



Multiple sclerosis information

for health and social care professionals

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Section 3

Vision

Multiple sclerosis can affect vision by various mechanisms, although frank blindness is very rare in MS. The NICE clinical guideline states that each professional in contact with a person with MS should consider whether the individual's vision is disturbed, by considering, for example, the individual's ability to read the text of a newspaper, book or other written material and to see the television.

If there are some problems with vision it is worthwhile initiating an optometrist assessment to ascertain whether the visual problem can be helped by glasses. Any individual who experiences reduced visual acuity, despite using suitable glasses, should be referred for a specialist opinion. The optometrist can assess whether the visual problem may be caused by an eye problem that is not due to MS, such as cataracts or macular degeneration. A decision can therefore be made as to whether the visual problem is best dealt with in an ophthalmology or neurology clinic.

Some visual problems that are specific to MS are:

Optic neuritis

Optic neuritis is the most common eye problem in MS. It is the first manifestation of MS in up to 30% of cases and most people with MS will have optic neuritis at some point during their disease course. It is characterised by an inflammation and demyelination of the optic nerve. The optic nerve is the second cranial nerve that joins the eye to the brain, transmitting the retinal image to the brain.

Optic neuritis usually presents with unilateral impairment of vision, although bilateral cases can occur. There is usually some degree of pain behind the eye and pain on eye movement, although 10% of cases are painless. The visual impairment comes on acutely and vision can get progressively worse for up to two weeks. The degree of visual loss can vary from mild blurring through to loss of light perception in the affected eye. There is loss of colour vision, decreased ability to see contrast and a visual field defect in the affected eye. The visual field defect is usually over the central part of vision and is termed a central scotoma.

On examination there will usually be a defect in the

pupil's reaction to light in the affected eye called a relative afferent pupillary defect. The optic nerve head may appear swollen when viewed through an ophthalmoscope, although in over half the cases the nerve head is not swollen because the part of the optic nerve that is affected is away from the eye. In these cases the condition is often termed retrobulbar optic neuritis.

Optic neuritis can usually be diagnosed on clinical grounds, although sometimes further tests are needed. These can include blood tests, magnetic resonance imaging (MRI) of the orbits and brain (Figure 1), an electrical test called visual evoked potentials and a lumbar puncture.

Spontaneous recovery of vision usually starts to occur by the third week. Most recovery takes place over the next three months, although there are signs of recovery for up to two years following an episode of optic neuritis. Most people with optic neuritis make a good recovery, although 10% are left with significant visual impairment. Despite a good recovery of visual acuity there are often subtle defects in colour vision or contrast sensitivity. Vision can often get transiently worse in the affected eye due to heat or exercise. This is called Uhthoff's phenomenon.

Treatment in the acute phase with a short course of high dose oral or intravenous corticosteroids will speed up recovery, although their use has not been shown to affect the final level of visual recovery.

Optic neuritis may occur as a one-off. In a third of cases it can recur, in either eye. Only about 2% of people, though, will develop permanent blindness due to repeated attacks of optic neuritis. About 60% of people who present with optic neuritis will go on to develop MS. The risk of conversion to MS can be ascertained by looking for asymptomatic brain MS lesions on MRI. If there are no brain lesions then the long-term risk of MS is 20%; the risk rises to 80% if any brain lesions are seen.

Double vision (diplopia)

Double vision (diplopia) may be another early symptom of MS. This occurs when the nerve pathways that control eye movements are damaged. It is due to a misalignment of the two eyes so that they look in slightly different directions and they may not move together in a coordinated fashion. The nerve pathways commence in the brainstem, which is a common site of relapses in MS (Figure 2). Diplopia may be accompanied by vertigo, nausea and unsteadiness (ataxia). If

diplopia occurs as part of a relapse then it will usually recover. This recovery may be speeded up by treatment with corticosteroids, as described above. If the diplopia is persisting, particularly in someone with progressive MS, then putting a prism in one lens of glasses or patching one eye can abolish the double vision.

Nystagmus

Nystagmus is the repetitive to-and-fro motion of the eyes. The movement can be horizontal, vertical or have a rotational component. It may just occur with eye movements, when it is termed gaze-evoked nystagmus. This is often asymptomatic, but is clearly seen by an observer. In progressive MS nystagmus can occur in the primary position of gaze. This can then cause the symptom of oscillopsia, where there is a failure to maintain fixation and therefore objects appear to move and vision is blurred. This can be very disabling and it can cause a significant reduction in visual acuity. This is a very difficult symptom to treat. Initial studies have indicated that gabapentin and memantine may be effective.

On-going visual problems

If there are persisting difficulties with vision, despite all available treatment, then the person with MS may benefit from being registered as having a sight impairment. In addition, a referral to a low vision service should be made, to see if there are specific areas where help can be given, such as the provision of appropriate magnifying devices to permit reading.

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Figure 1

Coronal MRI of the orbits in an individual with acute optic neuritis showing an inflamed optic nerve (arrowed).

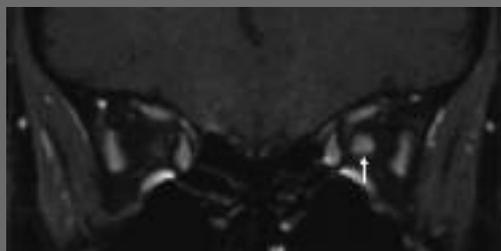
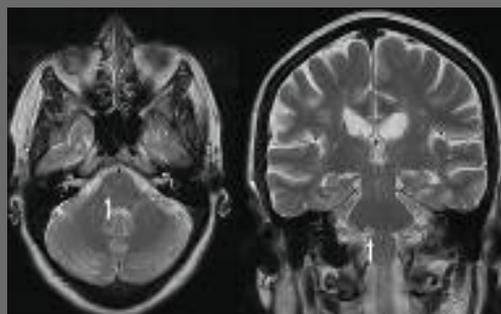


Figure 2

Axial (left) and coronal (right) MRI of the brain in an individual with MS showing a lesion in the brainstem (arrowed) that was responsible for acute double vision.



Fatigue

Fatigue can be described as an overwhelming sense of tiredness, lack of energy and feeling of exhaustion. More formally, it has been defined as “a subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with the usual and desired activity”¹. MS fatigue is different from normal tiredness and does not correlate with age, severity of MS or mood.

Fatigue is reported to be the most common symptom experienced by people living with MS. In a survey of 2,265 people with MS², 94% experienced fatigue, with 87% reporting an impact on their activities of daily living, which was between moderate to high. Fatigue is often described as an invisible symptom and is variable in nature. Fatigue can be the predominant reason for disability, even early on in the disease course and is reported to be one of the key factors most likely to influence people to give up their jobs. Mental fatigue can affect learning, memory, attention and concentration. Fatigue has a huge impact on participation in everyday tasks, work, leisure and social activities and can therefore impact on psychological well-being.

A good explanation of fatigue is important early on in treatment as MS fatigue exacerbates symptoms and people can fear that they are having a MS relapse. The symptoms will subside after rest which distinguishes them from a relapse.

Brain scans of people who have fatigue show that they use larger areas of the brain to carry out activities than people without fatigue. This would mean that more ‘brain power’ is required to carry out an activity, which may cause fatigue³.

Fatigue can be classified as primary or secondary fatigue depending on its cause¹.

Types of fatigue

Primary fatigue

Primary fatigue describes aspects of fatigue that are thought to be directly related to the disease process but much of the understanding of these features remains theoretical.

Short-circuiting fatigue is sometimes known as ‘nerve fibre fatigue’ or ‘conduction block’ where

performance deteriorates during continued/sustained activity but responds to a short rest break allowing activity to be resumed. For example, a person with MS may notice he or she is starting to limp when walking for a while but after a short rest walking has improved. Research suggests that a build up of sodium ions during continued activity, sometimes referred to as ‘flooding’, causes a conduction block, while stopping the activity allows time for the cell membrane to return to its resting state⁴.

Lassitude refers to ‘an overwhelming tiredness not directly related to participation in activity or exercise’. The pathogenesis of lassitude is even more poorly understood, although various immunological theories have been suggested.

Heat sensitive fatigue is well recognised in MS and has long been considered a unique dimension of MS fatigue differentiating it from fatigue in other conditions. A rise in body temperature of as little as half a degree can interfere with nerve conduction and cause fatigue. This is often described as Uhthoff’s syndrome where symptoms can become worse with an increase in body temperature⁵.

Secondary fatigue

Secondary fatigue is not unique to MS; it relates to factors that can be generalised across a variety of chronic and disabling conditions. The relationship between these factors is complex and their influence on the overall experience of fatigue is often difficult to discern. However, the ability to isolate these contributory factors can be invaluable in the medical management of fatigue since many secondary factors can be avoided or treated directly⁶.

Medications may cause tiredness or drowsiness as a side effect, for example baclofen, commonly used in the treatment of spasticity. Side effects of the beta interferon disease modifying therapies have also been documented as having a negative impact on fatigue⁷. It should be noted if there is a correlation between a change in fatigue levels and a change in medication.

Exertion or increased effort required by the body if mobility or coordination is affected, can cause fatigue. Reduced activity can also lead to deconditioning of the muscles and cardiovascular system, resulting in a less efficient use of energy and therefore the experience of more fatigue.

Infection, for example having a cold, flu or urinary tract infection, can all be associated with

increased tiredness and the need to rest, therefore worsening fatigue.

Disturbed sleep can exacerbate fatigue and may be due to symptoms that can be alleviated or lessened, for example spasms, pain, urinary urgency at night, depression or anxiety.

Depression or low mood can affect motivation and activity and increase lethargy therefore exacerbating fatigue.

Environment including lighting and temperature are crucial, as poor lighting increases visual effort and heat can exacerbate fatigue. The general layout of home and work environments should be ergonomic to allow energy to be used efficiently. Also, walking distance and number of stairs need to be considered.

Fatigue management

Explanation and information may be the only tools necessary for people with MS to accept that some fatigue is inevitable, to help them minimise precipitating factors and manage their lifestyle to accommodate the problem.

For other people further help may be necessary and various fatigue management programmes have been developed and are well documented¹. This approach to managing fatigue relies on a person reflecting on their own fatigue and the way that it affects their daily life. A fatigue diary can help in this process. The approach does not take fatigue away but aims to make living with fatigue easier. Fatigue management requires a coordinated approach involving family and colleagues as well as health professionals^{8,9}.

The principles are as follows:

Take frequent rests

Balance activities with rests and learn to allow time to rest when planning a day's activities. Rest means doing nothing at all and it is better to take short frequent rests rather than one long one. It is crucial to rest before fatigue sets in. Some people also find relaxation techniques helpful.

Prioritise activities

Prioritising activities can mean that you save energy for the things you really want or need to do. Decide if jobs could be done by other people, consider outside help, and consider jobs that could be cut out of your

daily routine or done less often, such as ironing.

Plan ahead

A daily or weekly timetable can be useful to schedule activities and rest in a balanced way. Spread heavy and light tasks throughout the day. Set realistic targets and breakdown large complicated tasks into smaller stages that can be spread throughout the day. 'Time, not task' is a good rule to work to.

Organise living and work spaces

This involves looking at energy effectiveness/efficiency when carrying out daily activities at home, work and in leisure. This may involve re-organising desks or cupboards, or adjusting the temperature or lighting.

Adopt a good posture

Activities should be carried out in a relaxed and efficient way minimising stress on the body, which will in turn save energy. Maintain an upright and symmetrical posture during all tasks and rest on a perching stool while carrying out tasks if necessary. Avoid excessive twisting and bending.

Lead a healthy lifestyle

Keep generally fit. Exercise is essential but should be balanced with rests. Physiotherapists can advise on specific exercises that may be relevant. Eat a well balanced diet and remember that excess weight, alcohol and smoking can all have a negative impact on fatigue.

An occupational therapist can offer education regarding both fatigue management principles and a practical problem-solving approach. As well as clinical guidelines which support fatigue management programmes, research demonstrates that a fatigue management programme for people with MS that combines cognitive behavioural and energy saving approaches, is effective in reducing fatigue severity and increasing self-efficacy¹⁰.

Generally, medicines targeted at fatigue should not be used routinely. However, a small clinical benefit might be gained from taking amantadine (Symmetrel, Lysovir) which has been shown to reduce fatigue in 20-40% of people with mild to moderate MS. Amantadine is generally well tolerated with mild side effects including constipation, nausea, anxiety and hyperactivity. It is suggested that the dose is taken in the middle of the day to avoid problems of insomnia or vivid dreams from the drug being taken too close to the individual's normal bedtime^{11,12}.

Modafinil is a drug that promotes wakefulness and is licensed for treating people experiencing excessive sleepiness due to narcolepsy. Research has suggested that it may be an effective treatment for the management of multiple sclerosis fatigue in some people where sleepiness is a factor in their fatigue¹⁴. However following the findings of a safety review, the European Medicines Agency recommended that the use of modafinil should now only be associated with narcolepsy.

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MS Trust resources

Living with fatigue
MS and me: a self-management
guide to living with MS



Diet factsheet

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Cognition

Because MS is often thought of as primarily a physical disease, problems with attention and memory are often overlooked. On formal laboratory tests, about half of all people with MS experience some inefficiency in concentration, or other mental tasks (known as cognitive difficulties)¹⁻³.

Cognitive difficulties in MS can affect⁴:

- relationships and families
- competence in legal and financial matters
- adjustment to disability
- ability to benefit from rehabilitation
- employment
- driving
- quality of life.

Cognitive problems can arise early in the course of the disease although the greater the disease duration and severity the more likely significant problems are to occur. As with physical symptoms, MS may affect some cognitive functions whereas others may be left intact. This is important because it gives the person assets with which to compensate for (and sometimes mask) deficiencies. Cognitive symptoms can worsen during relapse and improve during remission but more commonly symptoms develop slowly and gradually over time.

Although cognitive dysfunction is a sensitive area to broach with people with MS and their families, it is now generally accepted that openly recognising the problem is considerably more helpful than pretending it does not exist, or misunderstanding why problems are occurring. Recognition opens the door to support, acceptance, constructive discussion and possible compensatory strategies^{5,6}.

Forms of cognitive dysfunction

Memory loss is probably the commonest problem. Apart from the obvious difficulties presented by everyday forgetfulness, memory loss also has implications in terms of learning new skills.

Reasoning and judgment, including new learning, problem solving and behavioural regulation may be impaired but, because of the subtle nature of reasoning, this problem is often much less obvious.

Speed of information processing is the most vulnerable cognitive domain. This is particularly noticeable when people have to deal with information coming from different directions ("multi-tasking").

Attention and concentration lapses can also cause problems, especially when there are distractions in the environment, such as a busy office.

Visuo-spatial perception is also sometimes impaired, although less often.

Cognitive functions which are less likely to be affected by MS include: language, remote knowledge, 'old knowing', previously learned motor skills (eg riding a bicycle), long-term automatic social skills.

Therapy

Two studies have suggested that disease modifying drugs may offer some protection from cognitive decline in MS^{7,8}.

Neuropsychologists, speech therapists and occupational therapists are able to assist people in understanding, assessing and managing cognitive problems in MS. The objectives of cognitive rehabilitation are to support the person with MS in maintaining:

- independence
- reliability as a family and community member
- capacity to contribute to society.

Coping strategies

Generally, two complementary approaches may be employed:

- a retraining approach whereby progressively more challenging exercises are given by health professionals and used to strengthen impaired function
- a compensatory approach, which might involve, for example, memory prompts or the recording of information.

There are many practical compensatory strategies which can be employed and a number of publications which people with MS and their families may find useful ^{9,10}.

- use of large page-to-a-day diary and establish systematic habits of consulting it¹¹
- use technology eg dictaphones, beepers, mobile phones¹¹
- establish a fixed routine, eg always keeping things in the same place
- do only one thing at a time and remove distractions (background noise, TV, etc)
- use white boards, post-it notes or notebooks, especially by the phone
- avoid doing jobs which need concentration when fatigued or anxious.

