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# **Multiple sclerosis – the quick guide**

For hospitals,  
residential homes &  
nursing homes



Multiple Sclerosis Society

## About this information

- It's for any staff who care for people affected by multiple sclerosis (MS)
- It's a quick guide – it gives an instant understanding of a symptom, how it can affect people, and how you can help
- It points to resources with further information

## Further questions?

If you have questions about MS not answered by this guide, visit [www.mssociety.org.uk](http://www.mssociety.org.uk), call the MS Society UK Information Team on 020 8438 0799 (weekdays 9am-4pm) or email [infoteam@mssociety.org.uk](mailto:infoteam@mssociety.org.uk)

## Why did we produce this?

Care professionals and people affected by MS have asked for basic information about MS to be made available in hospital wards, care homes and similar settings.

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# An overview of MS

## What is MS?

- Autoimmune disorder characterised by episodes of inflammation in brain and spinal cord (CNS)
- Progressive disorder – but rate of progression unpredictable
- Cause unknown – multifactorial: genetic, environmental and geographic factors involved
- Not hereditary (but there is a familial risk)
- Not infectious (but *possibly* triggered by a virus?)
- Currently no known cure
- Most common cause of neurological disability in young adults
- Most common in white Europeans
- Affects more women than men (approx 3:1)
- Estimated 100,000 people in the UK diagnosed and living with MS
- Usually diagnosed in young adulthood (20-40) and most people live with MS for decades
- 3 main types/ patterns
- Most people start with a 'relapsing remitting' pattern

## How can this affect the person with MS?

- Unpredictable course
- Varies from person to person, in presentation, symptoms experienced, disease course and progression
- Person has to adjust to the diagnosis, the uncertainty and possible changes to ability, lifestyle, quality of life
- Although mobility difficulties are common, fewer than 1:4 people will use a wheelchair

## How might this affect the partner/ carer?

- Change of role – partner to carer?
- Sees changes in partner – has to adjust to them too

## What can make things better/ worse?

| Better   | Worse   |
|--|---|
| Positive mental attitude   | Stress  |
| Self management – including regular exercise, healthy diet               | Aggressive form of disease/ frequent relapses |
| Disease modifying drugs<br>(can reduce relapse rate by approx one third) |   |
| High-dose steroids to treat acute relapses                               |   |
| Treatments for individual symptoms                                       |   |
| Support/ counselling/ talking therapies                                  |   |

## What can I do to help manage this?

- Encourage and support positive mental attitude and self-management techniques
- Ensure person has information to aid self management
- Ensure evidence-based treatments for relapses and symptoms
- Ensure person has contact with MS specialist nurse (if available)

Turn the page for further information and key points

## Where can I get further information?

MS Society – free publications to download or order, including *What is MS?*  
Access online at [www.mssociety.org.uk/publications](http://www.mssociety.org.uk/publications)

*Helping you explain MS* – available to order or download from MS Society at  
[www.mssociety.org.uk/professionals](http://www.mssociety.org.uk/professionals)

NICE (2003) *Clinical guideline 8. Multiple Sclerosis. Management of multiple sclerosis in primary and secondary care*. Access online at <http://guidance.nice.org.uk/CG8/Guidance/pdf/English>

In Scotland, the findings and advice of NHS Quality Improvement Scotland –  
[www.nhsqis.org](http://www.nhsqis.org)

## Key points

- Cause of MS is unknown
- Disease course is unpredictable and variable
- MS affects more women than men
- Self management and positive mental attitude can help people come to terms with diagnosis and change
- Although there is no cure for MS, there are treatments which can modify the disease course and there are symptomatic treatments

# Types of MS

## What are the different types?

There are 3 main types (or presentations) of MS

- Relapsing remitting
- Secondary progressive
- Primary progressive

## Relapsing remitting MS

- 85% of people diagnosed have relapsing-remitting MS
- The pattern is a relapse or flare-up of symptoms (also known as an attack or exacerbation) followed by remission (a period of recovery)
- A relapse is defined by the appearance of new symptoms, or the return of old symptoms, for a period of 24 hours or more, in the absence of a change in core body temperature or infection
- Relapses usually take a few days to develop and can last for days, weeks (most commonly) or months, varying from mild to severe
- Relapses that affect someone's function should be treated with high-dose methylprednisolone
- Remission occurs when the inflammation subsides and symptoms settle down
- In the early stages of relapsing remitting MS, symptoms can disappear completely during remissions
- However, after several relapses there may be more residual damage to the myelin and nerve fibres, resulting in only a partial recovery
- The 'disease modifying drugs' are licensed to treat people diagnosed with relapsing remitting MS
- Sometimes, the term 'benign' is used to describe MS – if, after 10 to 20 years, someone's MS hasn't worsened and they have very little or no disability, they might then be said to have 'benign' MS

### Secondary progressive MS

- Most people who start out with relapsing remitting MS later develop a form that is known as secondary progressive MS
- Around 65% of people with relapsing remitting MS will have developed secondary progressive MS within 15 years of being diagnosed
- Usually, the number of relapses decreases, but symptoms do not go away completely after a relapse and there is a steady increase in disability
- To determine if a person has moved on to secondary progressive MS, they must have shown a continued deterioration for at least six months, whether they continue to have relapses or not
- Some of the disease modifying drugs are licensed to treat people who have secondary progressive MS with relapses

### Primary progressive MS

- About 10-15% of people diagnosed will have primary progressive MS
- It tends to be diagnosed in older people, usually in their forties or later
- From the outset, people with primary progressive MS experience steadily worsening symptoms and an increase in disability
- The rate of progression can vary
- Symptoms may level off at any time, or may continue to worsen
- Unlike relapsing remitting MS, men are just as likely to develop this type as women

## Where can I get further information?

MS Society – *What is relapsing remitting MS?; What is secondary progressive MS?; What is primary progressive MS?; MS Essentials 01: Managing a relapse; MS Essentials 06: Disease modifying drugs.*  
Access online at [www.mssociety.org.uk/publications](http://www.mssociety.org.uk/publications)

NICE (2003) *Clinical guideline 8. Multiple Sclerosis. Management of multiple sclerosis in primary and secondary care.*  
Access at <http://guidance.nice.org.uk/CG8/Guidance/pdf/English>

In Scotland, the findings and advice of NHS Quality Improvement Scotland – [www.nhsqis.org](http://www.nhsqis.org)

## Key points

- 3 main types/ patterns of MS
- MS is a progressive disease, but the rate of progression varies from person to person
- Relapses should be treated with high-dose methylprednisolone when function is affected
- People with relapsing remitting MS and secondary progressive MS (with relapses) may be eligible for disease modifying drugs

# Relapses

## What is a relapse?

A relapse is an episode of neurological symptoms (caused by inflammation or demyelination) that happens at least 30 days after any previous episode began, lasts at least 24 hours and is not caused by an infection or other cause. A relapse is often described by other names, including an attack, exacerbation, flare-up, acute episode or clinical event.

### Pseudo-relapse

Sometimes people experience a flare-up of symptoms which is not a relapse. For example, a cold or a bladder infection could raise the body temperature and make symptoms temporarily worse. These 'pseudo-relapses' can be treated by tackling the cause of the fever – the cold or infection. Exercise or hot baths can also raise the body's temperature, but any temporary symptoms that it causes (such as fatigue, or visual symptoms) are not a sign of a relapse.

## How can this affect a person with MS?

- New symptoms appear, or old symptoms re-appear, either gradually or suddenly
- Symptoms usually come on over a short period of time – hours or days
- They often stay for a number of weeks, usually 4 to 6, though this can vary from only a few days to many months
- Typical MS symptoms in a relapse include weakness, unsteadiness, bladder disturbance or double vision
- Other symptoms, such as fatigue and spasms, might get worse during a relapse

## How might this affect the partner/ carer?

- Fear/ worry
- Increased care requirement (temporary or lasting)

## How are relapses treated?

The options for managing an MS relapse are:

- treatment with high-dose steroids, either as an in-patient, a 'day-case' or at home
- rehabilitation – after steroids, or without steroids being given
- no treatment

Some people want to know if they should rest or exercise when having a relapse.

- There is no straightforward answer to this question.
- The benefits of exercise have not been studied in relation to relapses (and it would be very difficult to carry out a study). But fatigue is usually much worse with relapses, and resting would often be recommended.
- In MS, studies have shown that exercise is beneficial in relation to levels of fatigue and fitness, as well as muscle strength and psychological wellbeing (feeling good). However, it is important to prevent the person's core temperature from rising. This can temporarily make them feel worse or experience symptoms.
- It is advisable to discuss exercising with a physiotherapist.

