But the ABN does recommend that the following features are among those that should be taken into account for stopping treatment with beta interferon and glatiramer acetate:

Development of an increased number and severity of relapses or lack of relapse reduction compared with 1-2 years pre-treatment, especially if MRI shows new or enhancing lesions. This might warrant consideration of a more powerful treatment option (such as natalizumab).

Development of non-relapsing secondary progressive MS with loss of ability to walk.

Other reasons for stopping treatment include intolerable side effects, planning pregnancy, or people not experiencing any benefit. Positive tests for neutralising antibodies to beta interferon strengthen the case for discontinuation when the above clinical or MRI features are present. However, these tests are currently not commonly administered. People can stop taking disease modifying drugs immediately without fear of resulting problems.

Patient information

[Disease modifying drugs](#)

The Department of Health funded website www.msdecisions.org.uk is designed to help patients decide which of the five drugs on the risk sharing scheme is best for them. This site also has details of side effects, travel and storage tips.

Beta interferon

Three types of interferon – gamma, beta and alpha – are natural components of the immune system and are especially important in anti-viral responses.

Gamma interferon causes an inflammatory response that increases the frequency of exacerbations or relapses⁴⁷ but alpha and beta interferon work to dampen down the immune response and lessen the inflammation that is responsible for damage.

The mechanism of action of beta interferon is not clear, but may include suppressing immune responses and the trafficking of lymphocytes across the blood-brain barrier into the brain.

When starting treatment, the most common side effects are flu-like symptoms and problems at the injection site.

Flu-like symptoms vary from mild with just a slight increase in fatigue to more severe with shivering, aches and general feelings of malaise. Symptoms normally occur within two to five hours of the injection, and usually wear off after a few hours. Analgesics such as paracetamol or

ibuprofen taken soon after the injection can minimise these effects, and many people find they can sleep through the worst of the symptoms if they have the injection at night. Many people find that the worst effects have subsided after two to three weeks and by four to six weeks have become much more manageable.³⁴

Occasionally, hardened red lumps form at the injection site, which becomes painful. Creams such as E45, witch hazel or mild steroid creams can help, and MS nurses should review the patient's technique and ensure that the injection site is rotated. Use of an auto-injector device can be helpful: these can be supplied by the MS nurse. Around 1 per cent to 2 per cent of people experience necrosis at a particular injection site and may need to temporarily suspend treatment until the site has healed. Antibiotics and regular dressings may be required.³⁴

There is an increasing amount of peer-review evidence suggesting that the appearance and persistence of neutralising antibodies (NABs) to beta interferon may reduce or negate the effectiveness of the drug. However, the clinical relevance of NABs remains a source of debate and the absence of a standard, readily available assay to measure NABs confuses the issue further. Prescribing neurologists will determine their approach to dealing with NABs locally.

Glatiramer acetate

Glatiramer acetate (Copaxone) is a synthetic compound that resembles one of the proteins found in myelin (myelin basic protein). The mechanism of action of glatiramer is not clear, but may involve interfering with the binding of autoreactive T-cells to brain targets, or inducing cells with regulatory properties in the immune repertoire.

Adverse effects of glatiramer acetate are usually mild and include local injection site reactions. Around 15 per cent of people experience a benign systemic reaction characterised by chest pains, palpitations or dyspnoea lasting up to 30 minutes. The reaction resolves spontaneously.³⁴

Natalizumab (Tysabri)

Natalizumab is licensed for use in the UK and has been approved by NICE for treatment for people with rapidly evolving, severe, relapsing remitting MS.⁴⁸

This is defined as two or more disabling relapses in one year and one or more gadolinium-enhancing lesion on MRI or a significant increase in T2 lesion load compared with previous MRI

People who are currently receiving treatment with natalizumab, but for whom treatment would not be recommended under the new guidelines

will have the option to continue therapy until they and their physicians consider it appropriate to stop.

It is not available in combination with beta interferon and people who have a history of immunosuppressive therapies may not be suitable for treatment with natalizumab.

Natalizumab works by preventing T-cells leaving the blood stream and entering areas of inflammation. Natalizumab is given once a month as an intravenous infusion.

Natalizumab can be associated with infections, headaches, dizziness, vomiting, nausea and infusion reactions. It has also been associated with an increased risk of progressive multifocal leucoencephalopathy (PML).

PML is a viral brain infection. It can cause severe neurological symptoms, which may at first be mistaken for MS relapses. But the symptoms rapidly worsen and may lead to death. Several people treated with natalizumab have died because of PML.

One large study suggests the chance of developing PML for someone using natalizumab for 18 months is around one in 1,000. This study looked at over 3,400 people taking natalizumab, but they did not all have MS. The long-term risk is not yet known. [49](#)

The relationship between developing PML and the duration of treatment with natalizumab is also not known. There is mandatory patient registration for people with MS who are prescribed natalizumab, including regular follow up checks to minimise the risk of developing PML.

8 Emerging therapies and agents under study

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- Oral therapies
- Cladribine
- Fingolimod
- Liquinimod
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- Statins
- Aimspro (goat serum)

Clinical Trials

GPs have a valuable role to play in informing people with MS about new clinical trials. Unfortunately, there are no specific, centralised resources in the UK to inform people about MS trials, making it difficult to find out what trials are currently recruiting or ongoing. All too often, people with MS have the frustrating experience of reading in the media about trials they would have been eligible to join, only to find they have missed out on the recruitment phase.

The MS Society recognises the benefits of having centralised information on disease-specific trials, mainly through the experience of clinical trial networks in cancer. Early discussion is underway to look at the potential for developing a UK MS Clinical Trial Network. Useful websites include:

www.clinicaltrials.gov
www.controlled-trials.com

The [latest MS clinical trial information](#) for patients and clinicians is available online at www.mssociety.org.uk

Mitoxantrone

Mitoxantrone (Novantrone) was licensed in the USA in 2000 for the treatment of aggressive relapsing remitting MS and progressive forms of the disease. It is not licensed in the UK or Europe. However, it is used as an “off-licence” treatment for MS in a few UK centres. Treatment needs to be carefully monitored due to the possibility of opportunistic infections, cardiotoxicity and haematological malignancies.

A summary of the data from mitoxantrone trials available on the MS Society website www.mssociety.org.uk suggests that people with relapsing MS can expect the frequency of relapses to be reduced by up to 80 per cent while undergoing treatment with mitoxantrone. Although this reduction is clearly greater than with beta interferon or glatiramer acetate, it should be remembered that the treatment involves a greater risk of side effects.

Currently licensed in the UK as an anti-cancer drug for the treatment of leukaemia and lymphoma, Mitoxantrone works in MS by suppressing the activity of the immune system.

Cannabinoids

Many people with MS have reported that using cannabis (illegally) has helped their MS symptoms. A study of 112 MS patients self-medicating with cannabis in the US and UK⁵⁰ found that 70 per cent of respondents reported improvements in the reduction of spasticity, muscle pain, tremor, depression, anxiety, tingling sensations, numbness, face pain, weight loss and weakness in the legs.

The use of cannabis-based drugs in clinical trials is complicated by its illegality and psychoactive properties, known to cause adverse reactions such as panic and anxiety attacks.

The largest study to assess the medicinal potential of cannabinoids was the Cannabinoids in Multiple Sclerosis Study (CAMS), designed to see if cannabinoids could reduce spasticity in 660 people with MS.⁵¹ In the double blind placebo-controlled trial participants were randomly assigned to oral capsules containing either tetrahydrocannabinol (THC) (an active compound found in cannabis) or a placebo, and treated for 15 weeks. Results were mixed. No overall change in spasticity was found in the treated group when assessed using the Ashworth scale. But in face-to-face interviews, two thirds of those taking cannabis reported a reduction in spasticity, as did almost half of those taking the placebo. The conclusion was that further research into cannabis-based MS treatments is needed using better independent assessments.

In addition to relieving symptoms, it is now thought that cannabinoids might exert an overall neuroprotective effect in MS. One study being carried out to test this theory is the CUPID trial which will evaluate whether THC might slow the development of disability in MS. CUPID stands for Cannabinoid Use in Progressive Inflammatory brain Disease. The trial began in 2006 with the researchers looking to recruit 500 people with progressive MS from across the UK. Recruitment is now complete and the study is due to complete in 2012. See www.pms.ac.uk/cnrg/cupid.php for more information.

Sativex

Sativex, a cannabis-based oromucosal spray for the relief of neuropathic pain, has been developed by GW Pharmaceuticals. In April 2005, Health Canada provisionally licensed Sativex as an adjunctive treatment for the symptomatic relief of neuropathic pain.

In November 2005, the Medicines and Healthcare Products Regulatory Agency agreed that Sativex may be imported from Canada for prescription to individual patients in the UK as an unlicensed medicine, on a named patient basis. Doctors wishing to prescribe Sativex should contact the Prescribing Adviser in their primary care organisation or the Home Office Drugs Branch on 020 7035 0474 or 020 7035 0467. GW are also able to provide information on the necessary procedure for ordering – enquiries@gwpharm.com

For [more on Sativex](#), including the latest on the licensing situation in the UK, see the 'A-Z of MS Research' at www.mssociety.org.uk

Alemtuzumab⁵²

Alemtuzumab (Campath-1H) is licensed in the UK for the treatment of chronic lymphocyte leukaemia. It is also an experimental drug treatment for MS (currently in Phase III trials and not generally available) as well as organ transplant rejection and several other types of leukaemia.