It is worth remembering that some medications including those used to counteract pain, fatigue and depression may have a negative impact on cognition.

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MS Trust resources

Cognition factsheet



StayingSmart

www.stayingsmart.org.uk

Depression

Experience of living with MS - as with many other chronic conditions - can undoubtedly result in a low mood. This however should be clearly distinguished from clinical depression, which is common in people with MS¹.

Health professionals should be mindful of an individual's mental health as well as their physical health at all stages of clinical intervention. Health professionals will then be better placed to encourage their patients to work towards maintaining stable mood and preventing the likelihood of developing the disabling symptoms of low mood and anxiety alongside the already challenging symptoms associated with MS.

Depression and MS

It is estimated that about half of all people with MS will experience an episode of depression at some stage, regardless of their clinical presentation. This may be recurrent in some and persistent in others. In one study, 28% of people with MS could be described as depressed at any one time².

People who experience depression may not recognise it as such or may find it difficult to talk about how they feel. The stigma that is associated with mental health problems also acts as a barrier to discussion about the symptom.

In some cases, depression may not be experienced as a reaction to the complexities of living with MS but as a symptom due to lesions in certain parts of the brain that directly affect mood and cause depression.

Risk factors and prevention

As part of an initial assessment, most health professionals will obtain a good history of an individual's physical health. The same is not always true for mental health.

Health professionals can play an important role in preventing depression by being aware of risk factors and can help people think about protective strategies and introducing changes, where possible and acceptable, to minimise risk.

It is important to know if there is a relevant family or individual history, to understand any previous

triggers, relevant anniversaries as well as the cause of a person's episode, experience of treatment and final outcome.

Health professionals need to be explicit in their discussions with patients about any history of depression and risk of recurrence. Plans for monitoring and identifying any early warning signs should also be put in place. Health professionals who see a patient on a regular basis are well placed to notice changes in mood or personality between appointments.

Risk factors for clinical depression in the general population include a history of significant loss, a family history of mental illness, major trauma or significant health problems. Depression is thought to be more common in women. It is also more prevalent in the 20-50 age range and following retirement.

These factors are also relevant to people with MS, but there are other specific risk factors³. There seems to be an increased risk for people who have:

- shorter disease duration
- greater disease severity
- lower education
- lower age
- less social support.

Some people also experience alteration in their mood just before or after a relapse.

There appears to be no correlation between risk of depression and extent of disability.

Many of the drugs prescribed for other symptoms of MS can have low mood as a side effect. Drugs that can lower mood include steroids, beta interferons and muscle relaxants.

These factors need to be considered in the early part of a person's care and any relevant risk factors recorded in the notes and shared with the individual and their GP. Advice should be given on prevention. This is particularly important as depression can exacerbate and amplify many of the primary symptoms associated with MS.

Symptoms, effects and management

Depression

Anxiety disorders are also common in people with MS⁴, with an estimated 25% of people experiencing them, but these are often overlooked and undertreated.

Diagnosis

Diagnosis of depression is often missed by health professionals. It is an essential diagnosis to make and responds to treatment^{5,6}.

Individuals and their families play a key role in identification and diagnosis of depression. Health professionals rely on their descriptions of the symptoms experienced to identify the best way of managing or treating the condition.

Symptoms such as sleep or appetite disturbance, poor concentration, fatigue or weight loss are not particularly useful in the diagnosis of depression in people with MS. This is because they are common symptoms in people with MS who do not have depression.

Symptoms which can aid the diagnosis of depression in people with MS include pervasive low mood (low mood all the time and in every situation) for at least two weeks; mood particularly bad at a certain time of day (diurnal variation in mood); negative thoughts about self, the world and the future which are out of context with the level of disability; suicidal ideas and the lack of ability to take pleasure in routine things such as eating, talking, watching TV or walking; especially things that would have given pleasure in the past.

NICE recommends⁷ asking two key questions to identify those who might be depressed:

- during the last month, have you often been bothered by feeling down, depressed or hopeless?
- during the last month, have you often been bothered by having little interest or pleasure in doing things?

The mnemonic – DEPRESSION - below can be useful in determining the psychological needs of people with MS.

D - Diagnosis	How are you dealing emotionally with the diagnosis of MS?
E - Expression	Observe mood and facial expression
P - Pleasure	What things do you enjoy most?
R - Remorse	Do you feel guilty about things you have or have not done? Do you feel a burden to your family/friends?
E - Explore	Past personal or family history or psychiatric illness?
S - Sadness	How would you best describe your mood?
S - Stress	Do you experience stress and/or anxiety? How do you deal with this? What activities do you avoid due to stress/anxiety? Has your concentration decreased?
I - Insomnia	How well do you sleep? Do you experience early morning wakening? Do you experience initial insomnia/inability to sleep?
O - Others	How is illness perceived in your family? How do others perceive your mood?
N - Nutrition	How is your appetite? Do you taste and enjoy food? Have you gained/lost weight?

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Treatment

Various approaches have proven effective in treating depression and the individual should play a key role in deciding which treatment plan works best for them.

In addition to the NICE guideline for managing depression in long-term conditions⁷, a significant amount of research supports the use of low level interventions in the first instance. These include advice on sleep hygiene and exercise, ensuring better peer and social support and treating any pain and other physical symptoms.

If further treatment is required, the options are antidepressant medication and psychotherapy, which are often used in combination.

Selective serotonin reuptake inhibitors (for example, Prozac) can be useful and tricyclic antidepressants, such as imipramine and amitriptyline, are also sometimes prescribed.

The psychotherapeutic approach may involve identifying the cause of depression, and trying to alter negative patterns of thinking and behaviour into a more positive approach and may include cognitive behavioural therapy (CBT).

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Depression factsheet



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Women's health

Women with MS outnumber men by 3:1¹ and disease activity appears related to hormonal fluctuations by as yet, poorly understood mechanisms. Hence there are special considerations that need to be taken into account for women with MS, and the health professional requires an understanding of the impact of menstruation, pregnancy and menopause on MS.

Menstruation

Many women report cyclical changes in MS symptoms and feel that their symptoms deteriorate two to three days prior to the onset of their menstrual period and improve once bleeding has started. A few small studies have confirmed this anecdotal evidence though more work undoubtedly needs to be done in this area²⁻⁴.

In one small study⁵ it was found that 78% of women had premenstrual worsening of their MS symptoms in one or more of the menstrual cycles analysed. Symptoms most likely to increase pre-menstrually were limb weakness, pain and nocturia. Additionally, another small scale study found that those on combined oral contraception reported that their MS symptoms worsened during the pill-free week⁶. A greater understanding of this 'menstrual cycle effect' by women with MS and health professionals would help to reduce anxiety associated with an unexpected increase in symptoms.

Current data suggests that premenstrual symptoms alone cannot account for the change in MS symptoms and other hormonally related factors may be important. It is tempting to assume that the decline in the level of oestrogens accounts for premenstrual deterioration in MS symptoms. Research into MS and pregnancy^{7,8} points to oestrogen having a protective effect as it may suppress autoimmunity. Unfortunately solutions are rarely simple and an obvious question that comes to mind is "if oestrogen is so beneficial, why do more women than men have MS?" Sadly this paradox is still to be solved.

Women who are disabled by MS and who are no longer contemplating having children may want to consider ceasing menstruation by hormonal means. They should be encouraged to explore available options with their GP or practice nurse. Adopting this strategy may benefit carers particularly where a male is looking after a female partner and the couple find this aspect of care particularly difficult to deal with.

Contraception

All forms of birth control are available for people with MS, although various factors should be taken into account when decisions about contraception are being made. These include patient choice, ease, comfort, effectiveness, interaction with medications, and physical limitations such as loss of dexterity or spasticity.

There are no contraindications specific to women with MS for oral contraceptives, although it is recommended⁹ that there should be discussion with a physician since certain drugs, including antibiotics, phenytoin and carbamazepine, may reduce oral contraceptive effectiveness. It should be borne in mind that there is an increased risk of thrombosis associated with immobility, and the usual checks on weight, smoking and so on should be made as for any other woman contemplating oral contraceptives. If cognitive impairment affects the woman's ability to take daily oral contraceptives reliably, then a transdermal weekly patch may be a good alternative.

Good manual dexterity is needed for the use of barrier contraceptives, such as diaphragm, condoms and spermicides; hand tremor, weakness or sensory loss could therefore be problematic. It may be prudent to inform women with MS that using a diaphragm may increase the likelihood of bladder infections.

Intrauterine devices (IUD) have been shown to be generally safe, effective and easy to use. Hormone-releasing IUDs (eg Mirena coil) have the advantage of reducing menstrual flow and duration¹⁰.

Another option is a progesterone implant, again requiring no maintenance and effective for up to five years. Progesterone can also be injected on a three monthly basis.

Pregnancy

Because MS is most commonly diagnosed in women aged between mid 20s and early 30s, the question of pregnancy is an important one. The main issues are: the effect of the pregnancy on the mother with MS, the overall outcome of the pregnancy in terms of the baby's health, and the risk that the baby will inherit MS. A study investigating the concerns of pregnant women with MS¹¹ identified labour, delivery issues, breast feeding and short and long-term parenting issues. The unpredictability of MS resulting in uncertainty permeated many of these concerns.

Effect of pregnancy on the mother with MS

Until 1950 and the publication of Tillman's paper¹² on the effect of pregnancy on MS and its management, women with MS were advised to avoid pregnancy. Since 1950, many researchers in both retrospective and prospective studies have borne out Tillman's findings that pregnancy has no long-term effect on disability. However, there are still many myths and misconceptions about MS and pregnancy and some people (including health professionals) express disapproval when a woman with MS becomes pregnant.

In common with many other autoimmune diseases (rheumatoid arthritis, myasthenia gravis, for example), fewer disease events may be experienced during pregnancy for women with relapsing remitting MS, especially during the third trimester. This suggests that there is some protection from pregnancy-related hormones. However, that protection does not seem to apply to women with progressive disease. During the three months postpartum the risk of a relapse increases. Overall, however, pregnancy does not affect disease outcome or level of disability, and a two year follow up study determined that birth relapse risk is similar to that in the pre-pregnancy year¹³. While one small scale study suggested that breast feeding may offer a degree of protection against postpartum relapse¹⁴, a second, larger study found that breast feeding did not reduce the relapse rate post delivery¹⁵.

NICE guidance states that women with MS should be offered the most appropriate analgesia for them during delivery. Concerns are sometimes expressed regarding the use of epidural anaesthesia, but there is no evidence that epidural administration of drugs has any effect on relapse rate or disability¹⁶.

The incidence of instrumental or caesarean section deliveries has been shown to be no higher for women with MS. Although a small study concluded that women with MS were more likely to have assisted vaginal deliveries than those without¹⁷, a larger scale Canadian study refuted these findings¹⁸.

Overall outcome of the pregnancy in terms of the baby's health

There is no increased risk of miscarriage, foetal malformations, stillbirths, birth defects or infant mortality when the mother has MS.

Risk that the baby will inherit MS

MS is not hereditary and the majority of people who develop MS have no previous family history of the condition. However, family studies have revealed that there is a higher, but still small, risk of developing MS for someone with a relative with the condition¹⁹. In the general population in the UK, the risk of developing MS is about 1 in 700. The risk is higher for people who already have someone with MS in their family. On average, the risk for first degree relatives (parents, children, siblings) of someone with MS is about 1 in 40. For second degree relatives (cousins, uncles/aunts, nephews/nieces) it is around 1 in 100. While there is a genetic predisposition to MS, the actual risk is considered low and should not deter a couple from starting a family.

Other factors

When considering pregnancy other factors may need to be taken into account. Many of the drugs used in the treatment of MS are inadvisable during pregnancy and breastfeeding. Steroids may be used with relative safety in pregnancy²⁰. However, many pregnant women choose not to have steroids, particularly as they have no bearing on the degree of recovery from the relapse.

There is limited data on the use of disease modifying therapies in pregnancy. Women are usually advised to cease treatment three months before attempting to become pregnant, and recommence once breast feeding has ended. Immunosuppressive and some symptom management drugs may cause physical defects in the developing embryo.

As more evidence emerges regarding the link between MS and vitamin D, it is prudent for women with MS to supplement with vitamin D during pregnancy, if they are not already doing so. Vitamin D supplementation during pregnancy may lower the MS risk for the foetus, as well as provide other health benefits, and is now recommended (at a low dose) for all women²¹. However, as yet there is no clear guidance on appropriate dosage for pregnant women with MS.

Another consideration is the level of disability of the mother and the availability of help with the care of the baby, should this be necessary. Women with MS should be encouraged to plan for the postnatal period, in the event of relapse, utilising practical help from family and friends, or statutory assistance eg from social services, or via the health visitor. Local

MS mother and baby groups can be invaluable in providing peer support and preventing feelings of isolation. Levels of fatigue should also be taken into account, bearing in mind that this common symptom can be exacerbated by the pregnancy itself and by subsequent disturbed nights.

MS is unpredictable and therefore decisions about having children can be difficult to make. The health professional can achieve a great deal by encouraging exploration of all the issues, many of which will be uncomfortable, and providing up to date information and support.

Menopause

Menopause does not appear to have any effect on MS either positive or negative, although there has been little research in this area²². However, there is anecdotal evidence, as well as a few small studies, indicating that symptoms which worsen during menopause may be responsive to hormone replacement therapy (HRT). The majority of women with MS who have used HRT report improvement rather than deterioration in their condition, but any potential benefit must be evaluated against possible risks. Since loss of bone density and osteoporosis may be a problem for people with MS²³, the beneficial effect of HRT on reducing the risk of osteoporosis should be taken into account.

Health screening

It is important that women with MS should be offered all relevant health screening, for example for cervical and breast cancer²⁴. Unfortunately access to screening tests can be restricted for women with chronic disabling conditions, due to substantial physical barriers (eg mobile breast screening units with steps) thus limiting health promoting activities critical to a healthy life²⁵.

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MS Trust resources
Pregnancy and
parenthood factsheet



Bladder

Bladder problems are one of the most common symptoms reported by people with MS with studies frequently citing around 75% of people experiencing this symptom¹. They tend to occur as MS advances, appearing on average six years into the illness, although one in ten people may report symptoms at the time of initial onset². This highlights the importance of raising bladder issues in routine assessments.

Poor bladder control is disabling and many regard this as one of the most constraining aspects of their MS³. Unpredictable urinary urgency with a danger of incontinence can cause a person to become housebound, unwilling to venture out where access to toilets is uncertain. Although urinary urgency and frequency are the most common problems, many people with MS can experience difficulty in completely emptying their bladder. In some situations, such as prior to going out, they can find it difficult to initiate passing urine even in the absence of urgency. They may have a reduced flow rate, an interrupted stream and the sensation of incomplete bladder emptying. It is important to emphasise that much can be done to improve this.

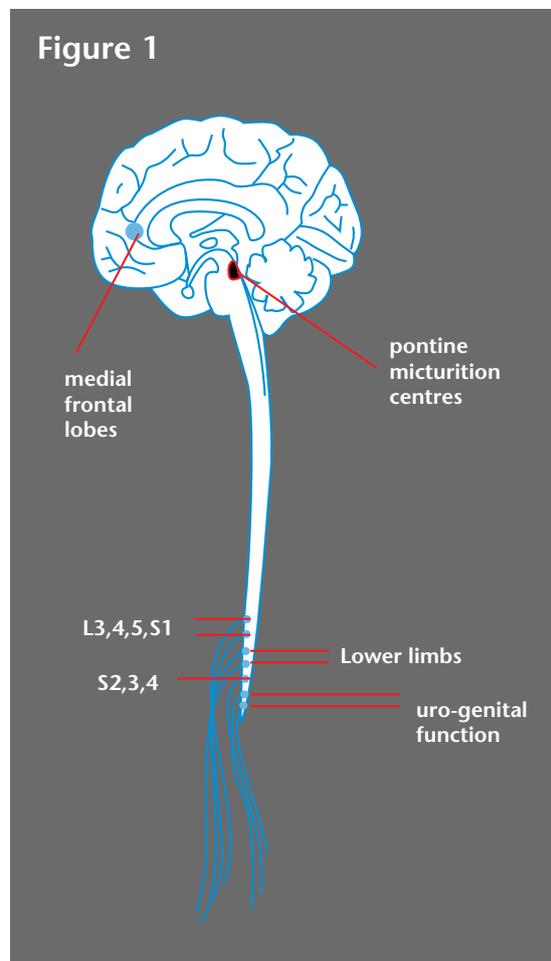
Bladder disorders that occur in MS are of two distinct types: overactivity and incomplete emptying⁴.