## What can I do to help manage this?

- Check for infection
- Inform MS nurses/ GP/ neurologist
- Discuss possible treatment options

## Where can I get further information?

MS Society – *MS Essentials 01: Managing a relapse*.  
Access online at [www.mssociety.org.uk/publications](http://www.mssociety.org.uk/publications)

NICE (2003) *Clinical guideline 8. Multiple Sclerosis. Management of multiple sclerosis in primary and secondary care*.  
Access at <http://guidance.nice.org.uk/CG8/Guidance/pdf/English>

In Scotland, the findings and advice of NHS Quality Improvement Scotland –  
[www.nhsqis.org](http://www.nhsqis.org)

## Key points

- Relapses are unpredictable in occurrence, duration, effect and recovery
- High-dose methylprednisolone should be offered to treat disabling relapses, as recommended in NICE (2003) *Clinical guideline 8. Multiple sclerosis: management of multiple sclerosis in primary and secondary care*. London, NICE

# An overview of common symptoms

## What symptoms are experienced in MS?

- MS varies from person to person and can result in a wide variety of symptoms, none of which are unique to MS
- Many people experience only a few symptoms – it is unlikely that anyone will develop them all
- People can have different symptoms at different times – although some are very common, there is no typical pattern that applies to everyone
- Symptoms can vary in duration and intensity
- Some symptoms, such as walking difficulties, are obvious to other people
- Other symptoms, such as pain or fatigue, are not obviously noticed and are often referred to as hidden, invisible or silent symptoms
- Hidden symptoms may be more difficult to understand, for those unfamiliar with MS

## List of common symptoms experienced in MS

- Fatigue – an overwhelming sense of tiredness making physical or mental activity difficult and, for some, impossible
- Balance problems and vertigo – walking difficulties, problems with coordination
- Visual problems – blurred or double vision, temporary loss of sight in one eye or both
- Numbness or tingling – commonly in the hands or feet
- Pain – sometimes mild, sometimes severe
- Loss of muscle strength and dexterity
- Stiffness and spasms – tightening or rigidity in particular muscle groups
- Anxiety, depression or mood swings
- Cognitive problems – difficulty with memory and concentration
- Speech problems – slurring, slowing of speech, or changes in pitch or tone
- Incontinence – a lack of control over bladder or bowel functions
- Sexual problems – lack of libido, erectile difficulties

### Can the symptoms be treated?

- There are treatment options for most of the symptoms experienced
- Most symptoms can be managed/ treated by prescribed (conventional) medicines
- Self-management techniques and/ or complementary and alternative therapies (CAMs) can also be beneficial
- Some of the medications used to treat symptoms in MS are used 'out of licence' – for instance, amantadine might be prescribed to treat fatigue in MS

### What can I do to help manage this?

- Listen to what the person with MS says about their symptoms
- Ensure the MS nurse is aware that the person is experiencing new symptoms
- Encourage self-management techniques
- Monitor medication use for compliance and efficacy

### Where can I get further information?

MS Society – The MS Essentials range of publications covers most of the symptoms and their management. Access them online at [www.mssociety.org.uk/publications](http://www.mssociety.org.uk/publications)

NICE (2003) *Clinical guideline 8. Multiple Sclerosis. Management of multiple sclerosis in primary and secondary care.*

Access at <http://guidance.nice.org.uk/CG8/Guidance/pdf/English>

In Scotland, the findings and advice of NHS Quality Improvement Scotland – [www.nhsqis.org](http://www.nhsqis.org)

## Key points

- There are many different symptoms experienced by people with MS
- Symptoms can vary in intensity and duration – and can come and go
- Some symptoms cannot be seen by the observer – they are known as ‘silent’ or ‘hidden’ symptoms
- There are treatments for most of the symptoms experienced
- CAMS and self-management techniques can be of benefit in managing many of the symptoms

# Fatigue

## What is it?

- One of the most common symptoms experienced by people with MS
- An overwhelming tiredness, unrelated to physical activity
- A 'silent' or 'hidden' symptom that cannot be seen by the observer
- Can be very variable in how and when it affects an individual
- Can differ between individuals in presentation, duration and effect

## How can this affect a person with MS?

- Overwhelming tiredness, might be unable to move
- Person feels unrefreshed, even after a full night's sleep
- Person might appear uninterested or seem to be ignoring what's going on around them
- Might affect cognitive processes – memory, thinking
- Person might have increased difficulty in using limbs
- Vision might blur
- Person might not participate in activities/ socialising
- Might prevent person from working

## How might fatigue affect the partner/ carer?

- Need to understand fatigue and its possible effects
- Lack of companionship/ conversation
- Lack of joint activities
- Financial concerns
- Concerns around cognition

## What can affect it?

| Reduces impact/ improves it                                 | Increases impact/ makes it worse                    |
|---|---|
| Normal core temperature                                     | Heat  |
| Refrain from over-zealous activity                          | Physical exertion                                   |
| Prevent/ treat infections                                   | Infection   |
| Medication review   | Medications   |
| Ensure good sleep pattern                                   | Tiredness/ disturbed sleep                          |
| Managing other symptoms                                     | Other symptoms (eg pain, spasms, urinary frequency) |
| Prevention recognition/ management of alteration of mood    | Alteration of mood (eg depression, stress)          |
| Recognising personal 'triggers' of fatigue                  | Unknown   |
| Energy conservation techniques                              |   |
| 'Re-charging' after activity/ appropriate physical activity |   |

## What can I do to help manage this?

- Ask the person how they manage their fatigue – everyone will have different strategies and techniques that work for them
- Be understanding of the variability of fatigue – it's not someone being 'difficult'!
- Go at the person's rate – plan activities/ day to suit the individual
- Consider energy conservation techniques (see further information)
- Ask the OT to assess the person regarding their fatigue

## Where can I get further information?

MS Society – *MS Essentials 14: Fatigue*. Access online at [www.mssociety.org.uk/publications](http://www.mssociety.org.uk/publications)

NICE (2003) *Clinical guideline 8. Multiple Sclerosis. Management of multiple sclerosis in primary and secondary care*.  
Access at <http://guidance.nice.org.uk/CG8/Guidance/pdf/English>

In Scotland, the findings and advice of NHS Quality Improvement Scotland – [www.nhsqis.org](http://www.nhsqis.org)

## Key points

- Most commonly reported symptom experienced in MS
- Variable in presentation, duration, impact
- Can be managed by a number of methods, including energy conservation techniques and possibly medication (see NICE 2003 guidance)

# Altered sensation

## What is altered sensation?

The term 'altered sensation' covers a wide variety of symptoms experienced by many people with MS. These include:

- Numbness (people often say they feel like they've had a local anaesthetic)
- Tingling or 'electric shocks'
- Feeling extremities swollen/ feeling of 'largeness'
- 'Band-like' sensation around chest or limb
- 'Burning'
- 'Pins and needles'
- Feeling like ants crawling under skin
- Not aware of temperature – can be heat or cold

## How can this affect a person with MS?

These symptoms can be difficult to describe and cannot be seen by the observer. They can be annoying, irritating and even painful. They can:

- Cause discomfort, frustration and anger
- Cause low mood
- Affect relationships and socialising
- Prevent sleep
- May interfere with or prevent work
- Be difficult to manage or treat – what works for one person might aggravate the symptom in another person

## How might this affect the partner/carer?

- Difficult to understand – it can be very difficult for partners/carers to understand the sometimes bizarre sounding descriptions of the symptoms experienced. There will be nothing visible to see and the symptoms can fluctuate, coming and going.
- Frustrating – it can also be frustrating, as it can be difficult to help the person with MS to get comfy or get relief from their symptoms.

| Reduces impact/<br>improves it   | Increases impact/<br>makes it worse |
|--|-------------------------------------|
| Consider possible causes<br>(eg infection) and investigate/ treat                            | Infection                           |
| Understanding and empathy  | Constricting clothing               |
| Massage (for some)   | Massage (for some)                  |
| Exercise   | Exercise                            |
| TENS   | TENS                                |
| Appropriate pain relief (often<br>anticonvulsants/ antidepressants<br>used with good effect) | Some medications                    |
| Look for/ recognise triggers   |                                     |
| Consider use of pain questionnaire   |                                     |
| Good posture/ positioning in bed   |                                     |
| Relaxation techniques  |                                     |
| Self-management strategies/ course   |                                     |

## What can I do to help manage this?

- Ask the person how they describe and manage their altered sensation – everyone will have different strategies and techniques that work for them
- Be understanding of the variability of the symptoms
- Consider possible triggers/ causes
- Review medications being taken/ therapies being used – could any of them be causing any of these symptoms?
- Ask physiotherapist/ occupational therapist to assess
- Possibly refer to pain specialist/ team

## Where can I get further information?

MS Society – *MS Essentials 17: Pain and sensory symptoms*.

Access online at [www.mssociety.org.uk/publications](http://www.mssociety.org.uk/publications)

NICE (2003) Clinical guideline 8. Multiple Sclerosis. Management of multiple sclerosis in primary and secondary care.