Alemtuzumab infusions work by specifically binding mature lymphocytes and targeting them to be destroyed by the immune system. Adverse events associated with the infusions are the development of autoimmune diseases such as Graves' disease or (less frequently) immune thrombocytopenia.

The phase II clinical trial of Campath-1H involved 334 patients with early active relapsing remitting MS split into three groups comparing Campath-1H (alemtuzumab) against a control group taking Rebif (beta interferon).

In the phase II study alemtuzumab gave at least 72 per cent reduction in the risk of relapse and at least 66 per cent reduction in the risk of progression of disability compared to Rebif (beta interferon 1a) treatment.

Oral therapies

Cladribine

Cladribine is an oral therapy traditionally used to treat cancers of the blood, but results of late-stage clinical trials show that it is also effective in treating relapsing remitting MS. The manufacturers have applied for a European licence and the drug may be available in 2010.

[More on cladribine](#)

Fingolimod

Trials of this emerging oral treatment have shown reductions in the frequency of relapses and a slowing of the underlying progression otherwise expected.

[More on fingolimod](#)

Laquinimod

A phase II clinical trial began in 2007 and is due to be completed in 2012. Published results so far have shown a reduction in the number of lesions showing on MRI compared to those taking placebo.

[More on laquinimod](#)

Lamotrigine

There is currently no safe, widely applicable treatment that has been effective for reducing the rate at which disability advances in secondary progressive MS. There is, however, an increasing body of evidence suggesting that the primary cause of disability in MS is axonal degeneration within the CNS. Considerable interest is therefore focused on developing treatments that can protect axons from degeneration.

Experimental work has established that axons may degenerate on exposure to the inflammatory mediator nitric oxide. The mechanism of the damage implies that protection might be afforded by partially blocking the sodium channels in axons through the use of sodium channel blockers (for example, with anti-epileptic drugs such as lamotrigine and phenytoin). In experimental models, both lamotrigine and phenytoin have proven to reduce axonal degeneration when optic or spinal nerve roots are exposed to nitric oxide.

With this background, a Phase II clinical trial is currently underway to assess whether the sodium channel blocker lamotrigine has a neuroprotective, disease-modifying effect on the rate of axonal degeneration, and the accumulation of disability in patients with secondary progressive MS. A successful outcome of this study (final

results expected in 2009) would enable Phase III trials to be implemented, but perhaps more significantly would demonstrate a novel, safe neuroprotective strategy to reduce long-term disability in secondary progressive MS.

[More on Lamotrigine](#)

Statins

Although best known for their cholesterol-lowering ability, statins may also play a beneficial role in MS. Laboratory studies suggest that several types of statins – including mevastatin, simvastatin and lovastatin – can inhibit the immune responses of cells taken from individuals with MS.⁵³ However, in these studies, statins also stimulated the release of some messenger proteins known to increase inflammation, leading to uncertainty about their ultimate value in MS.

A recent study of 30 people with MS given 80 milligrams of simvastatin (Zocor) daily for six months found they had a 44 per cent reduction in brain lesions compared to lesions measured before treatment.⁵⁴

[More on simvastatin](#)

Aimspro (goat serum)

This treatment uses the serum (the fluid portion of blood) of goats that have been inoculated with a variety of vaccines, to generate neutralising antibodies.

The strong anti-inflammatory component of the serum is thought by advocates to be 'potentially useful' in the treatment of MS.

Much anecdotal evidence seems to exist in support of a beneficial effect in MS but there is no research evidence or published information available to back up the anecdotal claims.

A controlled trial involving 80 participants all with Secondary Progressive MS was taking place at St George's Hospital in South London. This trial was halted early in 2005 and no further information about the trial has been made available.

A second controlled trial in Oxford, involving participants with optic neuritis has taken place. Neurologists stated that further evidence is needed after disappointing trial results.

A third trial is currently recruiting, with a focus on acute relapses in MS.

Aimspro is not licensed for use in the UK and is not widely available on the NHS.

[More on Aimspro](#)

9 Treating MS symptoms

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- Weakness and cardio-respiratory fitness
- Spasticity and spasms
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- Sensory loss
- Cognitive loss
- Depression
- Anxiety
- Emotionalism
- Swallowing difficulties
- Speech difficulties
- Sexual dysfunction
- Pressure ulcers

While neurologists are responsible for treating the underlying disease process, it often falls to the primary health care team to manage symptoms. GPs have a key role in recognising new MS symptoms as they develop and referring people to appropriate members of the multi-disciplinary team. Most GPs will be responsible for two to three people with MS at any time. Of these, one or two will have persistent symptoms that need attention.

Primary care professionals need to be aware of the hidden symptoms of MS. These can include cognitive dysfunction, depression or other mood changes, sexual dysfunction, pain, fatigue and bladder and bowel problems. Often, people with MS neglect to mention such symptoms, either because they are unaware of their relationship to MS or too embarrassed to talk about them. An essential component of every interaction with people with MS is to ask questions about any new or uncomfortable problems they may be experiencing. It is also important to appreciate the complex pattern of disability that can be created by the many symptoms of MS and that treatment of one symptom may worsen another. For example, anti-spasticity and antidepressant agents can exacerbate fatigue.

Fatigue

Fatigue, even within MS, is a broad term – and rarely has a uniform definition, either in research or clinical practice. However, despite this, it is possible to achieve a working understanding between clinician, patient and those around them – in order to recognise and manage the impact of fatigue for that individual.

Fatigue limits the lives of 85 per cent of people with MS,⁵⁵ and 50 per cent to 60 per cent of them consider it one of their most debilitating symptoms.⁵⁶ MS-related fatigue cannot be adequately explained by physical disability or by depression.

The first task of the professional is to explore exactly what the patient means by the term “fatigue”. The most common form of fatigue in MS is an overwhelming sense of physical weariness, which may come on suddenly, preventing further activity and demanding physical rest but not sleep. Motivation is not affected, so the person with MS experiences frustration. Such fatigue may occur as part of an MS relapse or be independent of any other symptoms. It can be the dominant symptom early in the course of the disease. Cognitive fatigue is similar: patients find they cannot sustain their normal level of concentration on a mental task for long, before their performance deteriorates and they need to rest. Less commonly, people with MS may have excessive daytime sleepiness, or a loss of motivation (as in depression).

Contributory factors are thought to include dysfunction of premotor, limbic, basal ganglia, or hypothalamic areas; disturbances of the neuroendocrine axis; and changes in serotonin pathways or other neurotransmitters.

Fatigue is a primary factor in the high unemployment rate among people with MS.⁵⁷ It significantly increases a person’s degree of impairment and disability and reduces their feelings of self-esteem and control over the illness.

NICE

Each professional in contact with a person with MS should consider whether fatigue presents a significant problem or is contributing to their current clinical state. If it is a problem:

- The nature of the fatigue needs to be explored.
- Explore potential contributing factors such as a poor sleeping pattern, nocturia, chronic pain, medication, depression, negative coping strategies.
- Consider referring to a physiotherapist, occupational therapist or MS nurse for a thorough, holistic assessment, education on energy conservation, and, if appropriate, suitable aids and equipment.

- Amantidine and modafinil are occasionally used, off licence, to treat fatigue but they offer only a very slight advantage over placebo.
- Depression in MS can be treated by conventional antidepressant therapies.
- Modafinil has a useful effect on, and is licensed to treat, excessive “daytime sleepiness associated with chronic pathological conditions” including MS.

Patient information

[Fatigue](#)

Bladder dysfunction

The two main types of bladder problems that occur in MS are storage and emptying dysfunction. With storage problems, spontaneous waves of detrusor muscle contraction occur irrespective of urine volume, causing urge-incontinence and increased frequency of micturition. Although contractions occur in response to small volumes, they are poorly sustained and often lead to incomplete bladder emptying. Problems with emptying also occur when, instead of bladder muscles being co-ordinated, the sphincter does not relax when the detrusor muscle contracts, interrupting the urine flow.

As well as creating secondary health problems, such as urinary tract infections, bladder symptoms in MS can result in social isolation, early retirement, difficulties with sexual activity and decreased self-esteem. It is estimated that as many as three quarters of people with MS experience bladder dysfunction.⁵⁸

NICE

Each professional in contact with a person with MS should consider whether the person with MS has problems controlling bladder function. If someone presents with bladder dysfunction:

- The possibility of a urine infection should be considered. UTIs in MS can have an adverse effect on both urinary symptoms and other MS symptoms, making it particularly important to treat any UTI.
- Post-micturition bladder volume should be measured. If the post-micturition residual bladder volume is under 100mls, then anticholinergic medications such as oxybutynin, tolterodine or detrusitol can be prescribed.*
- If the post-micturition residual bladder volume is greater than 100mls, referral to the continence advisory service and/or urology specialist nurse should be made for consideration of intermittent self-catheterisation.