Overactivity

Bladder overactivity is usually the problem a person with MS is most aware of. It results in a tendency for the bladder to contract unpredictably and sometimes uncontrollably, this results in urgency, frequency and urgency incontinence. At its worst, the bladder may seem to have 'a life of its own'.

In health, the bladder behaves a bit like a balloon although there is a significant difference - unlike a balloon it has a special property that enables it to expand without raising internal pressure. This remarkable property is the result of its nerve supply from the spinal cord, from controlling centres within the brain; particularly the micturition centre situated at the base of the brain (Figure 1). With spinal cord disease this connection is disrupted and the special property lost resulting in an overactive bladder. The bladder, after only partial filling, develops spontaneous, insuppressible contractions that provoke a sense of urinary urgency. Urinary

incontinence will occur if the contraction pressures are too high for the muscles at the bladder outlet to hold on.



This diagram shows how nerves supplying the legs branch off the spinal cord, above those to the bladder. The micturition centre at the base of the brain is shown by a large black dot. If there is disease affecting the spinal cord (in the cervical cord area, a common site for demyelination in MS), neural impulses between the micturition centre and the nerves to the bladder will be interrupted, as will impulses between the brain and nerves to the legs. For this reason difficulty with walking is usually associated with poor bladder control in multiple sclerosis: both problems can be the result of spinal cord disease^{5,6}. The effect of this is unfortunate because bladder control deteriorates at the same time as mobility worsens; making it increasingly difficult to respond to bladder urgency by hurrying to the toilet.

Another feature of the impaired nerve supply to the bladder muscle is that the normal capacity is

diminished, causing urinary frequency. In health, the bladder has a capacity of between 300 and 500ml (about a pint of fluid), whereas the capacity in people with bladder problems due to MS may be reduced to 100ml or less. This increases the frequency of emptying from every three to five hours (depending on how much is drunk) to hourly or worse in the day and at night.

Incomplete emptying

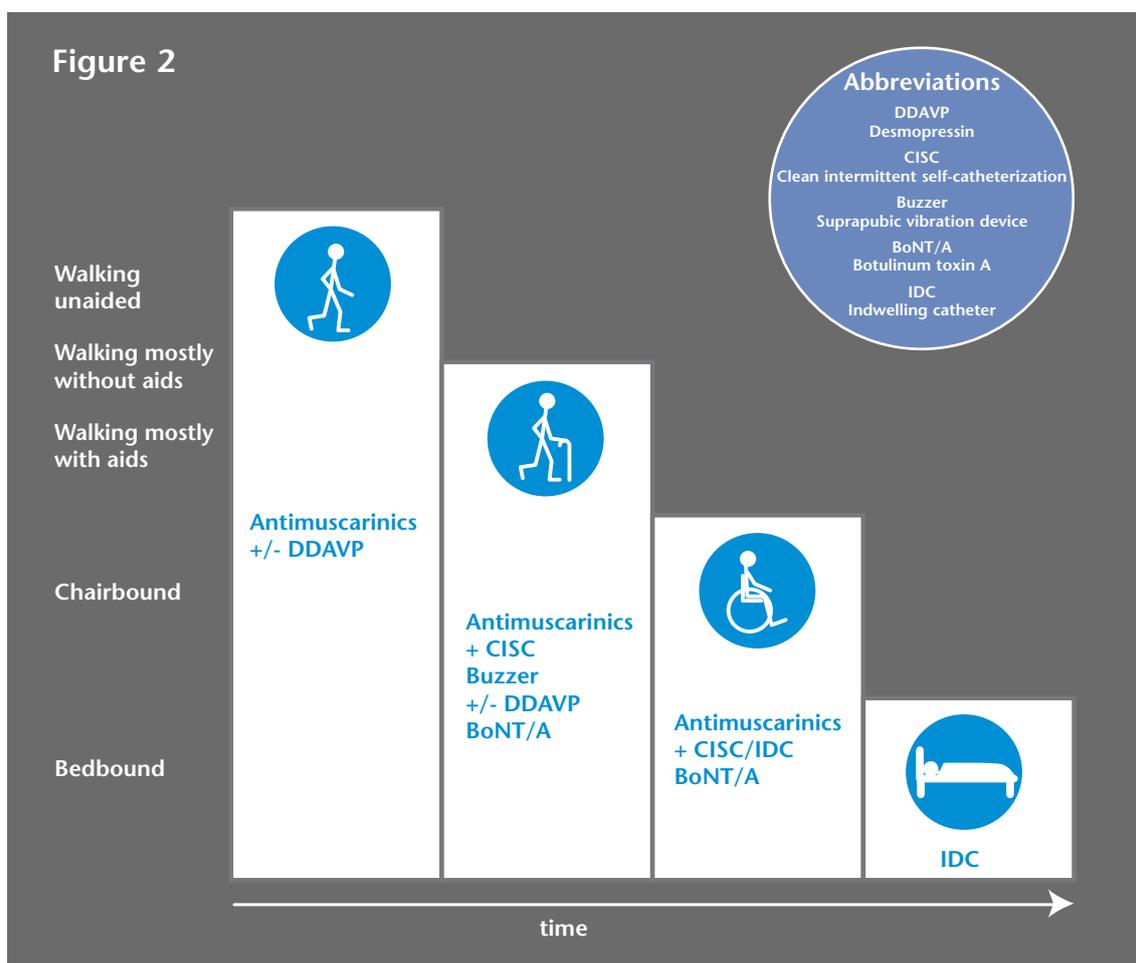
Although some people with MS are aware that their bladders do not empty properly, others with the same problem are not. For many, needing to void again soon after doing so is usually an indicator that bladder emptying is poor. Research has shown that if people with MS thought they were not emptying their bladder properly, they were usually correct. However, of those who thought they were emptying completely, about half were wrong and were surprised to find how much urine they had been leaving behind⁶. This results in hesitancy and retention.

Incomplete bladder emptying is the result of two things going wrong, both of which are due to spinal cord malfunction:

- the muscle which surrounds the bladder outlet tube (urethral sphincter) does not relax when the bladder muscle contracts, thus resulting in an interrupted flow
- the neural impulses that normally keep the bladder muscle contracting until it is completely empty do not get down the spinal cord. When the bladder does contract, the contractions, although frequent, are poorly sustained.

Management

In 2009 stakeholders involved in continence care, including neurologists, urologists, primary care professionals, MS nurses and nursing groups, formulated a set of guidelines for managing bladder problems in MS. Expert consensus was reached after discussion, and recommendations agreed on review of literature and expert opinion (Figure 2).⁷



The consensus states that a person with MS who complains of lower urinary tract symptoms must be assessed by a suitably trained health professional who is knowledgeable about MS and its effects on lower urinary tract function.

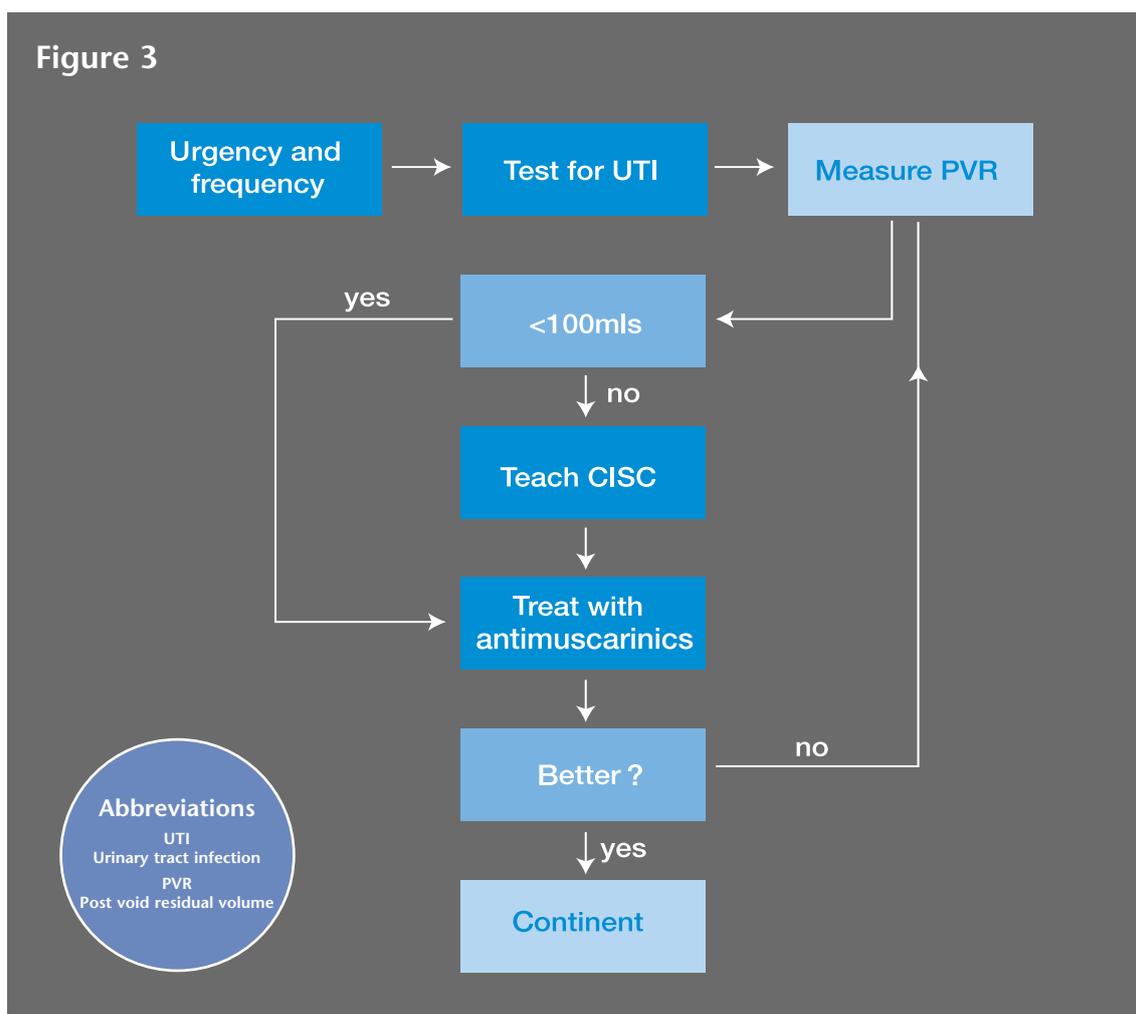
- “Dipstick” tests of the urine must be undertaken in patients with new symptoms of bladder dysfunction. The first step is to test for a urinary tract infection (UTI). UTIs can themselves worsen bladder symptoms. Importantly, they can also worsen other neurological symptoms, and potentially precipitate an MS relapse.
- If there is reason to suspect incomplete bladder emptying measurement of post micturition residual volume; the volume left behind after passing urine, should be carried out prior to any treatment intervention.

- Urodynamic investigation with filling cystometry and pressure/flow studies of voiding should be carried out in those who are refractory to conservative treatment or whose symptoms have significant impact on daily life and there is a need to undergo further investigations.

- It is recommended that for most people with MS, bladder problems can be successfully managed based upon a simple algorithm (Figure 3)⁷. Any person with residual volume in excess of 100ml should be offered the opportunity to learn clean intermittent self-catheterisation.

Reviewing someone’s daily fluid intake, both quantity and type of fluid, by completing a voiding diary is valuable. Fluid intake needs to be individualised, however intake of between one and two litres a day is recommended⁷. Pelvic floor exercises may be helpful especially when symptoms are mild.

Figure 3



Management of overactive bladder

Antimuscarinics

Antimuscarinic medications block the messages that initiate bladder contractions and reduce frequency of bladder emptying. The names of the commonly prescribed drugs are given in Table 1. These can be very effective in managing an overactive bladder⁸ but risk causing a dry mouth as common side effect. A dry mouth is evidence that an effective dose is being taken. It is important to adjust and titrate medication slowly, adding additional doses over intervals of weeks, so that the bladder remains under control but the mouth is not too dry. Artificial saliva may be prescribed, in either tablet or spray form if a dry mouth becomes too uncomfortable. Oxybutinin patches have been found to reduce this side effect.

Antimuscarinic medication can exacerbate problems when the bladder does not empty properly. In this situation, the medication, whilst lessening the tendency for the bladder to contract, also impairs its already poor emptying ability (Figure 4). The management strategy is to resolve incomplete bladder emptying as the first step.

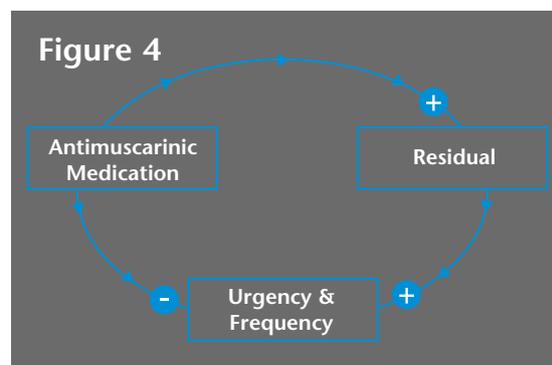


Table 1

Generic name	Brand Name	Dose	Frequency
Propantheline	Pro-Banthine	15mg	Three times a day
Tolterodine tartrate	Detrusitol	2mg	Twice a day
Tolterodine tartrate	Detrusitol XL	4mg	Once a day
Tropium chloride	Regurin	20mg	Twice a day
Oxybutynin chloride	Ditropan	2.5–5mg	Two to four times a day
Oxybutynin chloride XL	Lyrinel XL	5–30mg	Once a day
Propiverine hydrochloride	Detrunorm	15mg	One to four times a day
Darifenacin	Emselex	7.5–15mg	Once a day
Solifenacin	Vesicare	5–10mg	Once a day
Fesoterodine	Toviaz	4–8mg	Once a day

Botulinum toxin

For some people, the measures outlined above will not provide adequate bladder control. Injecting botulinum toxin into the bladder wall was first reported in Switzerland over ten years ago and is highly effective in reducing urgency and incontinence. In people with MS, the injections have been shown to be effective in managing detrusor over-activity and to improve symptoms of urgency, frequency and incontinence. It also improves quality of life⁹. A consistent response is seen in patients who receive repeat injections¹⁰. However bladder emptying is almost always affected by this procedure so acceptance to carry out clean intermittent self-catheterisation is crucial. The procedure can be done under local anaesthetic as an outpatient and the benefit seems to last for around a year. This treatment is recommended for those who have not responded to antimuscarinic medications, and are willing to perform clean intermittent self-catheterisation⁷.

Other approaches

Posterior tibial nerve stimulation (a procedure for stimulating the nerve behind the ankle) has recently been found to help with overactive bladder symptoms in people with MS¹¹.

Management of incomplete bladder emptying**Clean intermittent self-catheterisation (CISC)**

A persistent post void residual volume in excess of 100ml indicates that clean intermittent self-catheterisation should be offered⁷. This technique has been in use for nearly 40 years¹² resulting in the single greatest improvement in managing the bladder problems of MS¹³. This must be initiated and taught by a urology specialist nurse or continence advisor.