Access online at <http://guidance.nice.org.uk/CG8/Guidance/pdf/English>

In Scotland, the findings and advice of NHS Quality Improvement Scotland – [www.nhsqis.org](http://www.nhsqis.org)

## Key points

- Many people with MS will experience altered sensation
- Variable in location, duration and impact
- Management involves assessment and trying different therapies/ techniques/ medication

# Pain

## What is pain in MS?

- At least one third of people with MS will experience pain at some time
- Pain can be very variable, in presentation, location, duration and intensity
- Pain in MS can be a direct result of nerve damage (neuropathic/ neurogenic), or secondary to symptoms. Musculoskeletal pain is the pain in joints and muscles, caused by the effect that MS has on that person's body
- Pain can also be a result of other treatments/ medications
- Pain can also be nothing to do with MS
- Altered sensation (see page 19) comes under the heading of nerve pain
- Pain is more than just a physical symptom – circumstances, fatigue and emotions can affect how someone deals with pain

## How can this affect a person with MS?

- It can alter their mood – irritable, angry, withdrawn, low mood
- It can make them more fatigued
- It can disturb sleep
- It can stop them from doing things
- It can stop them socialising/ working
- It can affect relationships
- Inability to cope

## How might this affect the partner/ carer?

- The carer might find it difficult to work with the person – caring becomes difficult
- Carer might worry that they are the cause of the pain
- Relationship can be affected – by pain, low mood, lack of intimacy
- Disturbed sleep

## What can affect it?

| Reduces impact/ improves it | Increases impact/ makes it worse |
|-----------------------------|----------------------------------|
| Find cause of pain          | Infection                        |
| Use of pain questionnaire   | Pressure                         |
| Good positioning            | Poor positioning                 |
| Stretching/ physiotherapy   | Contractures/ spasms             |
| Complementary therapies     | Complementary therapies          |
| Relaxation/ sleep           | Lack of sleep/ fatigue           |
| Medication                  | Low mood/ depression             |

## What can I do to help manage this?

- Ask the person how they describe and manage their pain – everyone will have different strategies and techniques that work for them
- Be aware that mood might be low – cause or effect of pain
- Look for possible triggers/ causes
- Review medications being taken – could any of them be causing any of these symptoms?
- ‘Trial and error’ with different complementary therapies
- Ask physiotherapist/ occupational therapist to assess
- Possibly refer to pain specialist/ team
- Monitor medication – use and effect, review regularly

## Where can I get further information?

MS Society – *MS Essentials 17: Pain and sensory symptoms; MS Essentials 05: Vision and MS; MS Essential 06: Disease modifying drugs; MS Essentials 07: Managing bladder problems; MS Essentials 10: Mood, depression and emotions; MS Essentials 18: Complementary and alternative medicine; MS Essentials 19: Muscle spasms and stiffness; MS Essentials 21: Exercise and physiotherapy; MS Essentials 26: Balance and MS.* All available online at [www.mssociety.org.uk/publications](http://www.mssociety.org.uk/publications)

NICE (2010) *Clinical guideline 96. Neuropathic pain. The pharmacological management of neuropathic pain in adults in non-specific settings.*  
Access online at <http://guidance.nice.org.uk/CG96/Guidance/pdf/English>

NICE (2003) *Clinical guideline 8. Multiple Sclerosis. Management of multiple sclerosis in primary and secondary care.*  
Access online at <http://guidance.nice.org.uk/CG8/Guidance/pdf/English>

In Scotland, the findings and advice of NHS Quality Improvement Scotland – [www.nhsqis.org](http://www.nhsqis.org)

## Key points

- Pain is a common symptom experienced by people with MS
- Pain might be due to nerve damage, the effect MS has on the body – or due to a reason unrelated to MS (eg appendicitis)
- Pain and low mood often go hand in hand
- Treating pain can involve many members of the multi-disciplinary team
- Getting the ‘right’ pain relief in the ‘right’ form or dose can be a case of trial and error

# Cognitive issues

## What is cognition?

Cognition refers to memory and thinking. The processes involved include:

- Understanding and using language
- Recognition
- Learning, remembering and recalling information
- Concentrating
- Thinking, reasoning and problem solving
- Organising, planning, carrying out, reviewing and evaluating

If any of the above processes are affected so that a person has difficulty in coping with everyday situations, they might be deemed to have cognitive problems (often called cognitive dysfunction). These problems can be temporary or permanent. Approx 65% of people with MS will experience cognitive problems at some point, to a greater or lesser degree.

## How can this affect a person with MS?

- Difficulty in coping with day-to-day tasks
- More time needed to carry out a task
- Need to concentrate more on tasks
- Person has difficulty finding the right word to use or uses inappropriate word
- Person might become worried or frightened or even appear unbothered
- It can affect relationships with partner/ family/ friends/ carers
- Person might stop socialising/ working

### How might this affect the partner/ carer?

- Concerned/ frightened
- Lack of joint activities
- Frustration, anger

### What can affect it?

| Reduces impact/ improves it                   | Increases impact/ makes it worse |
|---|----------------------------------|
| Remove distractions, such as background noise | Depression, anxiety, stress      |
| Avoid multi-tasking – do one thing at a time  | Infection or relapses            |
| Break tasks into simple steps                 | Tiredness or fatigue             |
| Time and understanding                        | Some medications                 |
| Use of self-help strategies                   |                                  |

### What can I do to help manage this?

- Give person time and understanding
- Reassurance – these problems might be temporary and are not necessarily progressive
- Check for possible infection or even relapse
- Check with relatives/ carers – is this new?
- Talk to the person about the difficulties – are there any tips or strategies they use?
- Use of self-help strategies – writing things down, doing tasks in sequence (see further information, MS Essentials 28)
- Consider neuro-psychological assessment

## Where can I get further information?

MS Society – *MS Essentials 02: Memory and thinking* and *MS Essentials 28: Living with the effects of MS*.

Access online at [www.mssociety.org.uk/publications](http://www.mssociety.org.uk/publications)

NICE (2003) *Clinical guideline 8. Multiple Sclerosis. Management of multiple sclerosis in primary and secondary care*.

Access online at <http://guidance.nice.org.uk/CG8/Guidance/pdf/English>

In Scotland, the findings and advice of NHS Quality Improvement Scotland – [www.nhsqis.org](http://www.nhsqis.org)

## Key points

- Not everyone with MS will have cognitive problems
- Cognition can be affected by fatigue, mood, infection, relapses
- Give the person time to think/ do tasks
- Empathy and understanding can reduce fear and anxiety
- There are many strategies that people can use (self-help) to overcome or reduce their difficulties
- Neuro-psychological assessment and rehabilitation can be helpful
- Cognitive issues can arise early in the condition – even if there are no significant physical symptoms

# Mood, emotion and behavioural changes

## What changes can be experienced by people with MS?

Many people with MS will experience changes in mood, emotions and/ or behaviour. Changes can vary in intensity, duration and effect. The causes of these changes include:

### Factors related to MS

- nerve damage in the brain
- psychological reaction due to diagnosis or change

### Factors not directly related to MS

- individual's personality
- depression
- other health conditions
- social/ economic circumstances
- side-effect of medications/ drugs

## How can this affect a person with MS?

There is a wide variety of possible different reactions/ experiences, including:

- Shock/ denial
- Anger/ frustration
- Relief
- Fear (of the unknown/ future)
- Guilt
- Stress/ anxiety
- Altered mood – down or up (eg euphoria)
- Clinical depression (experienced by approx 50% of people with MS)
- Suicidal thoughts
- Mood swings
- Uncontrollable (and often inappropriate) laughing/ crying
- Lack of insight into situation
- Disinhibition
- Lack of initiative (nb – consider – does the person experience fatigue?)
- Withdrawal (from usual activities)

## How might this affect the partner/ carer?

Those close to the person with MS have to adjust to the diagnosis/ change, as well as possibly having to adjust to any mood/ emotional/ behavioural changes in the other person.

- Altered mood/ emotions/ behaviour
- Change in roles and responsibilities
- Difficulty in communication
- Reluctance to talk/ socialise

### What can affect it?

| Reduces impact/ improves it                       | Increases impact/ makes it worse |
|---|----------------------------------|
| Counselling/ talking therapies                    | Lack of understanding            |
| Cognitive behavioural therapy                     | Some medications                 |
| Anti-depressants if person clinically depressed * |                                  |
| Self-help/ support groups                         |                                  |

*\* There is some evidence to show St John's Wort can be effective to treat mild depression. It should not be taken in conjunction with other anti-depressants*

### What can I do to help manage this?

- Communication, encouragement, understanding
- Review all medications taken – including non-prescribed (eg cannabis)
- Consider referral to neuropsychologist/ neuropsychiatrist
- Reassurance and patience for emotional lability/ behavioural changes

## Where can I get further information?

MS Society – *MS Essentials 10: Mood, depression and emotions*.  
Access online at [www.mssociety.org.uk/publications](http://www.mssociety.org.uk/publications)

NICE (2003) *Clinical guideline 8. Multiple Sclerosis. Management of multiple sclerosis in primary and secondary care*.  
Access online at <http://guidance.nice.org.uk/CG8/Guidance/pdf/English>

In Scotland, the findings and advice of NHS Quality Improvement Scotland –  
[www.nhsqis.org](http://www.nhsqis.org)

## Key points

- Not everyone with MS will experience mood/ emotional/ behavioural change
- Counselling/ talking therapies/ self-help groups can help
- Changes might or might not be directly due to MS
- Approx 50% of people with MS will be clinically depressed at some point
- Suicidal thoughts and suicide are 7.5 times higher in people with MS than in the general population

# Bladder dysfunction

## What bladder problems occur in MS?

If someone with MS has mobility problems, it is highly likely that they will have bladder dysfunction.