* It is important to use these drugs with care in people with MS who are cognitively impaired, as there is a possibility of the onset of confusion or deterioration in memory.⁵⁹

- Nocturia may be treated by night-time desmopressin (100-400ug orally or 10-40ug intranasally), which reduces urine production. Desmopressin can also be used by people who need to control frequency during the day (eg when travelling) but it should never be used more than once in 24 hours.
- Anyone with MS who, despite treatment, has incontinence for more than a week should be referred to a specialist continence service for assessment and advice. Pads or a convene sheath should be offered as an intermediate solution.
- Anyone requiring long-term catheterisation should be referred to a urologist for consideration of a supra-pubic catheter.
- There is some evidence for the use of Botulinum toxin for urethral leakage of urine in a person with advanced MS who has a catheter in situ. There is also evidence to support the use of Botulinum toxin A injections into the detrusor muscle to treat neurogenic detrusor overactivity. This is currently out of licence use and agreement for its use will need to be obtained.⁵⁹

Urinary tract infections

Everyone with neurogenic bladder dysfunction is susceptible to urinary tract infections (UTIs), and those with indwelling catheters are especially vulnerable. UTIs pose a serious health threat and, if they result in sepsis, can lead to death, especially among individuals with advanced disease. Proactive involvement of the continence team is important.

NICE

If a person with MS experiences new urinary tract symptoms or develops general malaise or worsening of existing symptoms with a raised temperature:

- The possibility of a UTI should be considered and appropriate treatment instigated.
- Anyone with more than three confirmed episodes of UTIs should be assessed by a continence specialist for exacerbating factors and offered appropriate treatment and guidance.
- Any person with MS known to be at risk of UTIs should not be recommended prophylactic use of antibiotics or cranberry juice.*

*However, Fowler *et al.* (2009) state that there is some evidence to support the use of cranberry extract tablets in reducing the likelihood of UTIs.⁵⁹

[Summary of UK consensus paper on the management of the bladder in MS](#)

Patient information

[Managing bladder problems](#)

Bowel problems

The most common bowel symptoms are constipation and faecal incontinence, which frequently co-exist. Bowel dysfunction is reported by approximately 60 per cent of people with MS.⁶⁰

NICE

Each professional in contact with a person with MS should consider whether they have any problems controlling bowel function.

- Anyone with MS who has apparent constipation (pain or difficulty with defecation, or opening bowels less than twice a week) should be offered advice on fluid intake and dietary changes and considered for oral laxatives.
- If a person has apparent constipation despite treatment with oral laxatives, they should be considered for the routine use of suppositories or enemas.
- Referral to a district nurse or MS nurse should be considered for advice, support and monitoring.
- Faecal incontinence can have a devastating impact on individuals and referral to the continence service or MS nurse should be considered.

Patient information

[Managing the bowel in MS](#)

Weakness and cardio-respiratory fitness

People with MS can be affected by muscular weakness and deterioration in cardio-respiratory fitness that limits their activities.

NICE

Each professional in contact with a person with MS should consider whether muscular weakness is contributing to their current clinical state, and if so they should be assessed to determine the nature and cause of the weakness.

- People with motor weakness should be shown exercises and techniques to maximise strength and endurance, including aerobic training, usually by a neuro-physiotherapist.
- People with motor weakness should be taught techniques and given equipment to optimise performance.

Patient information

[Exercise and physiotherapy](#)

Spasticity and spasms

The symptoms of spasticity are painful involuntary contractions of muscles, sometimes causing the legs to kick out or flex in. When severe, limbs can go into involuntary rhythmic contractions (clonus) when put in certain positions. While many people with MS develop some degree of spasticity, those with severe MS are more likely to experience spasticity that limits their ability to undertake simple every day tasks and therefore affects their quality of life. It can have an impact on mobility, dexterity, bladder management, sexuality, hygiene, sleep, comfort and posture.⁶¹ Spasticity is both painful and uncomfortable, and can make it difficult to transfer or handle a person.

NICE

Each professional in contact with a person with MS with any muscle weakness should consider whether spasticity or spasms are a contributory factor to the person's current clinical state.

- Simple causative or aggravating factors such as pain and infection should be sought and treated.
- Everyone with persistent spasticity or spasms should be assessed by a neuro-physiotherapist and advised on physical techniques, such as passive stretching, to reduce spasticity and avoid development of contractures.
- Initial pharmacological treatment for bothersome regional or global spasticity should be with baclofen or gabapentin. Tizanidine, diazepam, clonazepam and dantrolene should only be given if treatment with the first drugs is unsuccessful or if side effects prove intolerable. Combinations of medications, and other potential medications should be used only after further specialist advice, preferably from the neurologist or consultant in neuro-rehabilitation.
- People with MS who have spasticity and spasms that are unresponsive to simpler treatments should be seen by teams specialising in the assessment and management of spasticity. They can then consider

specialised treatment options such as splinting, customised seating, intrathecal phenol or baclofen or intra-muscular botulinum toxin. People with severe spasticity will generally benefit from regular inter-disciplinary review by specialist teams.

Patient information

[Muscle spasms and stiffness](#)

Contractures at joints

One of the main complications of severe spasticity is a fixed shortening of the affected muscle, leading to a reduced range of movements in the limb. Severe contractures may result in people spending most of their time in bed. Contractures can also increase the risk of pressure sores.

NICE

Anyone with MS who has weakness or spasticity sufficient to limit their regular daily range of movements around a joint should be seen as at risk of developing a contracture of that joint and considered for preventative measures. The underlying impairment should be assessed and ameliorated if possible.

- People should be informed about their risk of developing contractures and referred to the neuro-rehabilitation team so that the individual or carer can be taught about preventative measures, such as regular passive stretching of joints at risk and appropriate positioning of limbs at rest. Specialist advice should also be sought on seating and positioning, including positioning in bed.
- Anyone developing a contracture should be assessed for treatment by a suitable specialist, with the assessment taking into account problems caused by the contracture, discomfort and risk of any treatment, and the wishes of the individual. Specific treatments include prolonged stretching using serial plaster casts and similar methods such as standing in a standing-frame and using removable splints. Such treatments can be combined with local botulinum toxin injections and surgery when necessary.

Patient information

[Muscle spasms and stiffness](#)

Ataxia and tremor

Tremor in MS occurs typically between five and 15 years after people's first symptoms of MS. Estimates suggest that as many as three quarters of people with MS experience some form of tremor.⁶²

Intention tremor and postural tremor are the two forms commonly experienced by people with MS. Intention tremor is triggered by any goal-orientated movement, such as reaching for a cup. When severe, intention tremor can have a devastating impact on people's abilities and independence.

Postural tremor occurs when people sit or stand, while their muscles try to hold part of the body still against the force of gravity. It can involve one or more limbs, the head and neck or the trunk, and may limit an individual's ability to walk and care for themselves. With such tremor, there is often also ataxia, the failure to coordinate the actions of the muscles involved in performing a movement.

NICE

Anyone with MS who experiences limitation of activities due to tremor should be assessed by a specialist rehabilitation team for medicines, treatment techniques and equipment. If their problems remain severe and intractable, the individual should be assessed by a neurosurgical team from a specialist centre for suitability for an operation to reduce ataxia.

Patient information

[Tremor](#)

Visual problems

Problems affecting vision and eye movement are common among people with MS. Optic neuritis typically causes unilateral loss of vision (particularly colour vision) with pain on eye movement. Inflammatory optic neuritis is distinguished from other forms of optic nerve disease by spontaneous improvement, usually within four to six weeks. A few people, however, experience lasting visual difficulties. The most common eye movement disorders in MS are breakdowns in the coordination of eye movement, such as an internuclear ophthalmoplegia or cerebellar nystagmus. These are only rarely symptomatic. Opsoclonus (spontaneous irregular jerking of the eyes in all directions) is sometimes a feature of advanced MS and can cause disabling visual impairment.

NICE

Each professional in contact with a person with MS should investigate whether vision is disturbed by considering if they are able to read the text of a newspaper or book, and to see the television. If not:

- They should be assessed for glasses by an optometrist, and anyone experiencing reduced visual acuity despite glasses should be assessed further in specialist ophthalmology clinics.

- If the person has nystagmus causing reduced visual acuity they should be offered a time-limited trial of treatment with oral gabapentin, initiated and monitored by a suitable specialist.
- Anyone unable to read or see the television despite all available treatment should be assessed for low-vision equipment and adaptive technology, referred to the appropriate specialist social services team and registered as partially sighted.

Patient information

[Vision and MS](#)

Pain

Pain syndromes affect approximately 45 per cent to 65 per cent of people with MS.⁶³ They may arise either directly from neurological damage or from musculoskeletal problems.

Neuropathic pain, caused by damage to the CNS, can lead to allodynia. Musculoskeletal or secondary pain can be caused by abnormal stress on joints, ligaments or muscles, which is often due to poor posture and walking patterns, or use of a wheelchair. It is important to distinguish between these causes of pain in order to determine whether to treat with anticonvulsants or antidepressants, which are more commonly used to treat neuropathic pain, or with opiates such as codeine, which can be useful in the treatment of musculoskeletal pain.

NICE

Each professional in contact with a person with MS should ask if pain represents a significant problem for them, or is contributing to their current clinical state.