People have varied responses to the suggestion that they should self-catheterise, some react with horror and fear. Fortunately, most people decide to try the technique once the fundamentals of pelvic anatomy have been explained (particularly important for women), reassurance given that it will not hurt, is not invasive, the discretion of the catheter shown, the personalised nature of the procedure emphasised and the technique expertly demonstrated. Talking to someone who has previously mastered the method can be helpful for some who are novice.

CISC will help reduce bladder symptoms of accumulating urine that cannot be eliminated naturally. The procedure will benefit those with symptoms of difficulty in voiding as well as those who have urinary frequency and urgency because of bladders that are persistently nearly full.

The recommended regime to self-catheterise is two or three times a day and, if nocturnal frequency is problematic, last thing before bedtime. The patient will become the expert on how often he/she should carry out their CISC. Some find it necessary to catheterise four or six times in 24 hours. More frequent CISC may indicate that bladder storage capacity is poor and antimuscarinic medications need to be increased.

Lack of motivation is a common cause of failure, and there are also some medical conditions that make it impossible. Poor hand function due to weakness or tremor is a major difficulty. A general benchmark is that people who can write and feed themselves are likely to have the necessary manual dexterity to self-catheterise. Lower limb spasticity or spasm may make thigh abduction difficult but with appropriate management CISC may still be possible.

Other approaches

There is some evidence that supra pubic vibration (a "buzzer") can improve bladder emptying for those with both incomplete bladder emptying and detrusor overactivity¹⁴.

Night-time urinary frequency and nocturnal incontinence

Nocturnal incontinence and night-time urinary frequency are two of the worst problems associated with urinary impairment. For most people with MS, symptoms are helped significantly by taking an oral antimuscarinic and carrying out CISC, before going to bed. Sometimes, despite these measures, difficulties persist and desmopressin at night may be effective as it reduces the volume of urine produced overnight by the kidneys (when they are at their most productive). Its action lasts for 3-6 hours and, despite its mode of action, is safe when taken precisely as instructed. Desmopressin is usually taken as a spray. It can be used during the daytime but it is essential that the user realises the possible dangers of retaining too much water if it is used more than once in 24 hours¹⁵. It should not be prescribed to people over 65.

Bladder management in advanced MS

With advancing disease, drugs, CISC and botulinum toxin may prove inadequate or unsuitable. An indwelling catheter inserted suprapubically, can transform the life of a person with MS. It is important that regular review, advice and support is sustained and is appropriate to the current level of disability or impairment⁷.

With the advent of botulinum toxin, the need for surgical intervention has diminished significantly. However there may be individuals whose symptoms are intractable and who may benefit from surgery and they should be under specialist care.

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MS Trust resources

Bladder factsheet



A UK consensus on the management of the bladder in multiple sclerosis

Bowel

Although bowel problems are common in patients with MS they are generally under reported and neglected¹. Wiesel² reported that the prevalence of bowel dysfunction in patients with multiple sclerosis is higher than in the general population. Up to 70% of patients complain of constipation or faecal incontinence, which may coexist^{2,3}. Sullivan and Ebers⁴ also reported that 53% of people with MS complained of constipation and another study of a large number of people with MS found that 43% had constipation and 53% faecal incontinence.

Bowel dysfunction is a source of considerable ongoing distress in many patients with MS. Symptoms related to the bladder and bowel are reported by patients as an important symptom limiting their ability to work². Management of bowel problems is influenced by many factors, including people's expectations of 'what is normal', tradition, and culture⁵. Bowel control is extremely complex, involving a delicate coordination of many different nerves and muscles. Overall bladder and bowel dysfunction has been linked to lower limb dysfunction, meaning that paralysis of legs and walking difficulties are often accompanied by bladder and bowel problems, thus compounding management difficulties.

Managing dysfunction begins with assessment by an experienced health professional followed by ongoing collaboration with the individual to develop an approach which meets their particular needs. Assessment should be repeated as an individual's needs change. In the absence of research evidence from studies with MS patients, findings in other similar patient groups, such as spinal cord injury, should be used to inform care.

Neurological control

In order to have voluntary control of defaecation (continence), it is necessary to have sensation of the presence of stool in the rectum, sometimes referred to as the 'call to stool'. This sensation occurs when the faeces move into the rectum, stretching the rectal walls and triggering messages of the need to evacuate to be sent via the sensory pathways to the sacral spinal cord and brain. Sensory information will differentiate between solid

or liquid stool or flatus in the rectum. In response to sensory messages motor impulses reach the anorectum from the brain and sacral spinal cord to coordinate reflex activity and to allow voluntary relaxation of the anal canal for evacuation; if defaecation is not convenient, the urge to defaecate can be voluntarily suppressed, stool moves back up into the rectum and away from the anal canal.

Damage to any part of this pathway, may reduce or completely interrupt transmission of motor and sensory nerve impulses resulting in reduced or lost sensation and control over voluntary muscle function leading to faecal incontinence.

Damage to autonomic nerve pathways in the spinal cord alters colonic motility due to impaired parasympathetic and sympathetic input. This may result in rapid transit and loose stool but more often results in slower transit and constipation. Reduced motility and impaired reflex coordination of the pelvic floor, left or descending colon, rectum and anal canal can result in evacuation difficulties. These pathophysiological problems are compounded by reduced mobility, polypharmacy, spasticity and fatigue⁶.

Management

Bowel dysfunction, particularly faecal incontinence, has a significant negative impact on the quality of life of individuals. It may be an important contributor to the decision to stop working, and may result in social isolation and admission to residential care. Minimising the impact on the individual and their family is important.

The NICE guidance on management of MS⁶ specifically identifies bowel problems as significant and commonly encountered by patients. The guidelines suggest that all health professionals in contact with individuals with MS should have in mind the possibility of bowel dysfunction. Where an individual reports problems with bowel function an assessment should be undertaken to clearly identify the problem and to support the development of an individualised bowel management programme.

There are few published studies to support bowel management for people living with MS, so much of the following is based on evidence and experience from the spinal cord injured population.

Aims

The aim of managing bowel dysfunction depends on the main symptom.

- **Faecal incontinence** - providing predictable, effective and reliable evacuation at a chosen time.
- **Constipation** - promoting an appropriate stool form with easy, effective evacuation on a regular basis.

In either case where an individual has faecal urgency, impaired mobility and therefore difficulty accessing a toilet in a timely way, or where help is required with toileting, promoting a regular routine, which allows evacuation to occur at an appropriate time, is essential. This is sometimes referred to as a pre-emptive approach; bowel evacuation and care is prompted at a suitable time when it is most manageable so pre-empting faecal incontinence or urgency at other times. Regular effective emptying of the bowel also helps to avoid the build up of constipated stool and development of faecal impaction.

Assessment

A bowel assessment should be holistic in nature, focusing on the objectives identified by the individual and placing the bowel issue in the context of the wider impact of MS for that individual. Co-morbidities should also be considered, an individual with MS may also experience gastrointestinal morbidity and referral for gastroenterological or colorectal opinion may be warranted.

A simple bowel diary completed for one week before assessment is a very useful adjunct. This should record timing, frequency and stool form at evacuation. Methods used to assist evacuation (laxatives, rectal stimulants, digital interventions), episodes of faecal incontinence and other problems should all be noted. A record of dietary and fluid intake can also be useful.

The assessment should consider:

- type of MS and level of disability
- brief medical history - including gut-related disease/surgery, obstetric history
- medication - including over-the-counter and complementary or alternative medicines. The following groups of drugs are associated with altered stool consistency, most often constipation:

aluminium antacids, antibiotics, antimuscarinics, antiepileptics, antidepressants, calcium supplements, diuretics, iron tablets, opiates

Individuals with MS will often be taking multiple medications. Where new medications are commenced or changes made to dosage, the patient should be educated to be alert for changes in bowel function and if necessary to seek advice.

- diet - appetite, frequency of meals/snacks, intake of fruit, vegetables and wholegrain foods
- fluid intake - volume and type
- bowel function - sensation of need for evacuation, voluntary control - ability to defer defaecation – for how many minutes after first urge
- frequency of evacuation
- stool form - use the Bristol Scale⁷ to describe stool form. Abnormal stool such as black-tarry, pale or bloody stool should prompt further investigation which may include onward referral
- frequency of faecal incontinence - volume and stool type
- other symptoms - abdominal bloating, passage of flatus, pain, rectal bleeding, haemorrhoids, fissures etc
- current/previously tried methods of managing - if any - oral laxatives, rectal stimulants, use of pads
- duration of bowel care
- level of dependence in bowel care - who provides care if required
- accessibility/suitability of toilet facilities - refer to local community occupational therapist if appropriate
- impact on social and work life.

Ideally, the assessment will include a digital rectal examination. This allows visual assessment of the perianal area, assessment of anal tone, sensation and voluntary anal squeeze, presence and type of stool in the rectum, local problems such as anal stricture, prolapse, haemorrhoids, fissure etc.

Radiographic colonic transit studies and anorectal physiology tests may be undertaken in some centres. However, the usefulness of such tests in managing neurogenic bowel dysfunction has yet to be established.

Interventions

Diet

The impact of dietary fibre on bowel function in individuals with MS is not clear. However, the general health benefits of an adequate intake of soluble and insoluble fibre through fruit, vegetables and whole grain foods are well recognised. The individual should be encouraged to aim for five portions of fruit and vegetables daily with one or two portions of wholegrain foods. Their intake should be increased gradually to avoid abdominal bloating or flatulence, and will be dependent on ability to eat and appetite. Fruit and vegetables may be fresh, frozen or dried; a standard portion is 80g. Impact on bowel function can be assessed as the diet is gradually changed and amended as necessary.

Fluid intake

The normal function of the large bowel is to absorb water. In conditions where transit time is extended, greater water absorption occurs resulting in increased risk of constipation. Inadequate fluid intake is also a factor. A good guide in assessing fluid intake is to observe the colour of the patient's urine⁸, pale straw coloured urine indicates an adequate intake, darker urine suggests that intake should be increased. While water, which is free of any additives, is the ideal any fluid that the patient will drink should be encouraged to maintain pale straw coloured urine.

Defaecation dynamics

In patients presenting with constipation who are able to use the toilet, correct positioning when toileting can promote improved evacuation of stool. Feet should be supported and the knees should be higher than the hips in a quasi-squatting position. Bracing the abdominal muscles and bulging the abdominal wall outwards to increase abdominal pressure may assist the passage of stool without raising intrarectal pressures unduly.

Opening the bowels over a toilet is the norm for adults and all reasonable efforts should be made to facilitate this. This may require adaptation of the toilet or bathroom. An occupational therapist assessment of the patient's own environment and appropriate risk assessment for carers giving bowel care in the home is required.

Establishing a routine

Having a regular routine is fundamental to gaining control over bowel function and avoiding constipation. The routine should be developed

individually and be designed to fit into the individual's life. Frequency of bowel care may range from once or twice daily to alternate days and some flexibility should always be maintained⁹.

Establishing appropriate stool consistency

Stool consistency is described here using the Bristol Stool Form Chart⁷, a copy of which can be found below.

The Bristol Stool Form Scale

Type 1		Separate hard lumps, like nuts (hard to pass)
Type 2		Sausage-shaped but lumpy
Type 3		Like a sausage but with cracks on its surface
Type 4		Like a sausage or snake, smooth and soft
Type 5		Soft blobs with clear-cut edges (passed easily)
Type 6		Fluffy pieces with ragged edges, a mushy stool
Type 7		Watery, no solid pieces ENTIRELY LIQUID

If the stool is too soft or loose it is difficult to control and can contribute to incontinence. A bulking agent such as Fybogel may help, along with increasing wholegrains such as wholemeal bread which help to absorb liquid. However, there is a risk of 'soft impaction' or overloading of the bowel with soft bulky stool in immobile individuals with slow colonic transit when using bulking agents.

Where the stool is constipated and diet alone has not been effective a number of laxatives which soften stool and/or stimulate colonic activity are available. It is important to match the introduction or increase in stool softeners or stimulant laxatives with planned management of evacuation. People usually begin with small doses of laxatives and increase gradually until the appropriate stool consistency is achieved; if the stool becomes too soft the laxative should be reduced gradually.

Bristol Stool Form Scale 4 is identified as the optimal stool form for the general population and for those with intact evacuatory reflexes. Some individuals prefer to have a more formed stool (Bristol Stool Form 3) as this gives them more control over evacuation; for instance individuals without evacuatory reflexes who use manual evacuation of stool as their main method of evacuation. Care should be taken to avoid development of constipation in the longer term.

Abdominal massage

Abdominal massage is used by up to 30% of individuals with neurogenic bowel dysfunction^{9,10}. It is regarded as a non-invasive technique to encourage stool transit, and while it may not eradicate the need for laxatives it may reduce it¹¹ and improve quality of life in constipated individuals. Massage may be used before and after digital rectal stimulation, insertion of stimulants or digital removal of faeces to aid evacuation¹². McClurg and Lowe-Strong¹³ also describe a technique for massage, and suggest regular use not directly associated with bowel evacuation can be beneficial.

Laxatives

Where stool form is not optimal due to slow transit or evacuation difficulty, oral laxatives may be used to improve stool form and evacuation.

Types of laxatives:

- **Bulk forming laxatives** include ispaghula (Fybogel, Regulan, Isogel), methylcellulose (Celevac), sterculia (Normacol). They must be taken with ample fluids to avoid obstruction; a good general fluid intake is essential. They may be

useful where dietary fibre cannot be increased and are suitable for long term use. They should not be used in existing bowel obstruction or faecal impaction. They take a few days to become effective and may cause flatulence and abdominal distension especially when first used. They should be used daily in a regular pattern.

- **Osmotic laxatives** such as lactulose and macrogols (Movicol, Idrolax) act by retaining fluid in the bowel due to osmotic action. They produce a softer bulkier stool. They take up to three days to become effective and may cause bloating and flatulence. Small regular doses to achieve optimal stool consistency may be best as doses large enough to cause evacuation may result in incontinence.
- **Stimulant laxatives**, such as senna and bisacodyl, stimulate intestinal motility. They take 8-12 hours to be effective. They are used to promote evacuation of stool and so are only taken 8-12 hours prior to planned evacuation of the bowel. While they are usually recommended for short-term use in the general population, in individuals with neurogenic bowel dysfunction, long-term use is more usual and they form part of the individuals ongoing bowel management programme.
- **Assisting evacuation of stool**
Being able to initiate bowel evacuation at a chosen time is an important part of achieving managed continence. This can be done by using pharmacological or digital rectal stimulation for those with reflex activity.

Rectal stimulants

Suppositories or micro enemas are used to trigger reflex rectal contractions to expel stool in individuals who have reflex activity in the anorectum. Glycerin, Lecicarbon E and bisacodyl suppositories (ranging from milder to stronger) may be used; Micralax, Microlette and Norgalax mini enemas may also be tried, usually when suppositories have not been effective.

- **Digital rectal stimulation**

Where an individual has reflex activity in the anorectum and is unable to voluntarily expel stool from the rectum, digital rectal stimulation (DRS) may be used to initiate defaecation at a chosen time. The technique stimulates increased reflex muscular activity in the rectum, raising rectal pressure to expel stool, and relaxes

the external anal sphincter, thus reducing outlet resistance^{2,12,14,15}. It also stimulates movement of stool into the rectum. It is often required in addition to the use of pharmacological rectal stimulants but for some patients digital rectal stimulation alone is effective. It can be conducted by the individual themselves if able or by a suitably trained nurse or carer.

Manual evacuation of stool

The need for and importance of manual evacuation of stool has been recognised in recent publications^{16,17}. Manual or digital removal of stool involves the insertion of a single gloved, lubricated finger into the rectum to break up and/or remove stool¹⁸. It is a very common intervention amongst individuals with neurogenic bowel dysfunction⁹ and is used by individuals with no anorectal reflexes¹⁹ as their main method of evacuation. It can be conducted by the individual themselves if able or by a suitably trained nurse or carer. Caution has been expressed in one text because the risk of stimulation of the vagus nerve in the rectal wall can slow the clients heart²⁰ but this is an uncommon side effect, rarely seen in practice.