Two main types of bladder problems:

- Problem with storing urine
- Problem with emptying bladder
- There can also be a combination of both of the above

## How can this affect a person with MS?

| Problem with storage          | Problem with emptying                    |
|-------------------------------|--|
| Frequency                     | Hesitancy/ difficulty in initiating flow |
| Reduced bladder capacity      | Poor flow, often interrupted             |
| Small amounts of urine passed | Incomplete emptying                      |
| Urgency                       | Stagnant pool of 'residual' urine        |
| Urge incontinence             | Recurrent UTIs                           |
| Nocturia                      | Nocturia                                 |

- Frequent trips to the toilet – often go before they need to – in case of 'accidents'
- Fatigue – especially due to frequent trips to toilet
- Low mood
- Embarrassment
- Possible incontinence
- Possible urinary tract infections
- Reduced quality of life

## How might this affect the partner/ carer?

- Lack of understanding can cause frustration
- Frequent trips to toilet = less time to do other things
- Tiredness
- Increased washing

## What can affect it?

| Reduces impact/ improves it  | Increases impact/ makes it worse             |
|--|--|
| Consider intake/ output monitoring   | Relapses                                     |
| Drink 1.5-2 litres water daily<br>Cranberry juice – possibly (see NICE guidance)           | Spasms                                       |
| Reduce/ remove exacerbating factors (see column on right)                                  | Infections                                   |
| Understanding, reassurance and empathy   | Constipation                                 |
| Pelvic floor exercises   | Mobility problems/ inaccessibility of toilet |
| Anti-cholinergic medication (providing residual urine is less than 100mls)                 | Caffeine/ fizzy drinks/ smoking              |
| Intermittent self-catheterisation to empty bladder (if residual urine is more than 100mls) | Weak pelvic floor                            |
|  | Difficulty removing clothing                 |

## What can I do to help manage this?

- Monitor intake/ output
- Urinalysis – check for infection
- Prevent/ remove exacerbating factors
- Referral to MS nurse or urology nurse for bladder scan/ assessment
- Urology referral may be required

## Where can I get further information?

MS Society – *MS Essentials 07: managing bladder problems*.  
Access online at [www.mssociety.org.uk/publications](http://www.mssociety.org.uk/publications)

NICE (2003) *Clinical guideline 8. Multiple Sclerosis. Management of multiple sclerosis in primary and secondary care*.  
Access at <http://guidance.nice.org.uk/CG8/Guidance/pdf/English>

In Scotland, the findings and advice of NHS Quality Improvement Scotland – [www.nhsqis.org](http://www.nhsqis.org)

Fowler, C.J. *et al.* (2009) A UK consensus on the management of the bladder in multiple sclerosis. *JNNP*, 80, 470-7.  
Access summary online at [www.mstrust.org.uk](http://www.mstrust.org.uk)

## Key points

- Someone with MS with mobility problems, is highly likely to have bladder dysfunction
- Preventing/ removing exacerbating factors can really help
- Good management includes referral and use of evidence-based guidelines – see Fowler, C.J. *et al.* (see further information above)

# Bowel dysfunction

## What bowel problems occur in MS?

- Not everyone with MS will experience bowel problems
- The main problems that occur are constipation and incontinence
- Approx 50% of people with MS will have problems with constipation
- Many factors can contribute to this, including possible nerve damage, reduced mobility, low fluid intake and medications
- Approx 30-50% of people with MS will have bowel incontinence at some point
- Bowel incontinence may be due to 'overflow' round impacted faeces (constipation)
- It is important to remember that bowel problems can be totally unrelated to MS
- Bowel management is time consuming for all – but can make a huge difference to the person with bowel problems

## How can this affect a person with MS?

- Pain/ discomfort
- Anxiety/ low mood
- Fear of leaving the house
- Impacts on employment and socialising
- Embarrassment
- Distress
- Low mood

## How might this affect the partner/ carer?

- Concern
- Increased care needs/ time
- Reduced socialising

## What can affect it?

| Reduces impact/ improves it | Increases impact/ makes it worse  |
|-----------------------------|---|
| Healthy diet                | Fatigue   |
| Good fluid intake           | Medications (especially anti-depressants, anti-cholinergics, anti-spasmodics) |
| Activity/ exercise          | Inaccessible or difficult-to-access toilet                                    |
| Regular routine             | Lack of support/ care input   |
| Appropriate medication      | Difficulty in removing clothing (possible sensory problems)                   |
|                             | Anxiety/ depression   |
|                             | Cognitive problems  |

## What can I do to help manage this?

- Ensure healthy diet
- Ensure adequate fluid intake – low caffeine content
- Review medications
- Try to establish a routine (about half an hour after breakfast is good for many people)
- Time and patience!
- Ensure person comfortable and supported on toilet – get OT assessment
- Physiotherapist to assess mobility and possible aids
- If person has bowel incontinence – check in case they are constipated
- Ensure medication to treat constipation is taken correctly
- Referral to continence nurse advisor

## Where can I get further information?

MS Society – *MS Essentials 25: Managing the bowel in MS*.  
Access online at [www.mssociety.org.uk/publications](http://www.mssociety.org.uk/publications)

NICE (2003) *Clinical guideline 8. Multiple Sclerosis. Management of multiple sclerosis in primary and secondary care*.  
Access online at <http://guidance.nice.org.uk/CG8/Guidance/pdf/English>

In Scotland, the findings and advice of NHS Quality Improvement Scotland –  
[www.nhsqis.org](http://www.nhsqis.org)

## Key points

- Many people with MS will experience bowel dysfunction – constipation or incontinence – at some point
- Remember – bowel problems can be totally unrelated to MS
- Many factors can be involved, including possible nerve damage, reduced mobility, low fluid intake and medications
- There are many ways to help establish a good bowel regime, but it can be time-consuming

# Sexual dysfunction

## What sexual problems can occur in MS?

- Approx 70% of men with MS experience erectile dysfunction
- There are a variety of options to treat erectile dysfunction
- Between 35% and 50% of men with MS will experience problems with ejaculation – without available treatment options
- Between 50% and 70% of women with MS will experience sexual problems, such as loss of libido, decreased vaginal lubrication, altered vaginal/clitoral sensation, loss of ability to achieve orgasm
- Treatment options for these problems are very limited
- If someone with MS has problems with mobility, bladder and/ or bowel dysfunction, they will probably have sexual dysfunction
- It should be remembered that sexual difficulties are experienced by many people in the general population
- Other symptoms might affect sexual function and wellbeing

## How can this affect a person with MS?

- Loss of self-esteem
- Low mood/ depression
- Altered sex drive
- Altered relationships

## How might this affect the partner/ carer?

- Feel unloved
- Low mood
- Altered relationship

## What can affect it?

| Reduces impact/ improves it   | Increases impact/ makes it worse                                 |
|---|--|
| Erectile dysfunction can be treated by oral medications (Cialis, Viagra, Levitra); injected prostaglandins (Caverject); urethral prostaglandin (MUSE) or vacuum devices | Fatigue  |
| KY-Jelly, Sensilube or even water can help overcome decreased vaginal lubrication   | Spasticity/ spasms – can make positioning/ penetration difficult |
| Vibrators can help women to achieve orgasm  | Pain/ altered sensation  |
| Review of medications (especially anti-depressants)   | Bladder and bowel problems                                       |
| Psycho-sexual counselling can help many couples   | Low mood/ depression   |
|   | Cognitive dysfunction  |

## What can I do to help manage this?

- Encourage person to talk to their partner
- Suggest they discuss with someone who is used to discussing these problems and knows treatment options – MS nurse or neurologist
- Referral for psycho-sexual counselling may be required

## Where can I get further information?

MS Society – *MS Essentials 12: Sex, intimacy and relationships*.  
Access online at [www.mssociety.org.uk/publications](http://www.mssociety.org.uk/publications)

MS Trust – *Sexuality and MS: A guide for women*.  
Access online at [www.mstrust.org.uk](http://www.mstrust.org.uk)

NICE (2003) *Clinical guideline 8. Multiple Sclerosis. Management of multiple sclerosis in primary and secondary care*.  
Access online at <http://guidance.nice.org.uk/CG8/Guidance/pdf/English>

In Scotland, the findings and advice of NHS Quality Improvement Scotland –  
[www.nhsqis.org](http://www.nhsqis.org)

## Key points

- If someone with MS has problems with mobility, bladder and/ or bowel dysfunction, they will probably have sexual dysfunction
- Erectile dysfunction affects 70% of men with MS – treatment options are available
- Sexual problems in women include loss of libido, decreased vaginal lubrication, altered vaginal/clitoral sensation, loss of ability to achieve orgasm – treatment options are very limited
- Refer to a professional who has experience in this area

# Spasticity and muscle spasms

## What do we mean by spasticity and muscle spasms?

- Spasticity refers to an increase in muscle tone that is evident when a relaxed muscle is stretched
- There is difficulty, or resistance to the muscle being stretched
- The increase in tone can result in the muscle being slow to relax again – this causes stiffness
- When the relaxed muscle is stretched, spasticity can cause the muscle to jerk, or spasm
- If the muscle jerks repeatedly, this is called clonus
- Some people get spasms without the muscle being stretched – these are involuntary spasms
- These involuntary spasms can be flexor, extensor or adductor
- Spasticity often occurs along with muscle weakness
- Approx 20% of people with MS will experience spasticity at some point
- For people with MS, degree of spasticity can vary – both within a day and from day to day

## How can this affect a person with MS?

- Limbs feel stiff or difficult to move
- This can interfere with walking or with hand function/ fine control
- Possible difficulty in carrying out personal hygiene
- Increased tiredness/ fatigue
- Pain
- Disturbed sleep pattern
- Change in posture
- Possibility of contractures
- Possible mood changes (due to difficulty in movement, pain, fatigue etc)
- Can affect work, socialising and relationships

## How might this affect the partner/ carer?

- Difficulty in carrying out care – limbs difficult to move
- Difficulty in ensuring optimum posture
- Difficulty in balancing person's comfort against optimum position
- Disturbed sleep pattern
- Possibility of getting hit/ kicked by an involuntary spasm

## What can affect it?

| Reduces impact/<br>improves things   | Increases impact/<br>makes it worse                                     |
|--|---|
| Multi-disciplinary team assessment   | Inactivity  |
| Stretching/ physiotherapy  | Poor posture/ seating   |
| Appropriate splinting  | Infection (eg UTIs)   |
| Anti-spasmodic medication – oral,<br>into local muscle groups<br>or intrathecal      | Physical triggers such as tight or<br>rumpled clothing, lying on tubing |
| Surgery is very occasionally required<br>to relieve pain or ease<br>movement/ caring | Full bladder  |
|  | Constipation  |