- All pain, including hypersensitivity and spontaneous sharp pain, should be subject to full clinical diagnosis, including a referral to an appropriate specialist service if necessary.
- Everyone with MS who has musculoskeletal pain secondary to reduced or abnormal movement should be assessed by specialist therapists to see whether exercise, passive movement and better eating might be of benefit.
- If non-pharmacological measures prove unsuccessful, they should be offered appropriate analgesic medicines.

- Neuropathic pain should be treated using anticonvulsants such as carbamazepine or gabapentin, or with tricyclic anti-depressants such as amitriptyline. If neuropathic pain remains uncontrolled after initial treatments have been tried, the person should be referred to specialist pain services.
- If they continue to have unresolved pain, they should be considered for transcutaneous nerve stimulation or antidepressant medication.
- Cognitive behavioural and imagery treatment should only be considered in musculoskeletal pain for individuals with well-preserved cognition. Treatments that should not be used routinely for musculoskeletal pain include ultrasound, low-grade laser treatment and anticonvulsant medicines.

Patient information

[*Pain and sensory symptoms*](#)

Sensory loss

Sensory symptoms are common at onset or in early relapse. MS sensory symptoms are complex and often difficult to describe (“like hot water trickling down my skin”). A common pattern is for abnormal sensations, tingling and numbness, to begin in one foot and, over the course of a few days, spread to both lower limbs, the buttocks and perineum. The normal sensations of micturition and defaecation may be lost, although control remains normal. Genital sensation is also diminished. People can experience reduced sensory input. Loss of thermal sensation may be noted in the bath. Loss of proprioception, usually from a plaque in the dorsal columns, causes a devastating disabling deafferentation and ‘pseudo-athetosis’ of the limbs when the patient is examined with their eyes closed.

NICE

Anyone with MS who experiences a limitation of activities not otherwise explained should be assessed for sensory losses by specialist rehabilitation teams, with advice given on personal safety and techniques and equipment to ameliorate their limitations.

Patient information

[*Pain and sensory symptoms*](#)

Cognitive loss

About 50 per cent of people with MS may have an impaired ability to learn and remember, plan, concentrate and handle information quickly.¹ The relatively high prevalence of these deficits may not be appreciated by health care staff, often because language and social skills are unaffected.

Cognitive problems in MS can have an impact on people's lives that goes far beyond the physical restrictions imposed by the condition. People with these difficulties are less likely to be employed, have fewer social contacts and often do less well in physical rehabilitation. Memory problems can be a major source of stress for carers.

NICE

Health care staff should always consider whether the person with MS has any impairment of attention, memory, and executive functions sufficient to be a problem, or to be a contributing factor to their current clinical status.

- Whenever a person with MS is involved in making a complex medical decision, or starting a course of complex treatment requiring active participation, they should have cognition sensitively assessed to ascertain their ability to understand and participate.
- Anyone complaining of cognitive problems, or suspected clinically, should be offered a formal cognitive assessment, advised about their vulnerability to financial or other abuse, and told how to reduce the risk. They should be asked whether the results can be communicated to other people.
- Anyone with MS experiencing problems due to cognitive impairment should have their medication reviewed to minimise iatrogenic cognitive losses, and be assessed for depression, and treated if appropriate.
- If their level of independence or social behaviour cannot be easily understood in terms of known impairments, they should be offered a formal neuro-psychological assessment by a specialist clinical psychologist, or speech and language therapist.

Patient information

[Memory and thinking](#)

Depression

Over 50 per cent of people with MS experience a major depressive episode at some stage,⁶⁴ and suicide has been reported to be as much as 7.5 times higher than in the general population.⁶⁵ Depression undoubtedly has much to do with the uncertainties of living with a disease that affects one's ability to work, earn a living, and live independently. Depression in MS does not appear to relate to the level of disability, how long people have been diagnosed or whether they have a family history of depression.

NICE

If depression is suspected, the person should be asked: "Do you feel depressed?" and if severely depressed they should be seen by a liaison psychiatrist.

- If someone is identified as depressed, contributory factors should be assessed and strategies to ameliorate these undertaken where possible. Referral to a counsellor should be offered.
- Specific anti-depressant therapy or referral for psychological support (such as cognitive behavioural therapy) should be considered as part of the overall programme of depression management.
- Other concurrent psychological diagnoses such as anxiety should be considered.

Patient information

[Mood, depression and emotions](#)

Anxiety

People with MS often feel anxious about particular symptoms or thoughts related to their MS. This can lead to panic attacks (which may be interpreted as being due to MS) or even a generalised anxiety disorder.

NICE

Anyone whose function or happiness is adversely affected by anxiety should be offered specialist assessment and management, with people with marked anxiety being offered psychologically based treatments. Pharmacological treatment of anxiety should be through antidepressants or benzodiazepines, observing the Committee on Safety of Medicines (CSM) guidelines.

Patient information

[Mood, depression and emotions](#)
[Living with the effects of MS](#)

Emotionalism

Uncontrolled laughing and crying occurring independently of any emotion are symptoms experienced by about 10 per cent of people with MS.³⁴ They result from demyelination in the emotion centres of the brain and can cause acute embarrassment and distress.

NICE

Anyone who comments that they cry or laugh with minimal provocation and little control should be offered a full assessment of their emotional state. If emotionalism causes concern or distress to the person with MS, or their family, treatment with a tricyclic antidepressant or a selective serotonin re-uptake inhibitor should be considered. Amitriptyline has been shown to be effective in doses up to 75mg daily.⁶⁶ If the individual is unwilling or unable to take antidepressants, advice on behavioural management strategies should be offered.

Patient information

[Mood, depression and emotions](#)

Swallowing difficulties

Dysphagia, a symptom of brainstem dysfunction, is estimated to affect 43 per cent of people with MS at some point⁶⁷ and is more common among the severely affected. Common problems include difficulties with chewing, food sticking in the throat, difficulty in moving food back through the mouth, coughing and spluttering during and after eating, anxiety, excessive saliva causing dribbling, and choking. If left untreated, people can be at risk from malnutrition, dehydration and aspiration.

Because people with MS often do not realise that they have a problem with swallowing, it is all too easy for GPs to remain unaware of their difficulties and the result is that few are treated at an early stage.

NICE

Anyone with MS who is unable to transfer from bed to chair independently or who has symptoms or signs of bulbar dysfunction (such as abnormality of eye movements, slurring of speech or ataxia) should be asked whether they have difficulties with chewing or swallowing, and if they have altered their diet as a result.

- Anyone with bulbar symptoms or a chest infection should be assessed with a standardised swallowing test. If an abnormality is found, they should be referred to a speech and language therapist who can, if necessary, arrange further investigations.

- If the problem persists, referral should be made to the neurological rehabilitation team who can review the need for seating, chest physiotherapy and short-term use of nasogastric tubes, especially if recovery is anticipated.
- A PEG tube should be considered if people experience recurrent chest infections, inadequate food or fluid intakes, prolonged or distressing feeding, and nasogastric tubes *in situ* for over one month.

Patient information

[Diet and nutrition](#)

[Swallowing difficulties](#)

Speech difficulties

The most common speech problem is dysarthria, due to brainstem or cerebellar damage. Typical symptoms include slurred, imprecise or slower speech, low volume or weak voice due to respiration problems, difficulty with resonance and pitch control, appearance of speaking through the nose and abnormally long pauses between words or syllables. The prevalence of mild to severe dysarthria is around 51 per cent.⁶⁸ Dysphasia occurs occasionally, usually in patients with severe cognitive problems.

NICE

Anyone who has dysarthria sufficient to affect communication with people outside the home or over the telephone, or who is concerned about their speech sound or clarity should be referred to a speech and language therapist. Family members should be involved in discussions about how best to communicate.

Patient information

[Speech difficulties](#)

Sexual dysfunction

Seventy to 80 per cent of men with MS experience erectile dysfunction and more than 50 per cent experience loss of libido.⁶⁹ Between 56 and 72 per cent of women with MS have sexual difficulties.⁷⁰

Primary sexual dysfunction in MS is a direct result of demyelinating lesions in the CNS, and can result in a decrease or loss of libido, decreased or unpleasant genital sensations, and decreased orgasmic response. For men, there may be problems in achieving and maintaining an erection, and diminished frequency of ejaculation. Women may experience reduced vaginal lubrication in addition to

inorgasmia and a lowered sex drive. Common MS symptoms such as fatigue and spasms can cause secondary sexual dysfunction.

Tertiary sexual dysfunction can occur as a result of changes in family roles, altered self-image, lowered self-esteem, fears of rejection by partners, and feelings of being less attractive. Emotional reactions can be a fundamental issue for both the person with MS and their partner, and relationship difficulties are commonly reported.

NICE

- Men should be asked if they experience erectile dysfunction (relative or absolute) and if so, whether it is of concern.
- Those who have persisting erectile dysfunction and do not have contra-indications should be offered sildenafil 25-100mg or similar.
- If they do not respond to pharmaceutical treatment they should be assessed for general and specific factors such as depression, anxiety, vascular disease, diabetes and taking medicines that may cause erectile dysfunction. Other treatments such as alprostadil or intra-cavernosal papaverine should then be considered.
- Women should be asked if they experience sexual dysfunction (such as failure of arousal or lubrication, or anorgasmia) and if so, whether it is of concern. Assessment of general and specific factors that might cause or worsen it should be undertaken.
- Everyone with MS should be given the opportunity to remark on difficulties they may have in establishing or maintaining sexual and personal relationships. They should be offered information about locally available counselling and supportive services.
- Anyone with persistent sexual dysfunction should be given the opportunity to see a specialist with expertise in sexual problems associated with neurological disease, and offered advice on lubricants, sexual aids and other suggestions to ameliorate their sexual dysfunction.