Transanal irrigation

Warm water (body temperature 36-38C) is instilled into the rectum and colon using a hand or electric pump or by gravity. This both stimulates colonic reflex activity and mechanically washes stool out. A small number of different systems are available and irrigation using either system can be given by a carer. Two recent reviews have suggested that transanal irrigation is superior to bowel management using suppositories^{21,22} but laxatives may still be required to maintain an effective programme. Irrigation can provide improved outcomes in terms of duration and completeness of evacuation, but it does not suit every patient and reliable selection criteria have yet to be identified. Assessment by an experienced health professional, and careful teaching and supervision of the irrigation technique increase the likelihood of success.

Biofeedback

Biofeedback is a behavioural therapy which aims to educate a patient about bowel function, diet and fluids, and re-educate them in terms of their muscle function and bowel control²³. Psychological and emotional support is also offered. Biofeedback may be useful for individuals with mild to moderate MS symptoms²⁴, and is offered at many specialist colorectal centres.

Sacral nerve stimulation (SNS)

SNS is delivered via an implanted device which provides continuous low amplitude stimulation of the sacral nerve plexus²⁵ which is interrupted to allow defaecation. Intact sacral nerves are required; SNS is not effective in individuals with complete spinal cord injury²⁶. The benefits of this technique for individuals with neurogenic constipation and faecal incontinence are still undergoing exploration^{26,27}.

Stoma formation for bowel management

For some individuals neurogenic bowel dysfunction and its management have such a severe impact on quality of life that they opt for a stoma to alleviate the problem. Approximately 3.5% of individuals with spinal cord injury in the UK have a stoma to manage their bowel dysfunction²⁸ and the outcomes appear very good in this highly selected group^{29,30}. The numbers of individuals with MS who make the same choice is unknown but for some individuals a stoma can significantly reduce the impact of bowel dysfunction on their lives when all other options have been explored.

Containment products

The goal of effective bowel management is to enable the individual to achieve managed continence; the use of containment products as the main method of management is only a choice where all other options have been explored and found ineffective. There is a wide range of equipment and disposable items, both body-worn and to protect bedding etc available to choose from³¹.

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MS Trust resources

Bowel factsheet
Diet factsheet



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Sexuality

The NICE clinical guideline¹ states that MS may disturb the normal sexual physiology and may result in other impairments that make normal sexual behaviour difficult. This may make it difficult for the person to establish or maintain relationships and as both aspects are important they should be recognised together.

Epidemiology

Sexual problems are common in multiple sclerosis. Estimates of the frequency of sexual dysfunctions vary from 50 to 90% in men and 40 to 80% in women, depending on the severity of disability of the group and duration of illness²⁻⁵. Such reports tend to focus on physical problems and the total impact of a change in an individual's sexuality is often overlooked.

Sexual dysfunction correlates positively with the presence of other disabilities in particular bladder and bowel symptoms, sensory disturbance of the genitalia, weakness of the pelvic floor and spasticity⁶⁻⁸. The associated factors may be recognised as 'risk factors' and alert health professionals to the possibility of sexual dysfunction. In common with other symptoms of MS those of sexual dysfunction can also relapse and remit. Studies have estimated that over 50% of people with neurological disorders may experience sexual dysfunction, but only approximately 25% express concern about problems they may have^{9,10}. People do not always voice their concerns and health professionals are sometimes reluctant to enquire but people with MS should be offered the opportunity to discuss any issues or problems. The NICE clinical guideline¹ recognises the importance of enjoying sexual health regardless of illness or disability and states, 'Every person (or couple) with MS should be asked sensitively about or given opportunity to remark upon, any difficulties they may be having in establishing sexual or personal relationships'.

Types of dysfunction

Kaplan¹¹ divided the sexual response cycle into three phases - desire, excitement and orgasm.

Sexual problems can be described as primary, secondary or tertiary². People with MS may experience dysfunctions as a consequence of one or all of the above. Primary dysfunction is caused directly by demyelination, for example numbness in the genital area. Secondary sexual dysfunction occurs as a result of

MS symptoms such as spasticity, and tertiary dysfunction can be seen as a result of the psychosocial impact such as depression or changes within the relationship. It is important to establish in which of these areas the sexual problem is presenting.

Medication commonly contributes to sexual dysfunction; for example, tricyclic antidepressants are associated with erectile dysfunction and the selective serotonin reuptake inhibitors are associated with delayed or absent orgasm or ejaculation. Loss of desire may result from depression or changes within the dynamics of the relationship. People should be offered information about locally available counselling and supportive services such as Relate. Psychosexual counselling may be appropriate for some.

The very nature of sexual problems can make discussion difficult for both people with MS and healthcare professionals. Individuals may not be aware that MS can affect sexual functioning and assessment of these needs is important.

Men with MS

The commonest dysfunction in the excitement phase is erectile dysfunction which brings a significant impact on quality of life^{3,12}. This is often a primary symptom, a direct result of demyelination. However, assessment must include psychosexual and relationship factors as well as the physical aetiology since the cause of sexual dysfunction is often multifactorial. Erectile dysfunction may also be the first sign of cardiovascular disease¹³.

The PDE5 inhibitors, sildenafil (Viagra), vardenafil (Levitra) and tadalafil (Cialis) are the most popular first line treatments and are probably effective in 70-80% of men. A double-blind, randomised trial involving 217 men with MS found that sildenafil significantly improved erections (90% of patients) compared with placebo (24% of patients)¹⁴. NICE guidance¹ recommends that men with persisting erectile dysfunction who do not have contraindications should be offered 25-100mg sildenafil.

Tadalafil has the advantage of being effective for up to 36 hours which may mean less planning and pressure to have sexual intercourse to a schedule. In an Italian study, 72 of 92 (78%) men with MS responded to 10-20mg doses of tadalafil, with statistically significant improvements in erectile function and in sexual satisfaction scores¹⁵.

Side effects most commonly experienced with PDE5 inhibitors include headache, flushing, rhinitis (nasal congestion) and dyspepsia. The only absolute contraindication to PDE5 inhibitors is concurrent nitrate therapy and nicorandil.

Where someone does not respond to PDE5 inhibitors they should be assessed for general and specific factors that might worsen erectile dysfunction; these might include depression, anxiety, vascular disease, diabetes and other medications. Alternative treatments such as alprostadil or intra cavernosal papaverine could then be considered, or intraurethral applications (eg MUSE), or a constriction ring. Vacuum devices are excellent at preventing penile atrophy and should be considered as an adjunct to pharmacological management.

Medications may not on their own solve psychological or relationship issues, but can be helpful in conjunction with counselling.

Women with MS

Most of our knowledge regarding sexual functioning has been derived from studies in men. Understanding of female sexual dysfunction is gradually increasing in what has previously been a neglected area.

Problems may include loss of libido, lack of vaginal lubrication, difficulty in achieving orgasm, pain during intercourse and numbness. As with men, both psychological and neurological factors are components of sexual dysfunction.

Women may experience alteration in the excitement phase and work is being carried out in this area, however trials have found that sildenafil is not effective in women¹⁶. There have not been many advances in the therapeutic options, with reliance on topical lubricants and creams. Poor vaginal lubrication can easily be solved by liberal application of water-based lubricants such as Sylk or Senselle.

Changed sensation in the genital area may respond to treatment such as carbamazepine or amitriptyline. Some women find that the use of vibrators and other sexual aids increases the intensity of stimulation. Education can also be important in helping women to explore other means of achieving orgasm and additional erogenous zones. Partners could be encouraged to experiment to find new ways to approach altered sexual functioning and not lose sight of the fact that this can be fun.

Partners and relationships

Masters and Johnson¹⁷ observed that there is no such thing as an uninvolved partner. The turmoil of emotions, which may occur in response to the onset of disability, impacts upon the partner and may alter their need for autonomy and intimacy. A change in roles within a relationship from an equal partnership to one of 'carer' and 'cared for' substantially alters the dynamics of the relationship. In addition the effects of cognitive changes on the relationship may need to be addressed. Some couples may adjust and adapt to a new type of relationship but others may experience great distress. Identified risk factors within relationships are the presence of a progressive condition, relationships begun before the onset of disability and the presence of a sexual dysfunction^{10,18-20}. The importance of intimacy and communication within couples is vital as people often have difficulty talking about problems with each other.

People who are not in a relationship

Sexual expression is no less of an issue for those not currently in a relationship. Often there is a greater degree of reticence about asking for help. Concerns about sexual functioning with a new partner, or about finding a partner in the face of mobility problems, continence and other difficulties, need the opportunity to be voiced.

Helping individuals and couples with sexual and/or relationship difficulties

A commonly used model in facilitating discussion of sexual dysfunction is known as the P-LI-SSIT model. This is a hierarchical model that can be applied by any health professional to the point at which they feel able to operate^{21,22}. The components of the acronym are pyramidal; many people will benefit from the first intervention but few from the fourth.

P - giving people permission to discuss sex and relationship worries. Professionals should be able to pick up cues or ask specifically about sex and relationship issues. "MS can have quite an effect on the more intimate side of life. Has that caused you any concern?"

LI - providing limited information about any areas of concern. This can be done by whoever the person with MS has confided in. If they feel unable to provide information, then having listened to the problem they can make a referral to another agency such as a sexual dysfunction clinic, counselling or Relate. Acknowledgement of the problem and empowerment to look further for help is very important.

SS - providing specific suggestions, for example about how to manage continence problems to allow sexual intimacy, managing fatigue, positioning to avoid spasm or pain. Many of these suggestions are made most appropriately by a professional with knowledge of neurological problems rather than just skill in treating sexual dysfunction.

IT - intensive therapy. Specialised psychosexual therapy. The majority of problems can be dealt with earlier in this model.

All health care professionals can undertake the first step in the P-LI-SS-IT model providing they are prepared to listen. This alone can be of immense therapeutic benefit.

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MS Trust resources

MS and sex: a guide for men
MS and sexuality: a guide for women



Further resources

Kessler TM, Fowler CJ, Panicker JN. Sexual dysfunction in multiple sclerosis. *Expert Rev Neurother* 2009;9(3):341-50.

Fletcher SG, Castro-Borrero W, Remington G, et al. Sexual dysfunction in patients with multiple sclerosis: a multidisciplinary approach to evaluation and management. *Nat Clin Pract Urol* 2009;6(2):96-107.

Mobility

Mobility can be defined as the ability “to independently and safely move oneself from one place to another”. In MS, altered movement is one of the more common symptoms and may be due to focal weakness or tightness in a muscle group.

Although this section considers a physiotherapeutic approach to these problems, it must be remembered that mobility can be adversely affected by altered sensation, fatigue, visual disturbance, ataxia, pain or depression. These symptoms and effects are dealt with elsewhere in this book, as is spasticity, which can be a major contributory factor to mobility problems.

Other factors with a major impact on mobility and which may need to be considered include:

- wheelchair and seating
- walking aids: sticks, elbow crutches, delta walkers, rollators (4 wheeled walkers)
- splinting and orthotics
- appropriate home adaptations: hoists, stair lifts, transfer aids, bath aids, railings.

This section describes the physiotherapeutic approach, considers group exercise, the importance of good positioning and individual exercises to encourage this, and describes the use of functional electrical stimulation (FES) and fampridine.

A physiotherapy approach

Physiotherapy aims to prevent unnecessary complications such as contractures, poor gait patterns, pressure sores and muscle imbalance. It addresses poor co-ordination, balance issues and reduces the risk of falls. It promotes exercise which is valuable in the reduction of fatigue, weakness and social isolation through becoming house-bound. Physiotherapy may also help with depression, which affects a high proportion of people living with MS. One of the goals of physiotherapy is to educate and to motivate people to reach their full potential at any stage of their condition. Thus, physiotherapy promotes well-being and quality of life of the individual throughout the whole spectrum of their condition.

Physical problems can be divided into

- primary problems which arise as a direct result of neurological damage
- secondary problems which arise as complications of altered movement and which are preventable.

It is important to distinguish between habilitation and rehabilitation. The former enables the individual to continue with their present lifestyle, whilst the latter enables them to return to the best level possible following a relapse or period of inactivity.

The therapy regime should be realistic and relevant in order to lead to improvement. Wherever possible, people with MS should be encouraged to start exercise early in their disease course. Maintaining ability is easier than regaining ability. One challenge in MS is the individual's ability to comply with a routine. It is difficult for fit people to persevere with exercises without becoming bored and disheartened; if you add the problem of pain, fatigue and disability then motivation can become an even greater challenge. Group sessions in a proactive atmosphere can be useful at all stages, however some people may prefer to exercise at home.

Group physiotherapy

Groups need to meet in a venue which is local, easily accessible, with ramps, good transport and parking and with disabled toilets nearby. Group therapy should be pitched at the appropriate level of ability and should suit different interests. It should be viewed as a supplement to individual therapy.

Groups have many advantages including:

- the opportunity to educate and teach preventative strategies to more than one person. Groups are more economical than one to one so can often continue to provide support by running for longer periods. Ongoing individual physiotherapy for people with MS is not a reality in most areas
- improved attendance and motivation to increase activity levels
- a positive way of monitoring progress, and picking up any problems before complications arise and therefore making appropriate referrals to other professionals when required
- social interaction leading to friendships, mutual support and empowerment through sharing new ideas and coping strategies

- promotion of a positive mental attitude by encouraging individuals to go out of the house
- reduction of stress level by incorporating elements of relaxation and teaching better breathing techniques.

Each person should be assessed individually before entering a class, and be given a home exercise regime when appropriate. At each class, a realistic goal could be set for every attendee to work on before the following class.

The goals of a group exercise routine include:

- maintaining good posture - looking at positioning in chairs, wheelchairs, cars or at work
- maintaining correct dynamic and static balance mechanisms
- maintaining standing to encourage weightbearing
- avoiding muscle imbalance - maintaining muscle strength and length, so a good daily stretching regime needs to be established
- pacing to reduce fatigue
- reducing complications
- developing a healthy self-image
- developing body awareness which allows better strategies for standing and walking
- increasing stamina and blood circulation
- maintaining supple joints and reducing pain
- improving motivation and compliance with exercises
- improving mood.

Group activities can be beneficial for those who are newly diagnosed and/or have minimal disability. If groups are kept small then those who are moderately disabled can also benefit but they may need some individual input from carers or physiotherapists. If appropriate, partners or carers may be involved and shown how to help with a basic stretching routine, positioning and manual handling. Those with severe disability need on-going support, long-term care facilities and

realistic, regular and long-term input from a physiotherapist. A multidisciplinary approach is vital for both the person with MS and the carer.

Exercises can be made more attractive by variety:

- hydrotherapy - individually and in groups
- equipment - treadmills, Swiss balls, poles, weights, cycles, vibrating plates, standing frame, parallel bars, pulleys, parachutes
- games - involving coordination, hand-eye control, cognitive skills and functional movements, from simple throwing and catching to competitive work
- T'ai Chi, yoga, Chi Qung, Pilates, circuit training, dance (movement with music) and other similar classes
- attendance at a gym and local exercise referral schemes
- hippotherapy - a physiotherapeutic treatment using the movement of the horse to challenge balance, core stability, increase body awareness and stretch tight soft tissue structures.

Education plays a vital role at all stages of MS. The person with MS needs to be involved in the treatment plan as an active participant, as well as learning about the condition and how to minimise complications and to maximise potentials. He/she needs to take responsibility for the quality of routine which, to be effective, should be carried out regularly, if possible daily. Management is a 24 hours a day, seven days a week challenge. In order to achieve maximum benefit, long-term care and support are needed, involvement of family, carers and friends, and forward planning of activities to ensure pacing and maximum enjoyment of life.

Posture and positioning

Posture describes the position one holds one's body in, whether sitting, standing or even lying down. If one has 'good posture', it will prepare and allow one to move in the way one wants.