## What can I do to help manage this?

- Involve a physiotherapist
- Ensure regular stretching/ exercise
- Slow, deliberate movements and handling
- If a spasm starts, wait for it to ease off before you continue
- Careful positioning – ask the person/ carer what works for them
- Ensure good hygiene – prevent infection/ constipation/ skin ulceration

## Where can I get further information?

MS Society – *MS Essentials 19: Muscle spasms and stiffness; MS Essentials 21: Exercise and physiotherapy.*

Access online at [www.mssociety.org.uk/publications](http://www.mssociety.org.uk/publications)

MS Trust – *Exercises for people with MS.*

Access online at [www.mstrust.org.uk/information/exercises](http://www.mstrust.org.uk/information/exercises)

NICE (2003) *Clinical guideline 8. Multiple Sclerosis. Management of multiple sclerosis in primary and secondary care.*

Access online at <http://guidance.nice.org.uk/CG8/Guidance/pdf/English>

In Scotland, the findings and advice of NHS Quality Improvement Scotland – [www.nhsqis.org](http://www.nhsqis.org)

## Key points

- Approx 20% of people with MS will experience spasticity at some point
- Degree of spasticity can vary – both within a day and from day to day
- It is vital to get appropriate, early assessment by multi-disciplinary team
- Regular stretching/ exercise can help prevent/ lessen spasticity

# Mobility, balance and weakness

## What is the relationship between these and problems experienced?

- Mobility is all about freedom of movement
- Problems with mobility are very common in MS
- The problems can be caused by muscle weakness, muscle stiffness (spasticity) or problems with balance
- Many other symptoms of MS can affect balance and mobility, including fatigue, pain, altered sensation, visual disturbances, mood and vertigo
- Mobility and balance are often affected during a relapse
- Problems with mobility and balance can fluctuate, from day to day and from person to person
- For some people, the problems will be permanent, due to damage to the brain and/ or spinal cord
- Sometimes, the causes are not related to MS – for example, many people in the general population also experience vertigo

## How can these affect a person with MS?

- Difficulty in walking – from unsteady gait (typically, accused of being 'drunk') to inability to stand
- Falls/ injuries
- Affects work, recreation and socialising
- May need to consider mobility aids
- May need to consider aids and adaptations in the home
- Adverse effect on mood and emotions – and relationships

## How might this affect the partner/ carer?

- Increased difficulty in moving and handling
- Possible increase in care input
- Consideration of aids and adaptations

## What can affect these problems?

| Reduces impact/<br>improves things           | Increases impact/<br>makes it worse                 |
|--|---|
| Assessment of causal problem                 | Inactivity  |
| Exercise/ physiotherapy programme            | Spasticity  |
| Compensation and balance retraining          | Poor posture/ seating                               |
| T'ai chi, Pilates, yoga, Alexander technique | Side-effect of medications, causing muscle weakness |
| Walking aids                                 | Contractures  |

## What can I do to help manage this?

- Assessment by neuro-physiotherapist/ occupational therapist
- Review medications – especially anti-spasmodics (can cause muscle weakness)
- Ensure safety as much as possible
- Encourage safe mobility and activity

## Where can I get further information?

MS Society – *MS Essentials 21: Exercise and physiotherapy and MS Essentials 26: Balance and MS.*

Access online at [www.mssociety.org.uk/publications](http://www.mssociety.org.uk/publications)

NICE (2003) *Clinical guideline 8. Multiple Sclerosis. Management of multiple sclerosis in primary and secondary care.*

Access online at <http://guidance.nice.org.uk/CG8/Guidance/pdf/English>

In Scotland, the findings and advice of NHS Quality Improvement Scotland – [www.nhsqis.org](http://www.nhsqis.org)

## Key points

- Mobility problems are common in MS, but vary from person to person and can vary day to day
- Weakness or stiffness in muscles can reduce mobility
- Problems with balance can result from many different causes – and can affect mobility
- It is important to get a neuro-physiotherapy assessment carried out
- Encourage safe exercise/ mobility

# Gait problems

## What gait problems can occur in MS?

- Problems with gait are very common in MS
- They can be caused by demyelination, muscle weakness, muscle stiffness (spasticity) or problems with balance
- For some people, the problems will be permanent, due to damage to the brain and/ or spinal cord
- Many other symptoms of MS can affect a person's gait, including fatigue, pain, altered sensation and vertigo
- People with MS are often accused of being “drunk”
- Problems with gait can fluctuate, from day to day and from person to person
- Remember – sometimes the cause might not be related to MS – many people in the general population also experience gait problems

## How can this affect a person with MS?

- Difficulty in walking – from unsteady gait (typically, accused of being “drunk”) to tripping/ falling
- Falls/ injuries often due to foot drop
- Affects work, recreation and socialising
- Embarrassment
- May need to consider mobility aids
- May need to consider aids and adaptations in the home
- Adverse effect on mood and emotions – and relationships

## How might this affect the partner/carer?

- Worry that person might fall/ injure themselves
- Possible increase in care input
- Consideration of aids and adaptations

## What can affect these problems?

| Reduces impact/<br>improves things   | Increases impact/<br>makes it worse |
|--|-------------------------------------|
| Assessment of causal problem   | Inactivity                          |
| Exercise/ physiotherapy programme  | Spasticity                          |
| Assessment for Functional electrical stimulation (FES) if foot drop an issue | Pain                                |
| Fampyra (fampridine)   | Side-effect of medications          |
| Walking aids   |                                     |

## What can I do to help manage this?

- Assessment by neuro-physiotherapist/ occupational therapist
- Review medications
- Ensure safety as much as possible
- Encourage safe mobility and activity

## Where can I get further information?

MS Society – *MS Essentials 21: Exercise and physiotherapy and MS Essentials 26: Balance and MS.*

Access online at [www.mssociety.org.uk/publications](http://www.mssociety.org.uk/publications)

NICE (2003) *Clinical guideline 8. Multiple Sclerosis. Management of multiple sclerosis in primary and secondary care.*

Access online at <http://guidance.nice.org.uk/CG8/Guidance/pdf/English>

In Scotland, the findings and advice of NHS Quality Improvement Scotland – [www.nhsqis.org](http://www.nhsqis.org)

## Key points

- Gait problems are common in MS, but vary from person to person and can vary day to day
- It is important to get a neuro-physiotherapy assessment carried out
- Encourage safe exercise/ mobility

# Visual disturbances

## What visual disturbances can occur in MS?

- The optic nerve is the largest nerve in the body and is often the target of an attack/ relapse
- **Optic neuritis (ON)** is inflammation of the optic nerve and a common presenting (and occurring) symptom in MS
- ON usually comes on over a few days; usually affects one eye; affects vision to a variable degree and tends to be very painful on eye movement (typically, there is no pain when eyes are closed, as in sleep)
- The majority of people (80+%) make a good recovery within a few weeks
- Some people will be left with visual impairments following an attack of ON
- Only about 1:3 people who present with ON will go on to be diagnosed with MS
- Damage to nerve pathways that control eye movements result in diplopia and/ or nystagmus
- **Diplopia (double vision)** occurs when the two eyes do not move together
- Diplopia is often accompanied by nausea, vertigo and incoordination
- **Nystagmus (involuntary eye movements)** can occur without the person being aware of it – it is the onlooker who notices the side to side, up and down or rotational involuntary movements
- Vision is not usually affected with nystagmus although some people will report that objects appear to move/ jerk
- If the optic nerve has been damaged previously in an attack, infection, heat, tiredness and anxiety can result in vision being affected until the stressor is removed
- Not all problems with vision are a result of MS

## How can these affect a person with MS?

- Disturbance of vision – reduced vision, loss of colour vision, ‘patchy’ vision, blurred vision, double vision
- Fear
- Low mood/ depression
- Reluctance to go to unfamiliar places
- Issues with employment/ socialising

## How might this affect the partner/ carer?

- Increased care input
- Increased technology/ aids and adaptations within home

## What can affect these difficulties?

| Reduces impact/<br>improves things   | Increases impact/<br>makes it worse |
|--|-------------------------------------|
| Steroids to treat acute episode  | Heat                                |
| Eye exercises/ glasses   | Anxiety/ stress                     |
| Patching/ prisms for diplopia  | Infection                           |
| Referral to neuro-ophthamologist   | MS relapse                          |
| Practical aids – often as a result of an assessment. Person might need to be registered as sight impaired in order to access this. |                                     |

### What can I do to help manage this?

- Reduce possible stressors (see above)
- Ensure environment is as safe as possible – do not move furniture around
- Referral to OT for assessment of aids/ adaptations that might help

### Where can I get further information?

MS Society – *MS Essentials 05: Vision and MS*.

Access online at [www.mssociety.org.uk/publications](http://www.mssociety.org.uk/publications)

NICE (2003) *Clinical guideline 8. Multiple Sclerosis. Management of multiple sclerosis in primary and secondary care*.