Patient information

[Sex, intimacy and relationships](#)

[Women's health – pregnancy, menstruation, contraception and menopause](#)

Pressure ulcers

Occurrence of a pressure sore is described as a sentinel event by NICE, warranting an investigation. Prevention is by far the best and most effective approach to dealing with pressure sores. Some GPs

routinely refer high-risk patients to the district nurse service for monitoring.

NICE

Every person with MS who uses a wheelchair should be assessed for risk of developing a pressure ulcer.

- When people are provided with wheelchairs their seating should be considered for pressure-relieving procedures and devices, and other activities such as transfers and sleeping should be considered.
- When they are admitted to hospital, people who use a wheelchair daily should be assessed for their need for pressure-relieving devices and procedures.
- For people considered at risk, specialist mattresses should be provided and the skin area at risk inspected.
- When pressure ulcers do occur, they should be considered adverse events worthy of investigation, with advice sought from specialist services. People should be nursed on a low-loss mattress and their ulcers dressed according to appropriate local guidelines.

Patient information

[Pressure sores factsheet](#)

[Support for people severely affected by MS](#)

[Support for people in Scotland severely affected by MS](#)

10 Ongoing management

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- National Enhanced Service
- Palliative/ end-of-life care
- Advance care planning
- The end of life
- The principles of a good death

The GP and primary health care team have an ongoing responsibility for the care of people with MS and cover the whole disease trajectory from diagnosis to the end of life.

National Enhanced Service

The [GMS contract](#) provides for a National Enhanced Service for MS that expands the range of local services to meet local need. The specifications, outlined below, establish a gold standard of care in general practice that can be used as a model by all primary health care professionals looking to provide well-rounded MS care:

- **register:** produce and maintain an up-to-date register of all patients with MS and, where appropriate, their carers
- **lead coordinator:** establish a lead contact/coordinator to liaise with external services to develop a practice-based plan identifying roles and responsibilities
- **regular assessment:** provide regular assessments to review physical symptoms and effects of medication, including use of steroids, painkillers, antidepressants, and drugs to relieve spasticity; and to check on the patient's broader health needs
- **training:** undertake training, covering the nature of MS, making the diagnosis, common complications, symptom control, monitoring and when to refer patients to a specialist
- **carers:** provide carer support, where carers are kept fully informed and encouraged and educated to play as full a role in the patient's care as they wish
- **personal health plans:** produce personal health plans for each patient, which include diagnosis, disease type, investigations, current treatments and social support
- **liaison:** liaise with secondary care and social services, and regularly discuss the ongoing care of each patient with any other relevant agency

- **review:** carry out an annual multi-disciplinary review which could include an audit of the MS patient register (including a check on complications); report on the existence of appropriate care packages; an audit of the effectiveness of symptom control techniques; and feedback from patients on the MS register and their carers

[Get Read codes, toolkit and templates](#)

As the condition progresses, GPs need to consider appropriate referrals to other members of the multi-disciplinary team, and suggest an assessment for respite care. As gatekeeper to the multi-disciplinary team, the GP needs to be proactive in getting the person with MS the help they need. Since the condition can constantly cause new problems, GPs need to be ever alert to enlisting the expertise of new team members. MS nurses can be a great help in providing details of local services

Emotional support is needed not just at the time of diagnosis but throughout the course of the condition. Each progression in disability can be regarded as a loss, and people may need psychological support to move along their journey.

Regular assessments enable GPs to determine whether people are developing new symptoms, and give them the opportunity to ask directly about hidden symptoms such as depression, sexual difficulties and problems with bladder and bowel function.

Palliative/ end-of-life care

The [End of Life Care Strategy](#) launched in July 2008 clearly seeks to address the issues, challenges and inequity around current provision of end of life care and aims to improve choice, quality and value for money. All ten of the Strategic Health Authorities have developed end of life pathways in line with the Strategy. The aim of the Strategy is to bring about a 'step change' in access to high quality care for all people approaching end of life, regardless of diagnosis, age, gender, ethnicity, religious belief, disability, sexual orientation or socioeconomic status. This care should be accessible in any setting – home, care home, hospice and hospital.

This aim can be achieved through the following 10 objectives taken from the Strategy:

- To increase public awareness and discussion of death and dying. This will make it easier for people to discuss their own preferences around end of life care and should also act as a driver to improve overall service quality.
- To ensure that all people are treated with dignity and respect at the end of their lives.

- To ensure that pain and suffering amongst people approaching the end of life are kept to an absolute minimum with access to skilful symptom management for optimum quality of life.
- To ensure that all those approaching the end of life have access to physical, psychological, social and spiritual care.
- To ensure that people's individual needs, priorities and preferences for end of life care are identified, documented, reviewed, respected and acted upon wherever possible.
- To ensure that the many services people need are well coordinated, so that people receive seamless care.
- To ensure that high quality care is provided in the last days of life and after death in all care settings.
- To ensure that carers are appropriately supported both during a person's life and into bereavement.
- To ensure that health and social care professionals at all levels are provided with the necessary education and training to enable them to provide high quality care.

To ensure that services provide good value for money for the taxpayer.

When symptoms become more complex, GPs can play a valuable role in visiting people at home, and ensuring that the appropriate members of the multidisciplinary team are in place. One of the cardinal rules for any health professional working with people with MS is that the person with MS must never be told there is nothing more that can be done, since there is always more that can be done to help their symptoms and make them feel more comfortable. In MS, palliative care can be said to be applicable in the wider sense to anyone who is no longer eligible for disease modifying therapy.

All professionals involved in the day-to-day care and support of people with advanced MS can be said to offer a palliative care approach. However, some people with complex needs may benefit from referral to specialist palliative care teams for a one-off assessment or continued support.

Historically, palliative care has been synonymous with end of life and cancer care, but it is now widely recognised that a palliative care approach has a vital role to play throughout the course of a non-curative disease and can be delivered in conjunction with active disease modifying treatments.

Most people seen by palliative care teams have advanced cancer. The proportion of those referred with neurodegenerative disease rarely exceeds five per cent of total referrals.⁷¹ There can be difficulties accessing palliative care for people with conditions other than cancer. Many hospice beds are funded by charities and bound by objectives that single out cancer for attention. However there are also charities that have changed the emphasis from cancer to all conditions and are working to ensure that services are provided out of hours and 24 hours a day, seven days a week. An [MS Society-funded project](#) at King's College, London aimed to combine neurology and palliative care expertise for the benefit of people with MS in the community. The National Council for Palliative Care (NCPC) examined the current provision for people with neurological conditions, identifying good practice and service models and providing a neurological care pathway ([Focus on Neurology – Addressing Palliative Care for People with Neurological Conditions](#)).

There is increasing awareness that with increased longevity many people will have co-morbidities. The NCPC has produced [Multiple Conditions: Multiple Challenges - Exploring Palliative and End of Life Care for Older People with Multiple Conditions](#) which supports the End of Life Care Strategy, together with the personalisation agenda and the NHS Next Stage Review.

While health care services are usually good at addressing individual single conditions or specific problems, when faced with a number of ailments coexisting, provision of appropriate care may not be as good, especially if a conditions approach is used rather than a needs-based approach. At present, provision of care can be reactive with services only weakly linked together.

Services are often still ones that people need to fit into rather than tailored for the individual need. The system is still service driven and not what many people want. People with MS fall within a broad age range and have an unpredictable future, and this may make end of life difficult to identify. If the person with MS has other coexisting conditions the likelihood of the person dying in hospital may be higher. For people with MS who have a slow disease trajectory, rehabilitation services have an important part to play, not only in enhancing personalisation, autonomy and independence, but also in more advanced symptom management/control in the later stages (neuro-palliative rehabilitation).

Challenges for the GPs, health and social care professionals and palliative care services:

- **Definitions** around end of life and dying need more research and standardisation.
- **Preferred place of death**
 - 70 per cent of people want to die at home but only 18 per cent do
 - 18 per cent of people die in a care home (which for many is their home)
 - 60 per cent die in hospital
 - Only four per cent die in a hospice

GPs are key in ensuring people die in their preferred place.