It is common for people with MS to adopt a compensatory posture, which, in the long term can exacerbate symptoms (eg spasms, pain) and worsen mobility problems.

Posture should be assessed:

In a chair:

- Does the person slump?
- Are they seated one-sided?
- Have they got diminished breath control/quiet voice/ability to swallow?
- Do they have to hold on with their hands to keep their trunk stable?
- Does their head stay upright through the course of the day?

In a wheelchair:

- All the above questions apply in addition to:
 - Is the chair giving the required support to the individual's back, head, seat, thighs and feet?
 - Is the chair contributing to poor posture?
 - Is the chair light enough to be self-propelled?
 - Is the person comfortable?

In bed:

- Do they lie in the 'windswept' position (body flat and legs turned to one side)?
- Do they hold their head to one side?
- Do they go into spasms?
- Are the heels rubbing too much?
- Do they seem comfortable?

Changes in positioning can become habitual, leading to further problems of poor circulation, increased risk of infections, pressure sores, shortening of muscles, stiffening of joints, increased spasms and general discomfort and pain.

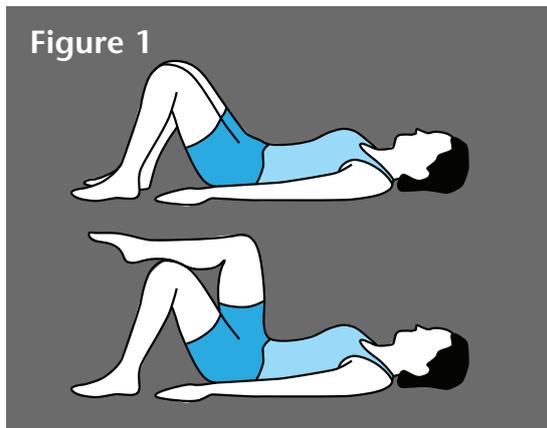
Many people are unaware of postures that they adopt because of the brain's ability to adapt when its equilibrium is compromised. For example, if one leg does not 'work' or 'feel right', the body will adopt a one-sided stance in order to stand up while shifting the weight away from the problematic side. If that compensation is not corrected, then the changes in posture could become permanent. A physiotherapist can advise on measures to prevent and/or correct postural problems and improve comfort when seated and when in bed.

Individual exercises

A variety of simple exercises can be done at home. All of these exercises can be done in a chair; some can also be done in bed.

Breathing exercises (e.g. deep breathing, whistling, singing, blowing in a balloon) will encourage diaphragmatic control and increased air flow and

Figure 1



circulation. Subsequently, people will usually sit up straighter and improve their posture automatically.

Stretching exercises that elongate the trunk muscles eg stretching forward across a table while sitting; holding a stick or a cardboard tube and raising it above the head or reaching out to the side; yoga-type exercises.

Balance exercises are very valuable to improve postural awareness (eg standing in front of the kitchen counter and with a chair behind, trying to stand unsupported; balance from one leg to the other, from heel to toe and then find 'the middle' so that the body weight is distributed equally on both feet; Tai Chi).

Core stability exercises aimed at improving the control of the trunk in response to disturbances generated by movements of the limbs eg bridging, pelvic tilt, quadruped arm and/or leg stretch, Pilates-type exercises (Figure 1).

Using a regular trigger for daily activity can make exercise easy to remember. This could be exercising whilst waiting for the kettle to boil or checking posture when looking in the mirror to comb hair.

Functional electrical stimulation

People with MS often experience foot drop where the foot drags along the ground or hangs down when walking. Functional electrical stimulation (FES) applies electrical stimulation to unresponsive or weak muscles and forces functional movement.

To be suitable for the treatment, the individual needs to be able to walk, even if only a few metres with a stick or crutch. By wearing a foot switch triggered stimulator, the person with MS - with corrected dropped foot - can maintain use of walking muscles for longer.

In January 2009, NICE issued guidance that FES can be offered routinely as a treatment option for people with foot drop caused by damage to the brain or spinal cord.

The use of FES is growing, with an increasing number of centres offering the treatment. An assessment by a physiotherapist trained in the use of FES is required to ensure that the treatment will be suitable for the individual. The physiotherapist will also make sure that the pads are placed properly and that the equipment is being used most effectively.

Fampridine (Fampyra)

Fampridine, a potassium channel blocker, may be effective for those whose walking impairment has been caused by reduced nerve transmission. Fampridine works by blocking some of the chemical processes in nerves to allow electrical signals to continue travelling along damaged nerves to stimulate muscles.

Fampridine, taken as one 10mg tablet twice daily, is licensed for the improvement of walking in adult patients with MS who have walking disability (EDSS 4-7).

In clinical trials, approximately one third to one half of people taking fampridine found walking speed improved, with an average improvement of about 25%. Initial treatment should be limited to a two week trial to identify responders. A timed walking test eg timed 25 foot walk, should be used to evaluate improvement. Side effects can include dizziness, nausea, some agitation or wakefulness, back pain and balance disorders. At higher doses the risk of more serious side effects, including seizures, increases. For this reason it is important not to exceed the recommended daily dose.

Further resources

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MS Trust resources

Are you sitting comfortably?
a self-help guide to good posture
and positioning

Falls: managing the ups and downs of MS

Functional electrical stimulation (FES) factsheet
Fampridine (Fampyra) factsheet

Exercises for people with MS
www.mstrust.org.uk/exercises



Spasticity

Spasticity can be a complex and challenging symptom to manage in neurological conditions and is a common symptom experienced by people with multiple sclerosis. The ongoing management of spasticity requires teamwork between the person with spasticity, their regular carers, and members of the multidisciplinary team^{1,2}. In a survey 84% of people with MS reported symptoms of spasticity with one third rating it as moderate or severe³.

What is spasticity?

The true nature of spasticity is still not clearly understood. The most common definition used is: 'a motor disorder characterised by a velocity dependent increase in tonic stretch reflexes with exaggerated tendon jerks, resulting from hyper-excitability of the stretch reflex, as one component of the upper motor neurone syndrome'⁴. More succinctly spasticity has been defined as 'the velocity dependent increase in resistance of a passively stretched muscle'⁵.

More recently these definitions have been challenged by a European working group as narrow and limiting. Specifically this group identified that the term spasticity is used differently by clinical and research communities and concluded that spasticity is not a pure motor disorder, or just a result of the hyper-excitability stretch reflex or dependent on the velocity of the stretch. They suggested a new definition as, 'Disordered sensorimotor control, resulting from an upper motor neurone lesion, presenting as intermittent or sustained involuntary activation of muscles'⁶.

The resistance to passive movement caused by spasticity is generated by abnormalities in the control of movement by the central nervous system (CNS). As well as this neural involvement of spasticity there are also biomechanical changes, which occur both in muscles and connective tissue, which through disuse and immobility can lead to reduced range of movement or contractures⁷. Increased resistance to passive movement felt by the clinician, often referred to as hypertonia, may be caused by a combination of spasticity, which is neurally generated, and biomechanical changes in the muscle and connective tissue. Together these changes can significantly affect function⁸.

Spasticity is one component of the upper motor neurone syndrome⁹ that occurs as a result of acquired damage to any part of the CNS, including the spinal cord. It has a range of effects, which can be categorised into positive and negative features (Table 1). Most people will present with a combination of features. One or several of the positive features will influence the resistance to passive movement. Often people are described as having spasticity, but it is likely they will also have other features of the upper motor neurone syndrome.

Table 1. Features of the upper motor neurone syndrome⁹

Positive features	Negative features
Spasticity	Weakness
Spasms (flexor, extensor, adductor)	Loss of dexterity
Increase in tendon reflexes	Fatiguability
Clonus	
Positive support reaction	
Extensor plantar responses	

Why does spasticity occur?

The control and regulation of normal skeletal muscle activity involves a complex combination of descending motor commands, reflexes and sensory feedback from the brain, spinal cord and peripheral sensation. During normal movement, influences from the cerebral cortex, basal ganglia, thalamus and cerebellum, travelling via upper motor neurones adjust, reinforce and regulate the lower motor neurone which connects directly via peripheral nerves to the muscle to form smooth, coordinated muscle activity and maintenance of posture.

In simple terms spasticity occurs when there is damage to these descending upper motor neurone tracts (eg a plaque in MS) which interrupts the regulation of spinal cord and lower motor neurone

activity. This can result in enhanced lower motor neurone activity and an increase in muscle activity, in response to peripheral stimuli (eg muscle stretch, a urinary tract infection or pressure ulcer)^{10,11}.

Consequences of spasticity

Spasticity can affect physical activities such as walking, transferring, picking up objects, washing, dressing and sexual activity. It can also have an emotional impact, on for example, mood, self-image and motivation¹²⁻¹⁴. Safety in sitting and lying can also be compromised due to spasms or persistent poor positioning^{15,16} which can lead to the development of contractures. This can potentially lead to restricted mobility and social isolation.

Symptoms of the upper motor neurone syndrome are not always detrimental and they may even be positive in improving vascular flow and assisting in transfers and even walking¹⁷. Therefore the treatment of spasticity needs to be carefully selected and reviewed over time in order to meet the individual's aims and to maintain and promote function.

Management and treatment of spasticity

Two core principles of spasticity management are^{2,15,16}:

Optimising an individual's posture and movement through use of appropriate seating, stretching and exercise programmes².

Preventing or managing factors that may increase spasticity and spasms. Primarily exacerbations can occur from cutaneous stimuli such as skin irritation, pressure sores, ingrown toenails, tight fitting orthoses. Visceral stimuli including incomplete bladder emptying, constipation, bowel impaction and infections, for example urinary tract infections, can be triggers^{2,10}. Patterns of movement in function and sustained postures throughout the day and night can also aggravate spasticity and spasms.

These principles need to be regularly considered and reviewed over time and used in conjunction with medical treatments. Pivotal to their success is ongoing multidisciplinary teamwork across hospital and community settings working collaboratively with the person with spasticity to effectively manage their symptoms^{1,2}.

A multidisciplinary approach

Effective communication between disciplines is vital to enhance the management of an individual's spasticity. Each discipline can be seen to have specific expertise within the team. However this is not exclusive and teamwork is essential^{1,2}.

Nurses have a significant role in educating a person on managing trigger factors and about the available treatments to manage spasticity. They can provide ongoing support and advice to a person and their family as they live with and adjust to managing spasticity and spasms over time.

Physiotherapists can carry out specific treatments to assist an individual to manage muscle tone particularly the biomechanical changes. Treatment may include appropriate exercise programmes that may encompass stretches, active exercises or standing. Advice can also be given regarding posture and positioning throughout the day.

Occupational therapists can play a key role in assessing and recommending appropriate adaptations to an individual's environment and advising on how to maximise activities of daily living within the context of spasticity. Appropriate seating is of particular importance in spasticity management.

Occasionally the expertise of speech and language therapists can be sought when spasticity affects neck and facial muscles¹⁸.

Medical management is important in terms of assessing, prescribing and evaluating the use of antispasticity drugs. In conjunction with other members of the team, doctors can decide the appropriate timing and selection of more invasive treatments.

Inpatient rehabilitation may be appropriate to provide a more thorough assessment of an individual's spasticity throughout a 24 hour period and to allow a more detailed management programme to be developed.

Sometimes despite optimal physical management programmes and optimisation of trigger factors pharmacological measures are necessary. Depending on the pattern of spasticity these can be generalised or focal.

Generalised treatments¹⁹

Baclofen acts on the CNS and is the most commonly used antispasticity drug. To avoid side effects it needs to be started at low doses, slowly increased and stopped at a dose that does not cause unwanted side effects. The effect of an oral baclofen dose can last between 4-6 hours so doses need to be taken regularly to ensure adequate control of symptoms. Side effects can include weakness, drowsiness and dizziness.

Gabapentin is useful for treating spasticity and spasms. It is particularly helpful in managing spasticity when pain is associated with it. Side effects can include drowsiness, dizziness and fatigue.

The NICE clinical guideline states that the following should only be given if treatment with baclofen or gabapentin is unsuccessful or side effects are unmanageable.

Tizanidine also works on the CNS and needs to be introduced slowly to avoid side effects. Regular blood tests should be performed to ensure there is no adverse effect on liver function. Side effects can include weakness, drowsiness and dry mouth.

Diazepam or **clonazepam** can be used alone or in combination with other drugs. Their daytime use is limited by sedative side effects, but if taken prior to sleep they can be very useful in managing nocturnal spasms. Side effects can include drowsiness and dizziness.

Dantrolene is the only antispasmodic drug that works directly on the muscles rather than on the CNS. It can be used in combination with other drugs. Often it is not well tolerated and can cause nausea, vomiting, diarrhoea and weakness. Regular blood tests need to be completed to ensure no adverse effect on liver function.

Sativex is a cannabis extract which works on the cannabinoid receptors in the brain and spinal cord. It is licensed in MS as an add-on therapy for those people whose spasticity and spasm has not responded to the other available drugs^{20,21}. It is available as an oral spray. Side effects can include dizziness, sleepiness and feelings of light headedness. Occasionally the spray can cause soreness in the mouth so it is important to change the spray site regularly. About half of people with

MS will respond to Sativex; whether someone is a responder can be identified after a four week trial of the drug. The dose of Sativex is then controlled by varying the number of sprays taken each day.

Focal treatments

Botulinum toxin can be injected into muscles and acts as a neuromuscular block which causes the targeted muscle to become temporarily weak. It can take 10-14 days for the full effect to be felt. It must be used in conjunction with physiotherapy/ occupational therapy and an exercise programme to maximise effect and to promote an ongoing change in the spasticity once the toxin has worn off (approx. three months)^{2,22,23}.

Phenol or alcohol motor point injections. The injection permanently destroys nerve fibres in the injected muscle. Some nerves may partially regrow, causing the effect to wear off after several weeks or months. Injections can however be repeated if necessary.

Intrathecal therapies

Intrathecal baclofen acts by binding to gamma aminobutyric acid (GABA) receptors and results in inhibition of mono and polysynaptic spinal reflexes²⁴ with associated reduction in spasm, clonus and pain. A concentration of GABA receptors is situated in the intrathecal space of the spinal cord. Delivering baclofen intrathecally accentuates its antispasticity effect whilst minimising the troublesome systemic side effects associated with oral intake.

An implanted pump can deliver baclofen directly to this area and can be used to treat generalised lower limb spasticity²⁵⁻²⁷. It requires commitment from the person with MS, not only during the trial and implant phase, but also for its ongoing maintenance of regular reservoir refills and pump replacements². It is however an extremely effective treatment and is being used earlier in people with MS to improve their walking²⁸.

Intrathecal phenol is a permanent destructive procedure²⁹. It can be helpful for some people, to treat very severe spasms that do not respond to other drug treatments. The effects of an injection can sometimes wear off but can be repeated if necessary.

Negative effects on lower limb sensation, sexual function, bladder and bowel management can occur so appropriate patient selection is critical to ensure effective strategies are in place to manage these³⁰.

Intrathecal treatments require a detailed clinical governance framework to ensure safety of administration, an example of guidelines and nursing care plans from one service have been published².

Surgery

Occasionally orthopaedic or neurosurgical procedures may be recommended. These can include myelotomy (severing of tracts in the spinal cord) and rhizotomy (resection of posterior roots)^{31,32}.

Complementary therapies

Some individuals with spasticity report that complementary therapies such as acupuncture can help relieve symptoms.

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MS Trust resources Spasticity and spasms factsheet



Care pathway: the role of the health care professional in the management of spasticity.

Tremor

Tremor is a complex movement disorder characterised by involuntary uncontrolled movements. It consists of oscillating movements of the upper limb at a frequency of 3-8Hz and may be present when a person is voluntarily maintaining a posture against gravity (postural tremor), or during voluntary movement (kinetic tremor) especially during target directed movement (intention tremor). The tremor amplitude increases during visually guided movements towards a target and occurs at the termination of the movement¹. This can be observed during the finger to nose test² when as the finger approaches the nose the tremor amplitude increases. It is uncommon in MS to experience tremor when the body is fully supported (rest tremor) although head and neck tremor can still be present when lying down. In some cases there is visual involvement, nystagmus, and severe tremor has been found to correlate with the presence of dysarthria.