Access online at <http://guidance.nice.org.uk/CG8/Guidance/pdf/English>

In Scotland, the findings and advice of NHS Quality Improvement Scotland – [www.nhsqis.org](http://www.nhsqis.org)

### Key points

- Many people with MS experience disturbance of vision at some point
- For the majority of people, recovery is good
- Visual disturbances include reduced vision, loss of colour vision, ‘patchy’ vision, blurred vision, double vision
- Optic neuritis can be very painful, as well as disturbing vision

# Speech and swallowing difficulties

## What speech and swallowing difficulties might be experienced by people with MS?

- Up to 50% of people with MS will have some problem with speech and/ or swallowing at some point
- For many people, the problems are mild and don't affect them greatly
- Dysarthria (unclear speech) is the most common speech problem occurring in MS. It results from damage to the parts of the brain involved in production of speech, causing impaired functioning of muscles of communication (lips, tongue, mandible, soft palate, vocal cords and diaphragm)
- It is usually accompanied by dysphonia (difficulty in voice production)
- Dysphasia (impairment of language function) may also be present
- Dysphagia (difficulty in swallowing) can occur due to damage to the brain stem or the part of the brain that controls swallowing
- Difficulty swallowing often accompanies unclear speech

## How can these affect a person with MS?

- Reluctance to speak/ eat – leading to malnutrition and/ or dehydration
- Frustration
- Low mood/ depression
- Withdrawal from socialising
- Choking episodes
- Dribbling
- Aspiration and possibility of aspiration pneumonia

## How might this affect the partner/ carer?

- Communication difficulties
- Fear
- Frustration
- Increased care input
- Dread of mealtimes

## What can affect these difficulties?

| Reduces impact/<br>improves things   | Increases impact/<br>makes it worse  |
|--|--|
| Remove distractions/noisy inputs<br>(TV, radio)  | Talking and eating at same time  |
| Referral to physiotherapist for advice<br>on posture and seating   | Poor posture   |
| Try to ask 'closed questions' that can<br>be answered with "yes" or "no"   | Rushing people for an answer/<br>finishing sentences for person                      |
| Give the person time to respond. Be<br>honest if you don't understand them   | Stress/ anxiety  |
| Do not prolong communication –<br>take a break   | Fatigue  |
| Referral to speech and language<br>therapist (for speech and swallowing<br>difficulties, including swallowing<br>assessment) | Certain foodstuffs (variable) – some<br>people choke on solids, others on<br>liquids |
| Aids and adaptations – OT referral   |  |
| Referral to dietitian for advice on diet/<br>consistency   |  |

## What can I do to help manage this?

- Ensure environment is distraction free if possible
- Ask the person with MS what is best for them – position, food, drink
- Give time; show understanding, empathy and honesty
- Ensure required referrals have been made
- Ensure person with MS receives and understands information on alternative methods of feeding if suggested (such as naso-gastric or PEG) so that they can make an informed choice

## Where can I get further information?

MS Society – *MS Essentials 23: Speech difficulties* and *MS Essentials 24: Swallowing difficulties*.

Access online at [www.mssociety.org.uk/publications](http://www.mssociety.org.uk/publications)

NICE (2003) *Clinical guideline 8. Multiple Sclerosis. Management of multiple sclerosis in primary and secondary care*.

Access online at <http://guidance.nice.org.uk/CG8/Guidance/pdf/English>

In Scotland, the findings and advice of NHS Quality Improvement Scotland – [www.nhsqis.org](http://www.nhsqis.org)

## Key points

- Dysarthria is the most common speech problem occurring in MS
- Swallowing difficulties often accompany unclear speech
- Ensure appropriate referrals are made
- Alternative methods of feeding might need to be considered

# Tremor

## What is tremor?

- Tremor is a rhythmic, trembling or shaking movement (occasionally it can be unpredictable and irregular)
- It is not under voluntary control
- It does not occur when the person is asleep
- It may be due to reasons unrelated to MS
- Small, shaking movements are described as 'fine' tremor
- Larger movements are described as 'gross' tremor
- If it occurs when the person goes to do something, it is called 'intention' tremor
- If it occurs when the person is at rest (sitting or standing) it is called 'postural' tremor
- It occurs due to demyelination in the cerebellum
- Tremor often occurs along with other disorders of movement, such as reduced coordination (ataxia) and muscle weakness
- It is difficult to manage

## How can this affect a person with MS?

- Tires the person – continuous movements use energy
- Most commonly affects upper limbs, but can affect lower limbs and head
- Can affect any/ all activities – for example, a person might have difficulty putting on make-up, shaving, eating (getting food onto fork and into mouth), writing
- Reduces independence
- Can be very frustrating
- Can affect speech
- Can affect head control
- Can affect eye movement
- Can cause embarrassment/ self-consciousness
- Can stop a person socialising

## How might this affect the partner/ carer?

- Increased care needs – person requires help with more activities
- Increased fatigue
- Communication difficulties
- Loss of social life

## What can affect it?

| Reduces impact/ improves it                       | Increases impact/ makes it worse    |
|---|-------------------------------------|
| Good posture, seating and support                 | Poor posture/ seating               |
| Task management (OT) and equipment                | Frustration/ stress                 |
| Sometimes splinting/ bracing/ weights can help    | Relapses                            |
| Limited benefit from medications (eg propranolol) | Can be a side-effect of medications |
| Occasionally surgery                              |                                     |

## What can I do to help manage this?

- Medication review
- Referral for rehabilitation (especially physiotherapist and occupational therapist)
- Reduce stress

## Where can I get further information?

MS Society – *MS Essentials 04: Tremor*.

Access online at [www.mssociety.org.uk/publications](http://www.mssociety.org.uk/publications)

NICE (2003) *Clinical guideline 8. Multiple Sclerosis. Management of multiple sclerosis in primary and secondary care*.

Access online at <http://guidance.nice.org.uk/CG8/Guidance/pdf/English>

In Scotland, the findings and advice of NHS Quality Improvement Scotland – [www.nhsqis.org](http://www.nhsqis.org)

## Key points

- Tremor is not under voluntary control
- People with MS usually experience intention or postural tremor
- Tremor can affect all activities and reduce independence
- It can be extremely tiring
- Tremor is difficult to manage
- Rehabilitation can help

# An overview of treatments

## Terminology:

What is the correct terminology to use? The terms ‘medications, medicines, drugs, treatments and therapies’ are often used interchangeably, but can have subtle differences in meaning.

For the purpose of this section, the term ‘treatment’ will be used generally; the term ‘medication’ will be used when discussing therapeutic drugs or other substances used (for treatment); and the term ‘therapy’ will be used with regard to non-medical treatments.

Treatments taken by people with MS can be described in different ways, or put into different categories such as:

- Prescribed (medicines)
- ‘Over the counter’
- Traditional medicines
- Complementary and alternative medicines/ therapies
- Medical treatments
- Physical therapies

Within the prescribed medications category, some medications will be used ‘out of licence’. This means that the medication is being used to treat a symptom that was not included in the original indication for use when the drug was licensed – for example, Amantadine to treat fatigue in MS. Amantadine is indicated for use in the treatment of Parkinson’s disease.

The treatments that will be covered in this next section are as follows:

- Disease modifying drugs (also called disease modifying treatments)
- Complementary and alternative therapies
- Other drugs sometimes used in MS

**Remember:** If you are ever in any doubt about the dosage or use of a drug, seek clarification from the prescriber.

# Disease modifying drugs/treatments

## What are disease modifying drugs/treatments?

- They can reduce the number and severity of relapses that a person might experience (they are licensed for use in relapsing forms of MS only).
- They do not stop the disease or its progression (although progression might be slowed down).
- They are not a cure.
- They do not work for everyone.
- They all have significant side-effects.
- These drugs are often referred to as 'DMDs' or 'DMTs'.
- There are currently 7 licensed DMDs for use in MS.
- The first oral DMD, Gilenya (fingolimod) was licensed in 2011, but approval by NICE is awaited. Other oral DMDs are still undergoing trial.

## What are the currently licensed disease modifying drugs?

| Drug               | Brand name | Route of administration   | Frequency of administration |
|--------------------|------------|---------------------------|-----------------------------|
| beta interferon 1a | Avonex     | IM injection              | Once a week                 |
| beta interferon 1a | Rebif      | SC injection              | Three times a week          |
| beta interferon 1b | Betaferon  | SC injection              | Every second day            |
| beta interferon 1b | Extavia    | SC injection              | Every second day            |
| glatiramer acetate | Copaxone   | SC injection              | Daily                       |
| natalizumab        | Tysabri    | IV infusion (in hospital) | Once a month                |
| fingolimod         | Gilenya    | Oral                      | Daily                       |

## What are the possible side effects?

| Drug (brand name)                       | Possible side effects   |
|---|---|
| Avonex<br>Rebif<br>Betaferon<br>Extavia | Skin reactions (unusual with Avonex)<br>Flu-like symptoms (last approx 48 hrs)<br>Mood changes<br>Menstrual irregularities<br>Neurological symptoms<br>Liver abnormalities<br>Reduced white cell count                            |
| Copaxone                                | Skin reactions<br>Rare – chest tightness, palpitations, perceived difficulty in breathing, sweating, anxiety – immediately following injection, usually settles within about half an hour   |
| Tysabri                                 | Joint pain<br>Fever, headache, dizziness, sore throat, blocked or runny nose<br>Fatigue<br>Nausea/ vomiting<br>Rare – liver abnormalities<br><b>Rare but possibly fatal</b><br>– progressive multifocal leukoencephalopathy (PML) |
| Gilenya                                 | Temporary lowering of heart rate and blood pressure associated with the first dose; increase in infections; leaking blood vessels in the eye (macular oedema);<br>localised, non-fatal skin cancers                               |

Other drugs that might be used to modify the disease course (but are not licensed for use in MS in the UK):