- **Pathways**
 - Long term conditions, SHA care pathways and End of life pathways (Darzi Review) need to be effectively linked together with the end of life care strategy, especially for those people who are frail or/and have co-morbidities.
- **Current patterns of work**
 - There may be changes necessary to ensure that care is accessible 24 hours a day, seven days a week in whatever care setting is chosen by the person dying.
 - This care must be of high quality and well coordinated for both the person dying and the family/ carers.
- **Culture**
 - GPs are well placed to appropriately instigate some trigger questions which may facilitate discussions regarding end of life.
- **Prognostication – recognition of dying**
 - Health professionals may overestimate life length because the trajectory for frailty is not easy.
 - Intermediate Care services – 60 per cent of care is end of life because 60 per cent of the referrals die in the first six months but this is not recognised. Therefore, end-of-life care is every body's business.
 - Average time in a care home is now 21 months and 17 months in a nursing home.
 - The focus on cancer
 - Reliance on “straight forward” examples
 - Non cancer patients feature less on registers
 - Huge education agenda around identification of the dying patient
 - Prognostic indicators need more work

The [Gold Standard Framework](#) is an excellent tool to facilitate high quality end of life care and is appropriate for people with MS and their family/ carers. The fact that the disease trajectory for people with MS is usually much longer than some cancers needs to be remembered and taken into consideration. Many GPs will be highly skilled in using this tool and will know the key tasks of communication, coordination, control of symptoms, continuity (including out of hours), continued learning, carer support and care in the dying phase. Many GPs will also implement the Gold Standard Framework in stages (levels 1-4) within the appropriate timescales for the individual situation and circumstances.

Currently the [Liverpool Care Pathway](#) is being adapted for use for neurological patients.

People with severe/ complex MS sometimes opt out, or fall out, of the hospital review system and since they are not sufficiently mobile to access appointments might not be seen by a neurologist for some time. The same often goes for general practice, making it all too easy for people to lose contact with their GPs unless the GP makes a special effort to undertake home visits. While time-consuming, seeing severely disabled patients regularly and anticipating their changing needs can help to prevent the need for crisis management. The reality of management is that many MS nurses and district nurses see people in their homes and are able to talk to neurologists and GPs about problems their patients need help with.

It is good practice for health care staff undertaking palliative care to have developed a reasonable understanding of a person's psychological, emotional and spiritual needs. This includes the nature of their spiritual and pastoral support needs, and their wishes for any (or no) religious support or ritual before and after death.⁷² It is important not to conclude that those who decline formal religious observance do not have spiritual needs.

Advance care planning

GPs may wish to raise the subject of advance care planning (including advance decisions to refuse treatment, often still called living wills) so that people can state preferences about their future care and treatment in the event of incapacitation or inability to communicate. The [Mental Capacity Act \(2005\)](#) came into force in 2007. It provides a framework to protect people over 16 years in England and Wales who might not be able to make some or all of their own decisions at present or in the future. There are number of ways for people to express their choices (advance care planning), including identifying people who should be consulted, making statements about their preferences for care and appointing a Lasting Power of Attorney. Within the MCA, there is also the option for someone over 18 years old to make an Advance Decision to Refuse Treatment (ADRT).

An ADRT is usually made when someone decides that they do not want some form of treatment in a particular situation in the future. In the event of lacking mental capacity – not being able to make a decision – the ADRT would come into effect. Issues that might be considered are whether they would want to be fed by a PEG, treated with antibiotics if they develop an infection or just made comfortable, and whether they wish to be resuscitated. ADRTs are binding, provided that they have been set up within the MCA framework.

It can be helpful for people to lodge a copy of their ADRT and advance care plan with their GP and to keep copies at home for the out-of-hours service. Many people find such decisions emotionally too difficult to address so it can be helpful to record any discussions and decisions to help guide health care workers.

If people lack capacity to make a decision, they are entitled to an independent advocate and all local authorities will have a scheme to provide this service.

The end of life

A survey of over 5,600 people with MS extending over 45 years determined that their life expectancy is on average around 10 years less than the general population.¹²

Causes of death can be classified into:

- unrelated to MS, such as stroke, myocardial infarction, malignancy
- complications due to immobility such as pneumonia and aspiration
- suicide – reported to be 7.5 times higher than the non-MS population⁶⁵
- death directly related to MS – an extremely rare variant of MS, Marburg's disease, can cause respiratory failure a few months from onset

Statistics from the Office of Population Census & Surveys⁷³ indicate that of all deaths in the UK, 67 per cent occur in hospital, four per cent in hospices and 29 per cent in the community. But even for those people with MS who die in hospitals, nursing homes or hospices, most will have spent their final year of life at home, with GPs and other primary care professionals playing a key role in guiding them through a bewildering time.

Professor Keri Thomas of the University of Birmingham, describes: "...small details that can make all the difference such as anticipating

future needs, talking sensitively about the dying process, forewarning and reassuring, and helping our patients approach death with more confidence. Being there is important.”⁷⁴

Caring for someone in the terminal phase of MS is not unlike caring for someone with any terminal malignant disease: the alleviation of pain is essential. The main difference is that MS can follow a protracted and erratic course and it is impossible to predict exactly when someone who is severely incapacitated with MS will succumb to a fatal infection. Persistent swallowing difficulties and clearing of secretions, and recurrent chest and urine infections lend themselves to a fatal pneumonia and overwhelming sepsis. Individuals who experience these severe difficulties may not always have full insight into the extent of their problems, although cognitive impairment cannot be assumed.

People with MS may not be as distressed by thoughts of death as health professionals may expect. Some are extremely frightened and require a great deal of support from specialist palliative care teams, but others who have suffered for a long time come to develop an acceptance of death; and there are those for whom cognitive impairment has developed to the extent that they are cushioned from the reality of their situation.

One way in which care for the dying can be optimised in both the community and nursing home setting in the last few weeks of life is by implementing the [Liverpool Care Pathway \(LCP\)](#). Although initially developed for cancer patients, LCP can be easily adapted for non-cancer patients, and provides clear descriptions of the ideal model of care and the processes and outcomes required to get there.⁷⁵

Also useful for primary care teams caring for end-stage MS patients is the [Gold Standards Framework \(GSF\)](#) for community palliative care. This is a practical tool, developed to facilitate better coordination, communication and delivery of primary palliative care, and to improve the patient’s experience of that care. It involves identifying patients who require care, assessing and responding to their needs, and improving communication. “The main message is that caring for the dying at home is an important and integral aspect of primary care, in which we generally do well, but in which we can, with help, do even better,” writes Professor Keri Thomas in her guide to the framework.⁷⁴

The GSF needs to be in place once the GP has issued a DS1500 or feels that the progression of the disease means they would not be surprised if the patient died in the next few months. It is helpful if the patient is placed on a supportive care register in recognition of their special needs.

Carers

Following the death of a person with MS, GPs are responsible for the carer. Bereavement following the death of a severely disabled person

is a quite different experience from the death of an able-bodied person. Not only are carers bereaved but they suffer the loss of their role, and might have become quite isolated with few social contacts because of that role. Primary care teams can keep in touch with the carer and ensure that they are adapting to their loss.

The principles of a good death

- 1. To know when death is coming and to understand what can be expected*
- 2. To be able to retain control of what happens*
- 3. To be afforded dignity and privacy*
- 4. To have control over pain relief and other symptoms*
- 5. To have choice and control over where death occurs (at home or elsewhere)*
- 6. To have access to any spiritual and emotional support required*
- 7. To have access to hospice care in any location, not only in hospital*
- 8. To have control over who is present and who shares the end*
- 9. To be able to issue advance directives that ensure wishes are respected*
- 10. To have time to say goodbye and control over other aspects of timing*
- 11. To be able to leave when it is time to go and not have life prolonged pointlessly*

The principles of a good death are from the *Millennium Papers* published by Age Concern in 2000. This publication follows the Debate of the Age, facilitated by Age Concern. It represents the views of a group looking at the future of health and care of older people and does not constitute Age Concern policy.

11 Complementary and alternative medicines

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- Regulating complementary and alternative therapies (CAMs)
- Complaints about CAMs
- Helpful information sources for evaluating CAMs

Many people with MS choose to use complementary and alternative medicines (CAMs) as a way of managing their symptoms and improving their sense of wellbeing.

One study reported that as many as 85 per cent of people with MS use CAMs at some stage over the course of their disease,⁷⁶ and another that half the GP practices in England provide access to CAMs in some form.⁷⁷

Each primary care organisation or local practice decides individually whether or not to provide CAMs on the NHS.⁷⁸ CAMs are provided in many hospices and palliative care services and in some hospitals and pain clinics. In addition, there are four NHS homeopathic hospitals in the UK offering outpatient services in Bristol, Glasgow, Liverpool and London. Many people will pay for private treatments and some private health insurance schemes cover the costs of certain CAMs.

The difficulty in assessing CAMs is that most have not been through the rigorous double-blind placebo controlled clinical trials that are used to assess orthodox treatments. When studies have taken place, the numbers treated are small, and few CAMs have been tested specifically for use in MS. Where limited studies are conducted, it is important to consider the placebo response.

The NICE guideline for MS¹ concluded that there is some evidence that reflexology, massage, t'ai chi, magnetic field therapy, neural therapy, fish oils and multi-modal therapy may help people with MS to improve their general sense of wellbeing. But it felt there was insufficient evidence to give more firm recommendations for these treatments.

NICE cautions that hyperbaric oxygen (where people breathe oxygen under pressure in specially constructed chambers) should not be used because research evidence does not show beneficial effects, and that people with MS at risk of urinary tract infections should not be recommended prophylactic use of cranberry juice.

NICE suggests that a person with MS who wishes to try CAMs should be encouraged to evaluate the alternative therapy themselves, and to consider the risks and the costs, both in terms of finance and convenience.