Ataxia often exists alongside tremor and is a term used to describe abnormal movements occurring during voluntary activity including lack of coordination, dysmetria (inaccuracy in achieving a target), dysdiadochokinesia (inability to perform movements of constant force and rhythm) and delay in movement.

At least one third of the MS population experience tremor¹ but estimates vary. In 5-10% of those experiencing tremor it will be severe, causing a high level of disability and a loss of independence in activities of daily living. Tremor can occur gradually or can appear rapidly. It may occur in one arm only but frequently occurs in both, with one arm usually more affected than the other.

Stress, anxiety, emotional upset and fatigue can make tremor worse.

Cause of MS related tremor

The exact mechanism of tremor is unknown but is thought to be due to lesions in the cerebellum and its connections. The cerebellum is responsible for coordinating movement and smooth muscle activity. Damage to the basal ganglia is also thought to cause tremor although the mechanism is unclear³.

Measurement of tremor

The Fahn Tremor Rating Scale⁴ and the 0-10 Tremor Severity Scale⁵ have both been validated for use in MS. The International Cooperative Ataxia Rating Scale (ICARS) has been shown to be a reliable and repeatable measure for ataxia⁶.

Impact of tremor on people with MS?

Tremor is one of the most disabling symptoms of MS causing the person to become dependent as many daily activities such as writing, eating, dressing and personal hygiene become difficult to perform.

Tremor can be socially isolating. The person with tremor will often avoid situations that make their difficulties obvious. As tremor most commonly occurs during purposeful movement, people may avoid eating and drinking in public, attending social events, shopping etc.

Treatment for tremor

Tremor remains one of the most difficult MS symptoms to manage^{7,8}. A multidisciplinary team (MDT) approach is required. Physiotherapist, occupational therapist, MS specialist nurse, speech and language therapist, psychologist, neurologist and neurosurgeon may all be involved at some point in the management of MS related tremor. Treatment can include advice on compensation strategies, physiotherapy, adaptations, drug treatments and surgery.

Compensation strategies

Movements that involve reaching away from the body, especially target-directed movements (intention tremor) make tremor amplitude increase. Strategies such as pressing the elbow firmly to the side of the trunk may reduce distal tremor although this also reduces reach.

Frequently people with tremor also have postural instability or insufficient trunk support which can make controlling movements more difficult. There are ways to compensate for the tremor to reduce its impact such as reducing forward reach, leaning against an arm rest, or using a head rest and back support to give more postural stability but this in turn can also limit function.

People with head tremor (titubation) may attempt to stabilise the head against the shoulder in an attempt to reduce the tremor. The use of a head

rest may reduce head tremor and make activities such as watching television easier.

Holding the wrist of the active hand with the other hand may help with tasks such as grooming.

The use of wrist weights has been of limited benefit in dampening tremor. They can be helpful if worn during eating in cases of mild/moderate tremor. Prolonged use should be avoided as it has been shown to increase the amplitude of tremor after the weights have been removed.

Some people find that mentally practicing or visualising a movement before attempting it can reduce tremor.

Physiotherapy

Physiotherapy treatment and advice can help manage tremor. The approach often used is aimed at stabilising the proximal limb and trunk. Maintaining joint range of movement and muscle length will allow better posture and movement.

Adaptations

Adaptation is a key element to coping with tremor.

Fatigue makes tremor worse and so planning the day's activities appropriately is important. New methods for daily activities may be found and aids adopted where useful. Aids for eating and drinking may be of benefit to people with moderate to severe tremor. Writing is often one of the first activities that may be stopped as handwriting becomes illegible. Developments in assistive technology can offer some help⁹. Voice activation, keyboard modifications and dedicated software programmes can enable independent use of a computer and charities such as AbilityNet¹⁰ can be a useful resource.

Experimental studies have shown that cooling of the arms markedly reduced intention tremor severity in patients with MS, the benefit is transient lasting for 30 minutes and therefore may be beneficial prior to performing specific tasks¹¹.

Drug treatments

There are no drugs specific for tremor and therapy using drugs licensed for other conditions has limited benefits. Beta-blockers may show some functional improvement whilst clonazepam and isoniazid are of little or no benefit. These drugs have not been evaluated for tremor in MS in

clinical trials. Botulinum toxin has been used with some success to treat intrusive head tremor in people with MS¹. Cannabinoids appear ineffective³.

Surgery

Stereotactic lesional surgery to the thalamus may be used in severe cases of tremor¹². Deep brain stimulation or thalamic stimulation, which has been used successfully in treatment of Parkinson's, may also offer a new approach. The outcomes of these approaches are continuing to be evaluated^{13,14}.

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Pain

Pain is common in people with MS. Studies have reported prevalence ranging from 30%¹ to 90%²⁻⁵ and it is often one of the presenting symptoms⁶. Pain in MS includes altered sensations such as pins and needles, numbness, crawling or burning feelings through to more classical symptoms of musculoskeletal pain.

The pain experienced by people with MS can be persistent or paroxysmal. Pain negatively impacts upon quality of life for people with MS⁷ and this includes impairment of physical and emotional functioning. Management of pain in MS is complex and success can be elusive.

The pain experienced by people with MS can be:

- primary, or neuropathic, a direct result of nerve damage, or
- secondary, or nociceptive, a consequence of musculoskeletal complications of posture, seating etc.

The NICE Clinical Guideline for the management of MS in primary and secondary care⁸ recommends that

- each professional in contact with a person with MS should ask whether pain is a significant problem for the person, or whether it is a contributing factor to their current clinical state
- all pain, including hypersensitivity and spontaneous sharp pain, suffered by a person with MS should be subject to full clinical diagnosis, including a referral to an appropriate specialist service if needed.

Assessment and treatment of pain

Pain is a complex, multidimensional phenomenon. It is an unpleasant experience, particularly when combined with the other symptoms of MS. It impacts upon many aspects of an individual's psychosocial and spiritual well-being, is often difficult for the person with MS to articulate or describe, and can be difficult to cope with.

A number of factors can amplify existing pain; heat, cold, fatigue, loss of sleep, mobility problems, financial insecurity, feelings of low self-esteem, loneliness and depression. The importance of developing coping strategies is paramount and can include relaxation, distraction, exercise regimes

and self-administered therapies such as TENS and massage.

People with MS can experience pain due to problems other than their MS. 7% of the general population have experienced pain for three months or more⁹ and other factors such as arthritis, rheumatism, previous injuries and surgery need to be taken into consideration.

Simply acknowledging the validity of pain felt brings some reassurance, particularly if the individual has experienced a negative response from some health professionals.

When people with MS present with pain they must be assessed to identify causative factors and the impact of pain on their life, prior to drawing up a treatment plan. If pain remains unresolved, a referral should be made to a specialist multidisciplinary pain team⁸ or pain clinic.

Broadly speaking, there are two types of pain: neuropathic (neurogenic) pain and nociceptive pain. People with MS may experience either type or both types and the pain may be continuous or intermittent and constant or variable in intensity. Treatment aims to minimise the level of pain and to develop coping strategies for day to day living.

Neuropathic pain

People with MS can experience neuropathic pain due to demyelination of the nerves in the brain and spinal cord.

Neuropathic pain or 'nerve' pain can be experienced in different ways by individuals. It can manifest as dysaesthesia or paraesthesia. These abnormal sensations may be variously described as burning, shooting, stabbing, crawling, prickling, itching, tingling, pins and needles, tightness and/or hypersensitivity.

Trigeminal neuralgia is a severe facial pain, which occurs 300 times more frequently in people with MS than in the general population¹⁰. In extreme cases surgery may be performed to alleviate the pain but this may leave the face numb.

L'hermitte's sign is an unpleasant sensation similar to an electric shock that shoots down the spine into the legs, often triggered by head movement and attributed to demyelination in the cervical area.

Banding, also known as the "MS hug" is a feeling of constriction, tightness or being squeezed around the chest.

Optic neuritis is a common early symptom of MS although it can occur at any time. A sharp knife-like

pain behind the eyes is caused by inflammation of the optic nerve, often accompanied by disruption to vision. It usually responds successfully to treatment with steroids.

Treatment of neuropathic pain

The main focus of the treatment of neuropathic pain is drug therapy^{5,11}. The NICE guideline for MS⁸ recommends anticonvulsants such as carbamazepine or gabapentin, or using antidepressants such as amitriptyline. The NICE guideline for neuropathic pain¹² indicates amitriptyline or pregabalin as first line treatments.

These drugs affect the chemical transmission of pain signals with a resultant reduction of symptoms, but they can cause unpleasant side effects such as drowsiness, dizziness, nausea and blurred vision. Some people find the side effects of the drugs intolerable and therefore choose not to take them. Controlled titration of the dose and support from health professionals minimises side effect risk and builds tolerance until side effects wear off.

Other treatments for neuropathic pain include TENS (see below) and complementary therapies such as acupuncture and aromatherapy¹³.

If the neuropathic pain remains uncontrolled after initial treatments have been tried, the individual must be referred to a specialist pain service⁸.

Nociceptive pain

Nociceptive pain, commonly referred to as musculoskeletal pain, is the type of pain experienced when someone hurts themselves, has an accident or surgery. Damage to muscles, tendons, ligaments and soft tissue results in nociceptive pain. Muscle spasm and spasticity, common symptoms of MS, can also be a source of nociceptive pain.

Many people with MS experience lower back pain, especially if immobility or fatigue means that they are sitting down for much of the time. Sitting places the lower back under more strain than standing and nerves can easily become compressed or pinched. Equally, an alteration of gait may place unusual stresses on the discs between the vertebrae. Such stress can cause damage to the discs and trapped nerves which results in pain in the part of the body served by these nerves.

Heavy lifting and awkward turning and bending can also contribute to back and leg pain. These movements may irritate the spinal nerves causing the muscles at the side of the spine to go into spasm; these muscle flexor spasms can be very painful and disabling.

Ligament damage can also occur in MS because of hyperextension of the knee when walking; the subsequent swelling of the knee can cause significant pain.

Treatment of nociceptive pain

Nociceptive pain is generally managed more successfully than neuropathic pain.

The NICE guideline for MS⁸ recommends that every person with MS who has musculoskeletal pain secondary to reduced or abnormal movement, should be assessed by specialist therapists to see whether exercise, passive movement, better seating or other procedures might be of benefit.

If these approaches are unsuccessful, the individual should be offered appropriate analgesic medicines. These range from paracetamol and codeine-based preparations, through to anti-inflammatory drugs and opiates, in combination with drugs such as baclofen, tizanidine and Sativex for spasm if indicated.

Any person with MS who has continuing unresolved secondary musculoskeletal pain should be considered for transcutaneous nerve stimulation (TENS – see below) or antidepressant medication¹⁴.

Cognitive behavioural and imagery treatment methods should be considered in a person with MS who has musculoskeletal pain only if the person has sufficiently well-preserved cognition to participate actively.

Other treatments indicated include trigger point injections, nerve blocks and complementary therapies such as acupuncture and aromatherapy¹³. Relaxation techniques can also be helpful.

Treatments that should not be used routinely for musculoskeletal pain include ultrasound, low-grade laser treatment and anticonvulsant medicines.

Use of TENS for the management of pain

Transcutaneous electrical nerve stimulation (TENS) is the application of electricity to relieve pain. It is not a new treatment; carvings from Egypt dating back to 2500BC illustrate the use of electric fish for the treatment of pain¹⁵. TENS units deliver a small electrical current to the sensory cutaneous nerve endings through electrically conductive pads. A buzzing, prickling, tingling sensation is experienced when the machine is switched on. TENS is recommended in the NICE guideline⁸ for people with musculoskeletal pain who have not responded to medication, but it can be used in conjunction with medication and also for neuropathic pain¹⁶⁻¹⁷.

TENS machines are battery powered, usually by a regular 9 volt battery. Machines should have the facility for a constant mode (also known as continuous or conventional), a burst mode (also known as acupuncture TENS), and a modulation mode. On the constant mode (high frequency/low intensity) a constant tingling sensation is felt, on burst mode (low frequency/high intensity) a pulsing sensation, and on modulation mode (variation of pulse duration and frequency in a cyclical pattern) an increase and decrease in the tingling sensation is felt. To accommodate these three modes the machine should have the facility to alter the pulse rate (frequency) and pulse width. TENS units either have one or two channels allowing the use of either two or four pads. The dual channel machines are preferable to allow coverage of a larger area or treatment of two separate areas. The self-adhesive pads are recommended if the machine is to be used over a long period of time, as they are much easier to use.

It is thought that TENS relieves pain by several mechanisms. The main principle behind the effect of TENS is the gate control theory of pain¹⁸. Electrical impulses are conducted more quickly than pain impulses and subsequently provide a competitive barrage of sensory input in the dorsal horns. This enhanced sensation inhibits the activity of the spinal cord pain neurons. Researchers hypothesise that TENS may stimulate the production of endorphins and enkephalins, the body's own natural analgesics at spinal cord level especially if used at low frequency when sharper and more intense pulses are experienced¹⁹.

TENS has been found to be as effective as the antidepressant drug nortriptyline for pain in multiple sclerosis and has fewer potential side effects²⁰.

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MS Trust resources

Pain factsheet
Spasticity and spasms factsheet



Further resources

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Communication and swallowing

Many people with multiple sclerosis experience communication or swallowing difficulties. Early referral to a speech and language therapist is important to ensure that problems are fully investigated and appropriate intervention and support provided. The therapist will provide advice that aims to improve or maintain communication and swallowing abilities, or will suggest strategies to adapt to the effects of changes in normal function. This will involve working with the person with MS as well as family members where appropriate. Speech and language therapy is ongoing throughout the course of the disease.

Communication

Communication is central to quality of life and integral to maintaining relationships. Changes in the ability to communicate can impact on social participation and emotional wellbeing.

At a physical level, MS can affect the production of speech, usually by delays in messages passing through affected nerve pathways to the muscles involved in speech production. The term used to describe this problem is dysarthria. Very precise control and coordination of a range of muscles is required for speech and anything affecting the muscles of breathing, larynx, tongue, lips or jaw can result in alterations in speech intelligibility.

Darley¹ studied 168 people with MS and found 41% displayed dysarthric speech. Hartelius² found that 62% of their MS sample reported speech and voice impairments. Symptoms are variable with some people experiencing a mild reduction in volume when tired or a slight slurring of speech at the end of the day. In more severe cases speech can be totally unintelligible.

There has been very little research into the effects of speech therapy on people with MS. Work reported so far does indicate that therapy can be beneficial³. General advice may include reducing background noise before speaking, saying half words on each breath, speaking slowly and facing listeners when speaking. Speech exercises may be beneficial if the problem is mild (eg to assist breath control for volume). Developments in technology mean that there are a range communication aids which can assist some people with very dysarthric speech.

A small number of people with MS develop dysphasia, or impairment of language function, but this is unusual. Associated problems include difficulty understanding and producing written and /or spoken words. Together with physical speech difficulties, cognitive problems can also impact on daily life⁴. A strong association between dysarthria and cognitive-linguistic deficit, in people with chronic progressive type multiple sclerosis has recently been reported⁵. The main deficits relate to attention, memory and speed of processing information, so that difficulties in retrieving the name of something or being unable to concentrate in a noisy environment are often experienced.

The most effective help is based on explanation, understanding and sharing of ideas. If the speech and language therapist can build up a trusting relationship with the person with MS and their family, then problems relating to speech and communication can be discussed and solutions explored.

Swallowing

Dysphagia (difficulty in swallowing) is present in around 30% of people who have MS^{6,7} and can increase to over 60% in people who have advanced MS⁸. It is particularly prevalent in individuals whose MS includes involvement of the brainstem.