- Mitoxantrone
- Alemtuzumab (formerly Campath 1H. Brand name Lemtrada)
- Intravenous immunoglobulin (IVIg)
- Azathioprine
- Rituximab

## Where can I get further information?

MS Society – *MS Essentials 06: Disease modifying drugs*.  
Access online at [www.mssociety.org.uk/publications](http://www.mssociety.org.uk/publications)

[www.msdecisions.org.uk](http://www.msdecisions.org.uk) – an independent, interactive, online resource for people considering treatment

NICE (2002) *Technology Appraisal Guidance No.32. Beta interferon and glatiramer acetate for the treatment of multiple sclerosis*.  
Access online at <http://guidance.nice.org.uk/TA32>

ABN (2009) *ABN guidelines for treatment of multiple sclerosis with Beta Interferon and Glatiramer acetate*. Association of British Neurologists, London.  
Access online at [www.theabn.org](http://www.theabn.org)

NICE (2003) *Clinical guideline 8. Multiple Sclerosis. Management of multiple sclerosis in primary and secondary care*.  
Access online at <http://guidance.nice.org.uk/CG8/Guidance/pdf/English>

In Scotland, the findings and advice of NHS Quality Improvement Scotland – [www.nhsqis.org](http://www.nhsqis.org) – and the Scottish Medicines Consortium – [www.scottishmedicines.org.uk](http://www.scottishmedicines.org.uk)

### Key points

- Disease modifying drugs can reduce the number and severity of relapses in MS but do not halt or cure the disease
  - They do not work for everyone
  - They all have side effects and require monitoring
-

# Complementary and alternative medicines/therapies

## What are complementary and alternative medicines/therapies?

- 'Complementary' refers to the fact that they are used alongside/ as well as prescription medicines/ therapies
- 'Alternative' refers to the fact that they are used instead of prescription medicines/ therapies
- The term 'complementary and alternative medicines' is often shortened to CAMs
- The terms 'therapies' and 'medicines' are used, often interchangeably (see box below)
- Sometimes, the term 'natural' is used to describe complementary and alternative medicines/ therapies – this can be misleading, as some medicines/ therapies will be 'man-made' (as opposed to natural)
- Sometimes, the term 'holistic' will be used to describe complementary and alternative medicines/ therapies, which might also be misleading – 'holistic' refers to the fact that physical, mental and social factors affecting the person are considered as well as the disease process/ symptom experienced
- For many of these treatments, there is little or no evidence to support their use
- Many people with MS use one or more of these treatments at some point, often for many years
- While some treatments do not appear to have side-effects or cause the user any harm, there might be a financial cost incurred

## Terminology:

In this booklet, 'medicine' is used to describe a treatment that is taken into the body (by swallowing/ injection/ absorption); 'therapy' is used to describe a treatment that is performed on a person.

However, even with this definition there can be a blurring of these terms – see table overleaf for examples.

When both medicines and therapies are being referred to, the term 'treatments' are used.

### Examples of complementary and alternative medicines/ therapies

| Medicines  | Therapies  |
|--|--|
| Aromatherapy (could be considered a therapy, but oils are absorbed through the skin) | Massage (nb lotions/ oils could be absorbed through the skin, so could be considered a medicine) |
| Bee venom  | T'ai Chi   |
| Acupuncture (could be considered a therapy as no drug used – only needle inserted)   | Hyperbaric Oxygen (could be considered a medicine as oxygen inhaled)                             |
| Homeopathy   | Reflexology  |
| Herbal medicines   | Pilates  |
| Cannabis   | Yoga   |

### What do I do if someone is using one or more of these treatments?

- Discuss with the person when and how often they use the treatment(s)
- Get further information on the treatment if required
- Have an open discussion, involving person with MS plus relevant medical and therapy personnel as to whether the treatments can continue during the hospital admission, giving reasons as appropriate.
- Remember, for many people with MS, these treatments are something that they can do or use to try to help themselves and manage their symptoms

## Where can I get further information?

MS Society – *MS Essentials 18: Complementary and alternative medicine*.

Access online at [www.mssociety.org.uk/publications](http://www.mssociety.org.uk/publications)

(This booklet includes a list of organisations to contact for further information)

Sense about science (2008) *“I’ve got nothing to lose by trying it”*.

Access online at [www.mssociety.org.uk/research](http://www.mssociety.org.uk/research)

NICE (2003) *Clinical guideline 8. Multiple Sclerosis. Management of multiple sclerosis in primary and secondary care*.

Access online at <http://guidance.nice.org.uk/CG8/Guidance/pdf/English>

In Scotland, the findings and advice of NHS Quality Improvement Scotland – [www.nhsqis.org](http://www.nhsqis.org)

## Key points

- Many people with MS use complementary and/ or alternative medicines/ therapies
- There is often very limited or no evidence, other than anecdotal, to support their use
- For many people with MS, these treatments can represent hope and control over their MS

## **Drugs sometimes used in MS**

Drugs sometimes used for MS have been mentioned previously in some detail, such as the disease modifying drugs (licensed for use in relapsing forms of MS) so will not be included here.

The list of drugs below is not exhaustive. Any queries about a drug and its use should be discussed with the prescriber, the medical practitioner involved in the person's care, or a pharmacist.

| Drug                | Route of administration | Indication                               | Used out of licence? |
|---------------------|-------------------------|--|----------------------|
| Amantadine          | Oral                    | Fatigue                                  | Yes                  |
| Amitriptyline       | Oral                    | Neuropathic pain                         | No                   |
| Carbamazepine       | Oral                    | Neuropathic pain (trigeminal neuralgia)  | No                   |
| Cialis              | Oral                    | Erectile dysfunction                     | No                   |
| Citalopram          | Oral                    | Depression                               | No                   |
| Desmopressin        | Nasal spray             | Nocturia                                 | No                   |
| Diazepam            | Oral                    | Spasticity<br>Spasms                     | No                   |
| Gabapentin          | Oral                    | Spasticity<br>Spasms<br>Neuropathic pain | No                   |
| Fluoxetine          | Oral                    | Depression                               | No                   |
| Methyl-prednisolone | IV or oral              | Treatment of an acute relapse            | No                   |
| Modafinil           | Oral                    | Fatigue                                  | Yes                  |
| Movicol             | Oral                    | Constipation                             | No                   |
| Oxybutynin          | Oral                    | Neurogenic bladder instability           | No                   |
| Pregabalin          | Oral                    | Neuropathic pain                         | No                   |
| Sativex             | Oral spray              | Spasticity<br>Spasms                     | No                   |
| Tizanidine          | Oral                    | Spasticity<br>Spasms                     | No                   |
| Viagra              | Oral                    | Erectile dysfunction                     | No                   |

# **An overview of self management, 'wellness' and 'independent living'**

This section looks at general health, wellbeing and quality of life – and how a person can effectively keep control of their life, regain control if they have lost it and hopefully have a better quality of life, while living with their MS.

The previous sections have discussed aspects of MS, including some of the more common symptoms and their management. Under each symptom, the possible effects on the person, as well as their family/ carer were discussed, as well as what could be done to reduce the effect of the symptom and improve the person's quality of life. The ideas in this section take this a step further.

There are many and varied definitions for the three terms, 'self management', 'wellness' and 'independent living'. We hope those below are helpful.

## **What is self management?**

Self management is a person's ability to manage all aspects of their life when living with a long-term condition (LTC). This will include physical, psychological and social aspects, as well as any changes that occur as a result of the LTC.

## **What is wellness?**

Wellness is an holistic concept, involving a balance of mind, body and spirit. The aim, for the person who uses a wellness approach, is to achieve an overall feeling of control, well-being and optimum quality of life.

(Note: wellness is not the treatment or absence of illness; neither is it the use of health promoting activities)

## **What is independent living?**

Independent living is a framework in which services and support should be provided, to enable disabled people to take full and active control of their lives in exactly the same way as non-disabled people.

# Self management and living with MS

MS is a long-term neurological condition. Long-term – it requires ongoing management, possibly for years. Neurological – it occurs in the central nervous system.

Within the UK, it has been estimated that:

- 17.5 million adults live with at least one long-term condition (LTC)
- 60% of all adults have an LTC
- 70% of adults over 65 years of age are likely to have more than one LTC (co-morbidity)
- There are approx 100,000 people diagnosed and living with MS in the UK
- Many of these people will be living with another LTC as well as MS
- The person has to adjust to the diagnoses, the uncertainty and possible changes to ability, lifestyle, quality of life
- Self management – regular exercise, healthy diet, etc can help lessen the effects of the diagnosis/ condition

## Why is self management important?

- It enables people to remain in/ take back control
- It can lead to reduced health care costs and hospital admissions
- It increases a person's self-efficacy
- It might lead to improved quality of life

## What are the possible effects of living with one or more LTCs?

- Reduction in physical health
- Constant symptoms (eg pain, fatigue)
- Reduction in emotional/ psychological wellbeing
- Possibility of losing job – and financial security
- Behavioural changes
- Reduction in quality of life
- Care becomes more complex
- Increased difficulty in negotiating health and social care systems
- Unplanned hospital admissions more likely

## What can the person do to help themselves?

- Get information about the condition and how to manage the symptoms
- Come to terms with the diagnosis – this can take time and might require input from other people
- Consider attending courses or programmes, such as 'Newly diagnosed with...'; 'Getting to Grips'; symptom management; chronic disease self-management/ Expert Patient
- Consider attending self-help/ peer groups

## What can you do to help?

- Ask the person what help/ support they might like from you – they might not know what is available, so be prepared to explain/ show it
- Remember that people react differently to receiving a diagnosis and will take different lengths of time to adjust
- Ask the person what input/ follow up they would like
- Ensure the person has access to relevant, up-to-date information
- Give written, as well as verbal information on all matters
- Work in a partnership with the person
- Ensure the person retains control – don't take it away
- Ensure family and carers also get support (see next section)

## Where can I get further information?

MS Society – *MS Essentials 28: Living with the effects of MS*. Access online at [www.mssociety.org.uk/publications](http://www.mssociety.org.uk/publications). In Scotland, the MS Society runs self-management courses (see back cover for contact details).