Regulating complementary and alternative therapies (CAMs)

Currently only osteopaths and chiropractors are statutorily regulated: by the General Osteopathic Council and General Chiropractic Council. Other CAM professionals are at different stages of developing voluntary systems of regulation, and do not require practitioners to register with a regulatory body. There may be more than one association keeping lists of practitioners and each may have different standards of training and practice.

A 2005 publication, *Complementary Healthcare*⁷⁸ recommends that people selecting a practitioner should first check that they are trained and registered with a professional association or regulatory body, then telephone to establish the following:

- the length of the practitioner's training and their qualifications
- whether the practitioner is experienced in treating the condition
- whether the practitioner is insured so that compensation can be claimed if anything goes wrong
- the charges
- the likely length of a course of treatment
- whether the practitioner can send information about their practice and the therapy
- whether it is necessary to prepare – for example, by not eating before treatment
- how a client might feel after treatment
- whether the premises have wheelchair access

Complaints about CAMs

People should know how to complain if they are unhappy with the treatment. If the practitioner is employed by the NHS, people should discuss concerns with their GP practice, and if they decide to make a complaint, use the NHS complaints procedures. For practitioners registered with a regulatory body or professional organisation, people can raise the issue with that organisation.

If the practitioner does not belong to a professional association it can be hard to have redress. Possible sources of help in this situation include:

- WITNESS is a national charity that assists people with concerns about abusive health professionals. Call 08454 500 300 or go to www.popan.org.uk
- Action Against Medical Accidents, a charity helping people who have been harmed during health care treatment. Call 0845 123 2352 or go to www.avma.org.uk

People should be warned that some CAMs are in themselves potentially dangerous. Risks should be discussed as they would be with any prescription medicine.

Further, some CAMs can affect other medicines. For example, St John's Wort can affect certain prescription medicines and contraceptive pills and can be dangerous if taken at the same time as anti-depressants.⁷⁸ Similarly, cod liver oil, coenzyme Q10, ginseng, and fish oils can interact with warfarin.⁷⁹

NICE Guideline 8¹ recommends that people tell their doctors about any CAMs they may be using, and tell CAM practitioners about their other medication. Such discussions would provide GPs with an opportunity to direct patients to those CAMs that may be effective, and to registered practitioners. GPs might consider asking patients to bring information about a particular product or service with them and take time to discuss the information, possibly in the annual review.

Patient information

[*Complementary and alternative medicine*](#)

Helpful information sources for evaluating CAMs

- *Complementary Healthcare*, by Margo Pinder. Published by Prince of Wales's Foundation for Integrated Health (2005): www.fihealth.org.uk

A guide taking people through the process of deciding on a suitable therapy, with details on how to find a well qualified, registered practitioner.

- The Rocky Mountain MS Center

A non-profit making corporation in Colorado that aims to create a worldwide community of people interested in CAMs and MS, and provide accurate, unbiased, and up-to-date information: www.ms-cam.org

- *Multiple Sclerosis. The Guide to Treatment and Management*, by Chris H. Polman, et al. Published by Demos Medical Publishing (2006)

Written by a team of neurologists, in which each CAM is reviewed for its evidence base. The book can be accessed online at www.msif.org

- **[Clinical Guideline 8, Management of multiple sclerosis in primary and secondary care](#)**. Published by NICE (2003)

12 Other support for people living with MS

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- Support from local authorities (social care/ social work services)
- Direct Payments and personalised budgets
- Personal health budgets
- Specialist equipment
- Housing adaptations
- Mobility equipment
- Motability
- Help for people in work
- Financial support

People will usually live with MS for a long time and will need different types of help and support at different stages of their lives. There are a wide number of agencies offering support and people can find it a minefield trying to find their way to the right agency to give them the help and support they need.

Support from local authorities (social care and social work services)

A range of support options are available for people with MS from the local authority although there are strict eligibility criteria that each individual will have to meet. These vary from area to area but people are unlikely to qualify if they do not need help with personal care (such as washing and dressing).

Services from the local authority are means tested and people may have to contribute to the cost of service provided.

Direct Payments and personalised budgets

Increasingly anyone who qualifies for social care support will be offered a personalised budget. This will enable the individual to choose how their support is provided, whether they want to spend the money available on that support or whether they wish to purchase other types of services (evening classes, for example) and have a carer or friend provide the personal care. They will be able to choose who manages the services and that can be either the local authority, a third party or the person themselves. If the latter, this becomes a [Direct Payment](#).

Direct Payments give the individual choice and control over both the funding and the services. They are given an agreed amount of money by the local authority and provide their own care services. They will

need a separate bank account for this money to be paid into and they will have to provide financial monitoring information. Whilst this will mean individuals have the responsibility for managing services themselves, it does give them the choice and control over what is provided, when and how.

People can choose to use care agencies to provide the assistance they need. They can choose their own agency or use an agency that is on the local authority's preferred provider scheme.

Patient information

[Getting the best from social care services](#)

[Getting the best from social care services in Scotland](#)

Personal health budgets

The Government is currently piloting [personal health budgets](#). This will enable people with MS to have greater control over the health services they use and will hopefully be working in conjunction with personal budgets from local authorities.

Specialist equipment

The local authority can provide a range of adaptations and equipment to help people remain within their own home. This can be anything from small equipment such as specialist eating aids to major building adaptations to enable a person who now uses a wheelchair to remain in their current home.

Individuals need to be assessed as eligible to receive local authority assistance. The benefits of the equipment and adaptations can be psychological as well as physical. Due to the changing course of MS, assessments cannot be considered a one-off, and anyone who has MS is entitled to ask for a re-assessment of their needs at any time.

The types of equipment available are changing all the time and some can now be linked to computers to enable the individual to have more control over their environment.

Individuals can choose to have specialist equipment supplied via a Direct Payment if they so choose. This option allows the individual a wider choice especially in terms of colour, so that they can decide to buy an item that meets the existing decoration in their home. Any additional cost, over and above what the local authority has supplied, will need to be met by the individual.

Many goods and services are VAT-exempt for disabled people and if people are purchasing something themselves, they should discuss this with the supplier and request an eligibility declaration form.

Some equipment that people may require (specialist beds, for example) are considered a health rather than a social care need. However most areas now have a joint health and social care equipment service and 'who pays' should not effect the service and individual receives. If there is not a joint service then such equipment must be applied for via the PCT.

Housing adaptations

Small adaptations, such as handrails, ramps to get in and out of a house, are provided as part of aids and adaptations (see above).

If major building work is required (such as adapting a downstairs room or building an extension) people will need to apply for a Disabled Facilities Grant (DFG). These are only available to people who are owner/ occupiers or living in private rented accommodation. There is a ceiling to the grant available and it is likely the individual will need to raise some of the money themselves. The process for applying for DFGs can be very long and local authorities have a limited number of grants they can award each year.

People who live in council housing or housing association properties are entitled to ask for the adaptations to be made without having to apply for a Disabled Facilities Grant.

Patient information

[Adaptations and your home](#)

Mobility equipment

A physiotherapy referral may be appropriate if an individual needs to be assessed for walking aids such as canes and frames. Orthotics referrals may also be helpful: lightweight inserts worn inside shoes can increase stability and decrease fatigue, help with spasticity, and help brace the foot against foot drop.

Wheelchairs

A local Wheelchair Service will carry out an assessment taking into account the clinical and practical needs of the individual for mobility, comfort, functional ability, posture and practical use. If appropriate, the service can provide a manual or powered wheelchair. What is available will vary according to local policies and budgets. Some areas in England (though not Wales) operate voucher schemes that give wheelchair users greater choice by allowing them to put the voucher towards the cost of more expensive, higher specification wheelchairs.

The [British Red Cross](#) can lend wheelchairs, and can arrange for them to be made available at holiday destinations.

Shopmobility

Shopmobility is a scheme that lends manual and powered wheelchairs and powered scooters in leisure and commercial facilities in towns and city centres.

Scooters

Scooters are used by many people with MS as a means of getting around their local area when an individual has difficulty walking any distance or where fatigue is an issue. Scooters are not available via the local authority but can be purchased using Disability Living Allowance (mobility component) via the Motability scheme.

Motability

Motability schemes help disabled people buy or lease new and used cars, wheelchairs or scooters, using Disability Living Allowance (mobility component) or War Pensioner's Mobility Supplement.

Cars can be leased for three years and occasionally four years. Grants are available for specialist adaptations to vehicles. Many cars require an advance payment and the amount of this payment varies from car to car. Insurance and repairs are included as part of the scheme. Individuals who cannot drive but receive higher rate DLA can still apply to the scheme and nominate a driver.

Motability also assists individuals to buy new cars, second hand cars and scooters.

Help with advance payments, adaptations or driving lessons for scheme participants or their nominated drivers is sometimes available.

Patient information

[Benefits and MS](#)

[Claiming Disability Living Allowance](#)

[Motoring with MS](#)

Help for people in work

People with MS are entitled to a range of support to enable them to continue working. The support available will depend on the hours worked and the amount of money they earn.