Swallowing difficulties can affect all four stages of swallowing (oral preparatory, oral, pharyngeal and oesophageal), and can include difficulty chewing, pocketing food in the cheek, fluids escaping from between the lips, residue in the pharynx after the pharyngeal swallowing, and episodes of coughing/choking when eating or drinking. These difficulties can be caused by weakness, impaired coordination and spasticity, or some combination of each. Severity of dysphagia is variable.

A speech and language therapist will assess safety and efficiency of swallowing through clinical (eg history from the individual, oro-motor examination, observation of eating and drinking, questionnaires) and possibly instrumental assessment (videofluoroscopy or fibro-optic endoscopic evaluation). Following assessment, rehabilitation can be undertaken, where the therapist will engage with the individual and, if appropriate, the family, and advise on posture, possible exercises, manoeuvres, consistencies of food and drink, and the eating environment.

If swallowing is considered unsafe (eg the person is experiencing recurrent chest infections), inefficient

(eg the person takes a long time to eat or drink, or is unable to maintain their weight through their oral intake), or is having an effect on quality of life, alternative ways of obtaining nutritional intake may be recommended. This is most likely to be percutaneous endoscopic gastrostomy (PEG) feeding. A PEG can be used alongside oral intake so that the person can eat and drink for pleasure while the PEG provides the required nutrients and calories. It is important that the decision to fit a PEG is fully discussed and is carefully considered by the person with MS and their family.

Ultimately, the most effective management of communication and swallowing in MS results from close collaboration between the person with MS, the speech and language therapist and other professionals and carers.

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Herbert S. A team approach to the treatment of

Pressure ulcers

Skin, as the largest organ of the body, is crucial for our health and well-being yet is often taken for granted¹. Whilst MS itself does not directly affect the skin there are a number of symptoms which can put people with MS at higher risk of skin breakdown. These include trauma wounds due to sensation changes and balance impairments, leg oedema and increased risk of pressure ulcers due to spasticity, reduced mobility and cognitive function².

Pressure ulcers, also referred to as pressure sores, bed sores, or decubitus ulcers, are areas of localised damage to the skin, which in adults usually occur over bony prominences in any area of the body³.

Pressure ulcers may range from minor breaks to very large deep areas of dead tissues extending over many square centimetres and down to bone. Once present they can be difficult to heal, and can cause general malaise and worsening of most impairments, and they carry a risk of generalised or localised infections. The European Pressure Ulcer Advisory Panel (EPUAP) classification system⁴ for pressure ulcers highlights that damage can be occurring even when the skin is not broken.

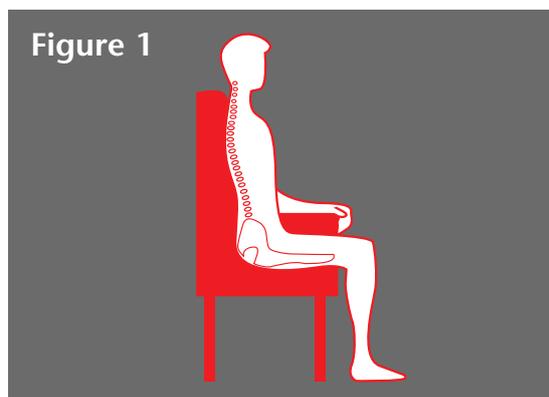
The NICE clinical guideline for management of MS states that prevention and management of pressure ulcers is a key priority. Each pressure ulcer should be reported, the cause investigated and action taken to reduce the risks of recurrence².

Patients and carers should be taught to check for signs of pressure ulcers on a daily basis.

Causes

Pressure sores are caused by a combination of factors both outside and inside the body. The three external factors which can cause pressure ulcers either on their own or in any combination are pressure, shear and friction⁵.

Pressure is the most important factor in pressure ulcer development⁵. Pressure in the seated position for example is caused by the downward forces of the body weight that compress the soft tissues of the buttocks against the sitting surface (Figure 1). This in turn occludes the delicate blood capillary network which supplies the soft tissues. Pressure is at its greatest in the area near bone, particularly the ischial tuberosities where pressure is known to be three to five times as great as that on surrounding tissues⁶.



Shearing forces can also deform and disrupt tissue and so damage the blood vessels. Shearing occurs when the body weight is sliding against a surface, for example when poorly seated or sliding down a bed away from a back rest. Whilst the skeleton and nearby tissues move, the skin on the buttocks

European Pressure Ulcer Advisory Panel (EPUAP) guide⁴ to pressure ulcer classification

Grade	Evidence
1	Non-blanchable erythema of intact skin. Discolouration of the skin, warmth, oedema, induration or hardness may also be used as indicators, particularly on individuals with darker skin.
2	Partial thickness skin loss involving epidermis, dermis, or both. The ulcer is superficial and presents clinically as an abrasion or blister.
3	Full thickness skin loss involving damage to or necrosis of subcutaneous tissue that may extend down to, but not through, underlying fascia.
4	Extensive destruction, tissue necrosis, or damage to muscle, bone, or supporting structures with or without full thickness skin loss.

Pressure ulcers

remains still. During this process the blood capillaries become distorted, damaged or occluded leading to skin ischemia (deprivation of blood) and pressure ulcers can develop.

Damage due to friction differs in that it causes visual damage to the surface of the skin and may be more superficial. It is caused when two surfaces rub together, often skin against a bed or a chair surface. Any moisture present on the skin as a result of excessive sweating or incontinence will exacerbate the problem⁵.

There are a number of additional factors that are known to place people at higher risk of acquiring pressure ulcers. People with MS, particularly those with more advanced disease, may fit into every category:

- neurologically compromised
- impaired mobility or who are immobile³
- impaired nutrition⁷
- obese or underweight⁸
- poor posture
- using equipment, such as seating or beds, which does not provide appropriate pressure relief⁹.

The development of a pressure ulcer is known to result in high costs both in human and financial terms⁹. The possible pain, systemic illness, reduced self-esteem and independence can result in a major burden of sickness and impact on quality of life for both patients, their families and carers¹⁰⁻¹².

Prevention

Prevention is far better than cure and most pressure ulcers can be avoided by good anticipatory management.

A number of risk assessment tools have been developed to assist in the identification of those individuals at risk of developing pressure ulcers including the Norton Scale, Waterlow scoring system and the Braden score¹³. However, in evaluations of the effectiveness of these scales there is clearly variation in their sensitivity of predicting those at elevated risk¹³ particularly when, as is frequently the case with an MS patient, they fall into a younger age category as many tools heavily weight older age. A factor frequently excluded from such tools is the presence or impact of spasms which can result in shearing and friction on the skin. This therefore highlights the importance of using risk assessment tools and scales as an adjunct to, but not a replacement for, clinical judgement¹⁴.

Patients and carers should be advised of warning signs that can increase the risk of developing a pressure ulcer. Questions to consider:

- are you eating or drinking less than usual?
- is moving becoming more difficult?
- is your skin regularly exposed to moisture?
- is your skin prone to being very dry, sore or red?
- have you been ill recently?
- have you lost or gained a lot of weight recently?
- has there been any change in your level of spasms?

The latter point can be an indicator of skin breakdown as this can be a trigger for spasms. These can then cause friction and shearing forces on the skin and a vicious cycle can be entered whereby the spasms cause the wound to worsen and the wound exacerbates the spasms.

Every person with MS who uses a wheelchair should be assessed for their risk of developing a pressure ulcer². The individual should be informed of the risk, and offered appropriate advice. Whenever they are admitted to hospital (for whatever reason), their need for pressure-relieving devices and procedures should be assessed. The assessment should be clinical, specifically taking into account the risk features associated with MS, and not simply the recording of a pressure ulcer risk score; it should lead to the development and documentation of an action plan to minimise risk.

Treatment and the multidisciplinary approach

There are a range of interconnecting factors which need to be tackled in order to treat existing pressure sores and prevent them developing again in the future. The involvement of a multidisciplinary team will often be required to achieve a positive outcome. Health professionals from different disciplines will need to work together and might include:

- MS specialist nurse
- district nurse
- GP
- continence adviser
- neurophysiotherapist
- dieticians
- wheelchair services
- speech and language therapist.

Simple tips for the prevention of pressure ulcers:

Reduce pressure	When possible alter position, even slightly, every 20 minutes during the day. If seated this could take the form of rolling slightly from cheek to cheek in the chair.
Appropriate equipment - cushions & mattresses	This includes: bed ¹⁵ , armchair, wheelchair, car seat, office chairs, all equipment when on holiday, hospital or away from home for any reason. Seek advice from a district nurse or occupational therapist. Avoid any form of ring cushion as this can occlude blood vessels and cause pressure damage itself.
Nutrition	Eat a well balanced diet. Advice and diet sheets can be obtained from a dietician. Even a short period of not eating well increases the risk of skin damage, particularly if you are unwell with flu for example
Hygiene and skin care	Skin should routinely be kept clean and fresh. Avoid allowing skin to be wet. Check for red areas on the skin once or twice a day. Reddened areas should fade within minutes when pressure is relieved. If they do not, seek advice from a district nurse.
Transferring	Obtain good instruction and support in transfer techniques and correct use of equipment. Avoid sliding and pushing when this may result in friction.
Positioning	Learn correct positioning for comfort and pressure relief, particularly when seated.

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Resources from the MS Trust

Are you sitting comfortably?:
a self-help guide to good posture
and positioning



Spasticity and spasms factsheet

Advanced MS

Advanced stages of MS may require the expertise and input of palliative care services to achieve the best quality of life when the illness is limiting time left and needs are complex. It can integrate skilled multidisciplinary assessment and management of MS with appropriate support for the social, psychological and spiritual needs of someone with MS reaching the end of their life. It will support families or carers, many of whom have lived for many years with the consequence of MS. It can ensure those decisions and wishes about dignity in dying with MS, perhaps made whilst living with MS, are appropriately acted upon and any changes to those early choices are promptly recognised and care choices reviewed.

It is now accepted that palliative care provision should be available for all patients with life-limiting illnesses, regardless of diagnosis and should not be restricted to the last few days, weeks or months of life. Input for MS may be variable over a lengthy time span.

Those involved in the day to day care of someone with advanced MS will be involved in providing general palliative care. Specialist palliative care input should be considered where there is an expected lifespan of 6-12 months, intractable symptoms, complex psychosocial needs and when discussion or support is needed in advance care planning.

Holistic assessment and support

MS is a variable condition with a wide spectrum of clinical presentations yet each individual's experience of MS is uniquely felt and influenced by many factors; individual coping mechanisms, past experiences and available support. The key to 'getting it right' for each individual is to listen to their narrative and know what matters to them in the moment and the time they perceive left to them. Holistic assessment identifies physical, emotional, social and spiritual needs, preferences or challenges. These are unlikely to be static or fixed.

The living end of MS has often been filled with uncertainty and unpredictability; the dying end may be no different.

As MS advances previous decisions may change and pro-active reassessment and review will be

required. This will avoid crisis led decision making and likely accompanying distress. Patients with advanced MS are housebound and assessment and review should be carried out in the patient's home or usual place of residence.

Spiritual needs are often overlooked, avoided or superficially addressed. Nearing the end of life and imminent death often triggers spiritual questions or fears and if unexplored can lead to significant distress.

Symptom control

A survey of patients with advanced MS cited that on average patients experienced around nine different symptoms¹. Pain, spasms and fatigue were the most common symptoms. Swallowing and communication problems, shortness of breath and nausea together with depression and cognitive impairment will also affect quality of life.

MS symptoms can become refractory to treatment, fluctuate in intensity or worsen with progression of MS. Symptoms may be:

- primary - a direct result of MS itself
- secondary - resulting from primary symptoms
- tertiary, arising from the social and psychochological problems of primary and secondary symptoms.

Carer needs

Families and carers provide invaluable support for patients with advanced MS, but the role is demanding and can place carers under significant emotional and physical strain. Carer needs often go unrecognised. The families of people with MS may have experienced many years of living with the consequences of MS and they will have a range of responses, questions, anxieties and needs that must be addressed. It is important to provide both practical and emotional support for carers as well as to consider respite options for families.

Estimating prognosis

Confident prognosis at any stage of MS is difficult and in advanced MS there is a risk of sudden deterioration and death from an infection². Intimate knowledge of someone with MS will help to gauge the rate of clinical deterioration and possible time frames. A framework for end of life care in long term neurological disease, published by the National End of Life Care Programme, describes triggers that can help to identify when a patient may be approaching the end of life³:

- swallowing problems
- recurring infection
- marked decline in physical status
- first episode of aspiration pneumonia
- significantly worsening cognitive function
- weight loss
- significant complex symptoms.

Deterioration may extend over many years and death usually occurs from respiratory or other overwhelming infection.

Planning for the future

People with MS should be afforded the right of self determination regarding their future care preferences or life-prolonging treatments. The initiation, pacing and any revisiting of any discussion about these choices must be led by the person with MS at a time they choose and it is critical to identify the cues they give. Some may fear that cognitive decline or communication impairment will prevent them articulating clearly their wishes at some point in the future. Some will not wish to enter into such a dialogue and prefer avoidance techniques.

Untreated depression and unidentified cognitive impairment in MS will negatively influence wishes and **must** be appropriately managed as part of the process of determining future directives.

The family and loved ones may also wish to be involved in discussion, but it may be that the person with MS wishes to have a private, confidential talk with a trusted other.

Each of the four UK nations has statutory guidance on safeguarding the wishes of people with mental capacity and those who do not have mental capacity and it is a duty of care for health care professionals to understand and follow the appropriate guidance (Figure 1).

The dying phase

MS is not in itself a terminal condition; the vast majority of people with MS live their normal life span and die of conditions completely unrelated to MS. In one study, death occurred as a consequence of the

Figure 1

England and Wales

Mental Capacity Act 2005⁴

Scotland

Adults with Incapacity (Scotland) Act 2000⁵

Northern Ireland

Currently no primary legislation
Mental Capacity Bill in preparation (Oct 2011)

secondary complications of chronic disease, such as pneumonia and septicaemia, in 50% of people with advanced MS². The proportion of deaths due to stroke, myocardial infarctions and malignancies was similar to the general population.

Recognising and acknowledging that someone with MS has finally reached the dying phase of life can be a challenge. Many features of progressing MS such as increasing weakness, deteriorating functional ability, difficulty in swallowing and cognitive impairments can also be features of imminent death in terminal disease.

As a life is ending for someone with MS information must be shared with the patient and the family and checked for understanding. They may have become accustomed to symptoms fluctuating in intensity and may not have insight into the significance or finality of change. They may have lived with change or progression for many years. They may need reassurance that ceasing to eat and drink is a normal part of the dying process and not the cause of deterioration.

Intrusive or uncomfortable MS symptoms together with other common end stage symptoms must continue to be pro-actively managed. Key drug interventions are likely to include the following medications or their equivalents:

Midazolam	agitation/ muscle relaxation
Hysocine butylbromide	respiratory secretions
Diamorphine	pain

Recognised tools are available to facilitate the assessment and management of patients at the end of life. With appropriate training, tools such as the Liverpool Care Pathway for the Dying Patient have been shown to improve the quality of care provided to dying patients⁶. The pathway helps ensure key needs are regularly assessed including areas which are often overlooked such as spiritual and psychosocial needs as well as guiding professionals with appropriate anticipatory prescribing.

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Further resources

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We hope you find the information in this book helpful. If you would like to speak with someone about any aspect of MS, contact the MS Trust information team and they will help find answers to your questions.

This book has been provided free by the Multiple Sclerosis Trust, a small UK charity which works to improve the lives of people affected by MS. We rely on donations, fundraising and gifts in wills to be able to fund our services and are extremely grateful for every donation received, no matter what size.

MS Trust information service

Helping you find the information you need

The MS Trust offers a wide range of publications, including a newsletter for health and social care professionals Way Ahead and the MS Information Update, which provides an ongoing update on research and developments in MS management.

For a full list of MS Trust publications, to sign up for Way Ahead and much more visit our website at www.mstrust.org.uk



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