MS Trust – *MS and me: A self-management guide to living with multiple sclerosis*. Access online at [www.mstrust.org.uk/information](http://www.mstrust.org.uk/information)

Expert Patient Programme. Access online at [www.expertpatients.co.uk](http://www.expertpatients.co.uk)

In Scotland, 'Gaun Yersel' *The Self Management Strategy for Long Term Conditions in Scotland*. Available online at [www.ltcas.org.uk/self\\_man\\_gaun.html](http://www.ltcas.org.uk/self_man_gaun.html)

In Wales, the Expert Patients Programme Wales – [www.wales.nhs.uk](http://www.wales.nhs.uk) (search 'expert patients')

# Recognising the needs of families and carers

## Why do I need to consider families and carers?

- Legislation around the UK gives carers the right to assessment and for their needs to be considered – this legislation also relates to NHS bodies, which have responsibility for identifying and supporting carers
- Mental capacity and confidentiality legislation sets out the rights of family and friends (including carers) and how they must be consulted and involved when discussing the best interests of the person being cared for
- Carers and families are partners in care and their role is crucial to the wellbeing of the person being cared for
- Effective admission and discharge relies on the principle of working in partnership with families and carers
- Families and carers undertake significant responsibilities and they are often unsupported and unrecognised
- Research tells us that it can take up to 3 years for a carer's role to be recognised and for them to get the benefits and support that they are entitled to
- Families' and carers' own health is put at risk due to the demands of caring and often the only time this will be noticed is when the situation reaches crisis point, often via a hospital admission
- Recognition by hospital staff may be the first time the carer has been identified

## When should I do this?

- For planned admissions, involving families and carers in any pre-admission planning will enable a smooth transition
- In an emergency admission, families and carers will have information that will help inform the situation – they will also need support and understanding
- During out-patient appointments (with consent from the person with MS), families and carers will need to understand any new treatments or change of care needs, and more about the diagnosis or a change in the condition
- If there have been previous admissions, don't assume that the details outlining care needs at home have been recorded or that a main carer has been identified
- Use each opportunity to update patient records
- Keep the family and main carer's contact details updated on patient records, in case you need contact in a medical emergency

## What should I be doing?

- Recognise and validate the carer's role
- Listen to the information they have about the person with MS and the role that they play in their health and wellbeing
- Give clear expectations about what is expected from them (i.e. visiting, food, provisions) during this hospital stay – if possible allocate one person as their link worker on the ward
- Record the information on the patient records
- Involve families and carers in planning meetings
- Give them access to information and support relevant to their situation
- Signpost carers to services that will give them more information and support
- Give them accessible information about the medical condition
- Provide opportunities to talk to you in confidence
- Determine if the person with MS themselves has a caring role

## How will I do this?

- Nominate a team member to be the Carers' Champion for your ward or department
- Collect and display relevant local and national information for carers using either a notice board or table in the reception or a communal area
- Use posters to encourage families and carers to identify themselves
- Know about your local Carers' Centre and have their information available
- A family and carers' charter would enable clear objectives to be set and give a framework for staff to be measured by – this enables the trust to meet its targets relating to supporting carers
- Work with families and carers who use the service, asking for their views on service provision and development – this would enable carers to feel that they have a voice and are being listened to, and enable the trust to demonstrate public involvement

## Whose job is it?

- The NHS trust has an obligation to carers and there should be clear policy statements that enable staff to comply
- The philosophy of supporting families and carers should be embedded in good practice and be measured and evaluated at all levels
- There should be a rolling programme of training that enables front line staff to be proactive and reactive when working with families and carers

## Where can I get further information?

Princess Royal Trust for Carers – [www.carers.org](http://www.carers.org)

Carers UK – [www.carersuk.org](http://www.carersuk.org)

Carers Direct – [www.nhs.uk/carersdirect](http://www.nhs.uk/carersdirect)

Direct Government - [www.direct.gov.uk/en/CaringForSomeone](http://www.direct.gov.uk/en/CaringForSomeone)

NI Direct (Northern Ireland) – [www.nidirect.gov.uk/carers](http://www.nidirect.gov.uk/carers)

MS Society Strategic Lead, Carers – [respitecare@mssociety.org.uk](mailto:respitecare@mssociety.org.uk)

## More about MS

The MS Society publishes a wide range of resources for professionals and people affected by MS. Information is available in print and online in a number of formats and languages.

### For health and social care professionals:

#### MS Society website

[www.mssociety.org.uk](http://www.mssociety.org.uk)

#### Masterclass: Evidence-based updates for GPs

Adapted from the original BMJ Masterclass series, with two chapters: one on multiple sclerosis and one on neuropathic pain. In association with the BMJ. Written by Dr David Rog, Consultant Neurologist, Greater Manchester Neurosciences Centre.

Download free at [www.mssociety.org.uk/professionals](http://www.mssociety.org.uk/professionals)

#### MS and palliative care

For all health and social care professionals. Includes the principles of palliative care, optimising quality of life, advance planning, and end-of-life care.

Download free at [www.mssociety.org.uk/professionals](http://www.mssociety.org.uk/professionals)

#### MS Society Library services

Keep up to date with weekly or monthly research alerts. Request research articles. Search the online library for books, articles, and DVDs.

More information at [www.mssociety.org.uk/library](http://www.mssociety.org.uk/library)

## For people affected by MS:

National MS Helpline – Freephone 0808 800 8000 (weekdays 9am-9pm)

### MS Society websites

[www.mssociety.org.uk](http://www.mssociety.org.uk) – our main site, with links to local, regional and national sites around the UK, including those listed opposite.

[www.youngms.org.uk](http://www.youngms.org.uk) – two websites in one, for under-18s living with MS.

With message boards for teens and Sparks the Robot for younger children.

### What is MS?

A comprehensive guide to MS. Includes diagnosis, symptoms, current treatment and management options, and sources of support. Available in a range of languages. Three smaller titles look more closely at the main ‘types’ of MS (*What is relapsing remitting MS?*, *What is secondary progressive MS?* and *What is primary progressive MS?* ).

### Just diagnosed – an introduction to multiple sclerosis

A pocket-sized booklet available in a range of languages.

### MS Essentials

A range of titles covering specific symptoms or aspects of living with MS. Titles include *Fatigue*, *Managing a relapse* and *Benefits and MS*.

### Childhood MS – a guide for parents

A comprehensive booklet looking at the symptoms, diagnosis and treatment of childhood MS. It looks at the effects there can be on the child, the family and school life, and support available for parents and young people.

### Personal details card

Filled in by someone with MS, this shows how MS affects them and assistance they might need.

**All these titles and more are available free of charge. Download or order from [www.mssociety.org.uk/publications](http://www.mssociety.org.uk/publications)**

If you have questions, requests or feedback about information on MS, contact the UK Information Team: [infoteam@mssociety.org.uk](mailto:infoteam@mssociety.org.uk) or 020 8438 0799 (weekdays 9am-4pm).



## MS Society

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

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

- promoting good practice in MS treatment and care
- publishing newsletters, reports and educational materials
- organising networking opportunities and events
- funding health and social care posts in community, rehabilitation, primary and acute care settings
- funding research into the cause of MS, as well as developing more effective treatments and improving care and services for people living with MS – with an overall research portfolio worth over £15million

Disclaimer: We have made every effort to ensure that the information in this publication is correct. We do not accept liability for any errors or omissions. The law, government regulations and latest evidence may change. Be sure to seek local advice from the sources listed.

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Edited by James Bailey

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# Join the MS Professional Network

The MS Society Professional Network links thousands of health and social care professionals. Members have a shared interest in improving services for people with MS and receive:

- e-newsletters to keep up to date
- access to a secure online discussion board
- opportunities for learning and information exchange
- opportunities to promote and share good practice
- priority access to the MS Society's new education and information resources
- support and advice on research, service audit and development

Membership is free. Simply register online at [www.mssociety.org.uk/profs](http://www.mssociety.org.uk/profs)

## MS Society contact information

|                                    |   |
|------------------------------------|---|
| <b>MS National Centre</b>          | 372 Edgware Road<br>London NW2 6ND<br>Tel: 020 8438 0700  |
| <b>MS Society Scotland</b>         | National Office<br>Ratho Park<br>88 Glasgow Road<br>Ratho Station<br>Newbridge EH28 8PP<br>Tel: 0131 335 4050 |
| <b>MS Society Northern Ireland</b> | The Resource Centre<br>34 Annadale Avenue<br>Belfast BT7 3JJ<br>Tel: 028 9080 2802                            |
| <b>MS Society Cymru</b>            | Temple Court<br>Cathedral Road<br>Cardiff CF11 9HA<br>Tel: 029 2078 6676                                      |
| <b>Website</b>                     | <a href="http://www.mssociety.org.uk">www.mssociety.org.uk</a>  |
| <b>National MS Helpline</b>        | Freephone 0808 800 8000<br>(weekdays 9am-9pm)   |

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