Access to Work

For people with MS who work 16+ hours per week, [Access to Work](#) can provide a range of help and support to enable the individual to remain in employment. This can range from assistance to get to work (fares to work scheme) and to provide an assistant to help someone whilst at work. In addition Access to Work will provide help with specialist equipment and individual needs for work such as specialist computer equipment, specialist adaptations to vehicles and can provide building work for the employer such as putting in a ramp or accessible toilet. Access to Work will only provide equipment that is necessary for the individual and is not considered standard equipment for that particular job.

[More information on employment and MS](#)

Patient and employer information

[Working with MS](#)

Financial support

MS can have major financial implications, especially if the individual is no longer able to work. When someone is more severely affected, it can also affect a partner's earning ability as they move into a caring role.

It is important that people with MS are aware of the full range of benefits that may be open to them. Many people do not claim their entitlements and it can be helpful to raise the issue in consultations and point people in the right direction. It is worth checking entitlements regularly as the rules often change and individuals may be entitled to new allowances if their symptoms worsen. Some people are discouraged from applying because of their (or their partner's) savings, salary or other income, but not all allowances are means tested.

Benefits advice is complex and ever changing. People should be referred to specialist agencies such as:

Job Centre Plus

All Job Centres have benefits advisers who can give information and advice to individuals out of work or working less than 16 hours per week.

Citizens Advice

The address and contact details for CABs is available either via their website www.citizensadvice.org.uk, the local library or through your local authority.

CABs have specialist benefits advisers who can help, not only with telling people what benefits they may be entitled to, but also assisting the individual to complete the relevant forms.

Local authority benefits advisers

Many local authorities have benefits advisers 'in house'. Check with your local authority whether this service is available in your area.

[Further information on benefits](#)

Patient information

[Benefits and MS](#)

13 Support for carers

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- Recognition of carers
- Checklist for GPs and primary care staff
- Carer assessment

Recognition of carers

People usually take on many of the responsibilities of caring well before recognising that the word 'carer' applies to them. As the condition fluctuates and progresses, so does the intensity of the caring role.

Over time, many carers become aware that they are not coping but may find it difficult to ask for help. Effective support for carers reduces the need for hospital and respite care admissions and, in the long-term, reduces the overall costs to health and social services. Primary care professionals have a key role to play in identifying carers. They can provide information about local authority carer's assessments, recommend support groups and carers' centres, and facilitate training to help carers care safely.

The emotional strain on the carer often begins with the strain of the changing relationship and grief at the constant losses in physical and cognitive ability. Every progression in the illness requires family members to adjust to the loss and redefine themselves accordingly. One of the biggest challenges many carers face is the need to balance their paid work with caring and looking after children. Although many carers are willing to take on the role, they may feel they have no choice, and this may lead to feelings of resentment.

A survey by the [Princess Royal Trust for Carers](#) identified common symptoms experienced by carers and noted the difficulties reported by some in obtaining support from their GP practice. The Trust used these findings to produce the 10-point checklist shown on the next page, to help primary care staff improve their service to carers.

Checklist for GPs and primary care staff

From [Primary Carers – identifying and providing support for carers in primary care](#), published by the Princess Royal Trust for Carers

- 1. Have you identified those of your patients who are carers, and patients who have a carer?*
- 2. Do you refer carers to local sources of advocacy, help and support, including carers' centres or carers' support groups?*
- 3. Do you take the needs of carers into account in the way you allocate appointments, your procedures for issuing prescriptions and arrangements in the waiting room?*
- 4. Do you check carers' physical and emotional health whenever a suitable opportunity arises, and at least once a year?*
- 5. Do you routinely tell carers that they can ask Social Services for an assessment of their own needs?*
- 6. Do you always ask patients who have carers whether they are happy for health information about them to be told to their carer?*
- 7. Do you give carers information about the diagnosis, treatment and prognosis for the person they care for, and about medication and its side effects?*
- 8. Do you arrange for carers to have information or training to help them care safely, particularly on lifting, moving and handling the person they care for?*
- 9. Do you ensure that there are leaflets and notices in the surgery to inform carers about available services and support, and to encourage them to identify themselves as carers to the practice?*
- 10. Are you willing to help with the establishment of a surgery-based carers support group?*

Carer assessment

Under the Carers and Disabled Children Act 2000, carers who provide "regular and substantial care" now have a right to their own assessment of need by the local authority. An assessment should look at the carer's ability to continue caring and take into account things like work and other family commitments.

This is reinforced by the Carers (Equal Opportunities) Act, which came into force in April 2005. This places a duty on local authorities to inform

carers about their rights and consider access to work and education and leisure activities as part of the carer's assessment.

As well as providing access to respite care to give the carer a break, local authorities are now able to provide services directly to carers. These can include anything that will assist the carer in their role or help to maintain their health and wellbeing.

Examples include:

- a mobile phone to give the carer peace of mind when they are away from the person they are caring for
- help with taxi fares so that the carer can get to hospital appointments or get to work on time
- counselling or complementary and alternative therapies to help deal with emotional issues and stress

This type of support may be means tested and can be provided as a Direct Payment.

Patient information

[*Caring for someone with MS – a handbook for family and friends*](#)

[*MS in your life – a guide for young carers*](#)

[*MS carers – the man's guide to caring for someone with multiple sclerosis*](#)

[*Childhood MS – a guide for parents*](#)

[*Guidance for carers – hospital discharge*](#)

14 Respite and long-term care

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- NHS Registered Nursing Care Contribution (RNCC)
- Respite for people severely affected by MS
- Long-term care

A planned programme of short breaks or respite care staged throughout the year as part of the care package can be vital in enabling a person with MS to live independently in their own home for longer. It can also save on the costs of crisis intervention measures and long-term care. Respite in a residential setting can have the additional advantage of providing rehabilitation and access to complementary therapies such as aromatherapy or reflexology.

GPs and district nurses are well placed to be proactive in raising issues of respite care with patients in a sensitive manner where it is felt that this would be of benefit to the person with MS or their carer. The first step is to refer the person with MS or their carer for an assessment of needs to the local authority social care services department. Carers also have the right to an independent assessment of their needs – a carer's assessment. District nurses and GPs may be involved as part of the assessment process.

The amount and type of respite care will be determined by the needs of the carer and cared for, the availability of services and local eligibility criteria. While local authorities have the power to provide respite services, there is no statutory obligation for them to do so. This results in local variations in eligibility criteria and charges for respite care, which in practice, means a postcode lottery. Some areas undertake means testing to decide on an individual's financial contribution, while others provide everyone with the same level of funding. If there is a gap between the cost of respite care and the amount that social services is prepared to fund, the [MS Society Grants Team](#) can advise on alternative sources of funding.

NHS Registered Nursing Care Contribution (RNCC)

People who would normally have nursing support at home are eligible to receive RNCC for any periods of residential respite care. GPs should ensure that the appropriate professional in the PCT is contacted well before the respite stay to allow enough time for the person to be assessed for RNCC. The RNCC contribution may be paid directly to the care home by the PCT or combined with the local authority contribution towards the cost of the respite placement. People with advanced MS and complex clinical and care needs who meet the local

continuing care criteria should be eligible for full funding from the PCT. GPs can identify patients for whom this may be the case and initiate an assessment through the PCT.

Respite for people severely affected by MS

The MS Society manages four specialist respite centres offering care and therapy for people severely affected by MS. These are Brambles in Surrey; Helen Ley in Warwickshire; Woodlands in York and Leuchie in East Lothian. The MS Society also works with other care providers to increase the choice and availability of appropriate respite across the country for people severely affected by MS. In partnership with service providers and the statutory authorities, several dedicated MS respite beds have been commissioned in areas of England not well served by the Society's own [centres](#).

Another recent initiative is the MS Society's preferred provider recognition scheme. This offers external providers of residential respite care the opportunity to be evaluated in terms of their ability to meet the respite needs of people with MS, particularly those with complex needs. The Society produces a respite care directory giving details of preferred providers and other respite services. This is available from the Respite Enquiry Line on 020 8438 0925 or can be downloaded from www.mssociety.org.uk

Long-term care

Some people with complex needs manage to live independently in their own homes with comprehensive care packages. For others, permanent residential care may be a more appropriate option. Statistics suggest that around five per cent of people with MS are eventually cared for in a nursing home.⁸⁰ The support of carers is often the most influential factor in this decision and GPs may become involved in supporting people to make the decision that is right for them.

It is vital that the residential care home is able to meet the needs of the person with MS. Unfortunately, there are too few homes catering for the needs of younger disabled people and even fewer able to meet specialist MS needs. Social services can advise on the suitability of residential homes in different areas and registration inspection reports for all care homes can be viewed on www.cqc.org.uk

Where it is agreed that residential care is the most appropriate option and finance is an issue, a referral can be made to the local authority for a full assessment. This will include a means test and an assessment of the registered nursing input required so that the Registered Nursing Care Contribution can be confirmed. People can choose a home costing more than their local authority is prepared to pay providing a third party top-up can be arranged. There are trusts and charities across the UK which may help with this.

The following benefits will be affected when a person goes into residential care: Disability Living Allowance, Attendance Allowance, Income Support, Jobseeker's Allowance, Housing Benefit and Council Tax Benefit, Employment and Support Allowance.

Where people have very high levels of disability, they may be entitled to [fully-funded NHS care](#), depending on the local continuing care eligibility criteria.

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