Multiple sclerosis in adults: management

Information for the public
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About this information

NICE guidelines provide advice on the care and support that should be offered to people who use health and care services.

This information explains the advice about multiple sclerosis (MS) that is set out in NICE guideline CG186.

This is an update of advice on MS that NICE produced in 2003.

Does this information apply to me?

Yes, if you are an adult who has or may have MS.

Multiple sclerosis

Multiple sclerosis (MS) affects the way nerve cells carry messages around the body.

'Sclerosis' means 'scarring', and in MS the coating around the nerves becomes scarred, affecting
how the body functions. MS causes scarring at 'multiple' (many) places in the nervous system causing different symptoms. People with MS tend to have their first symptoms before they are 50.

Depending on the areas affected, people may have problems with their eyesight. They may have weakness in their limbs, loss of feeling or find it difficult to move around, and can feel clumsy and have problems with balance. They may also have bladder and bowel problems.

A cure for MS hasn't yet been found. Some treatments can slow down some types of MS, and these are covered in other NICE guidance. There are also lots of different ways to manage MS symptoms.

**Types of MS**

MS affects people in different ways. It is often divided into 3 types which describe the pattern the disease follows.

**Relapsing–remitting MS:** Symptoms come and go. Periods of stable health (remission) are followed by sudden symptoms (relapses). About 85 out of 100 people with MS have relapsing–remitting MS from the start.

**Secondary progressive MS:** This is when there are gradually more or worsening symptoms with fewer remissions. Around two-thirds of people who start with relapsing–remitting MS may develop secondary progressive MS.

**Primary progressive MS:** Symptoms gradually develop and worsen over time. About 10 to 15 out of 100 people with MS have primary progressive MS from the start.

**Your care team**

A range of professionals who specialise in different areas of treatment or support may be involved in your care. These could include consultant neurologists (doctors specialising in the brain and nervous system), MS nurses, physiotherapists, occupational therapists, speech and language therapists, psychologists, dietitians, social care providers and specialists to help with bladder and bowel problems, as well as your GP. All these people should work together to care for you. You should be given the name and contact details for one of these people, so that you can make contact with the team if you have any questions.
Working with you

Your care team should talk with you about MS. They should explain any tests, treatments or support you should be offered so that you can decide together what is best for you. Your family or carer can be involved in helping to make decisions, but only if you agree. There are lists of the questions you might like to ask in each section that you can use to help you talk with your care team.

You may also like to read NICE's information for the public on patient experience in adult NHS services. This sets out what adults should be able to expect when they use the NHS. We also have more information on the NICE website about using health and social care services.

Some treatments or care described here may not be suitable for you. If you think that your treatment does not match this advice, talk to your care team.

Finding out whether you have MS

MS can be hard to diagnose because some of the symptoms are similar to those of other conditions. The doctor referring you should arrange for you to have some blood tests to rule out other conditions, before you see a consultant neurologist.

Consultant neurologists specialise in the brain and nervous system. Only a consultant neurologist should diagnose MS, after carefully assessing your symptoms or circumstances. Even if you have had an MRI scan that suggests you have MS, you still need to see a consultant neurologist who will look at the results of all of your tests before making a diagnosis.

If your symptoms and circumstances don't match the criteria for how MS usually appears over a period of time, but your consultant neurologist still thinks MS is a possibility, they should plan a review appointment. They should tell you when the appointment will take place and who to contact if your symptoms get worse or you get any new symptoms in the meantime.

If it's possible that you have MS, you should be given information about support groups and national charities.

Optic neuritis

If your GP thinks you have optic neuritis (which makes your vision blurred or your eye painful), you
should be referred to an ophthalmologist (eye doctor) and a consultant neurologist.

Questions you might want to ask

- Can you tell me more about the tests you’ve offered me?
- What do these tests involve and what will they tell us?
- Where will these be carried out? Will I need to have them in hospital?
- How long will I have to wait until I have these tests?
- How long will it take to get the results of these tests?
- What happens if the results of the tests are normal?

Information and support

When you are first diagnosed with MS

When you are diagnosed with MS, the consultant neurologist should ask you what information you would like and if you are happy for that information to be shared with family or carers.

The information offered should cover:

- what MS is
- what treatments are available
- how symptoms can be managed
- what help is available from support groups, local services (such as community rehabilitation programmes), social services and charities
- whether there is anything you need to do by law, such as telling the DVLA (Driver and Vehicle Licensing Agency) about your condition
- how MS affects your employment rights and benefits.

Your consultant neurologist should ask you and your family members or carers if you have any social care needs (such as extra help around the home or equipment to make things easier for you).
If you do they should refer you to social services so your needs can be assessed. They should also make sure that the needs of your children are addressed.

Your consultant neurologist should regularly check whether you need any more information or support.

You should also be invited to a follow-up appointment which should be within 6 weeks of your diagnosis. Your appointment may be with the consultant neurologist, an MS nurse or another healthcare professional who knows about MS.

See other NICE guidance for the general advice NICE gives about improving the experience of care for people using adult NHS services.

**Ongoing information**

Your consultant neurologist should tell you who to contact if your symptoms change significantly and explain what may be causing these changes, for example your MS getting worse or another illness such as an infection. They should also explain that your MS may affect your memory and thinking in ways that seem unrelated to MS.

When it is appropriate, your consultant neurologist should talk with you (and your family and carers, if you would like them to be involved) about what type of care you would like in the future if your MS gets worse. They should also talk to you about power of attorney (formally setting out who would be able to make decisions for you about your health or finances, if you were unable to).

**Vaccinations**

Although flu vaccination has its benefits, some people with relapsing–remitting MS seem more likely to have a relapse after having the vaccine. Your GP should discuss this with you and follow national guidelines about flu vaccination.

If you are taking drugs to suppress your immune system you may not be able to have 'live' vaccines. These are vaccines that contain living viruses that have been weakened.

**Pregnancy**

If you have MS and are thinking about having a baby, you should have the opportunity to discuss any concerns you may have (about for example, fertility, use of medicines and breastfeeding) with a
healthcare professional with knowledge about MS.

Becoming pregnant does not make MS worsen more quickly. Women with relapsing–remitting MS are less likely to have a relapse during pregnancy. However, they are more likely to have a relapse 3–6 months after having their baby. After this time a woman's risk of relapse is the same as before she became pregnant.

Questions you might want to ask

- Can you tell me more about MS?
- Is MS hereditary?
- Can you tell me more about how quickly my disease is worsening?
- Do I need to be careful about other vaccinations, for example if I travel abroad?
- Are there any support organisations in my local area?
- Can you recommend any good sources of information about MS?
- Can you provide any information for my family or carers?
- Is there any additional support that I might benefit from or be entitled to?

Questions your family or carers might like to ask

- What can I/we do to help and support the person with MS?
- Is there any additional support that I/we as carer(s) might benefit from or be entitled to?
- How do I apply for a local authority carer's assessment?

Changes you can make to your lifestyle

Regular exercise may help ease your MS symptoms. See fatigue and problems with mobility and fatigue for more information on how exercise can help these symptoms.

Smoking may make MS worsen more quickly, so if you smoke you should be advised to stop. You can
get help from your GP if you need advice or support. See other NICE guidance for details of our guidance on smoking.

Questions you might like to ask

- Are there any other changes I could make to my lifestyle that could help my MS?

Easing the symptoms of MS

You should be offered regular appointments with members of your healthcare team to review the different parts of your care and check that your symptoms are being managed as well as possible. How often you need these checks will depend on the needs of you and your carers, and what drugs and other treatments you are having.

Fatigue

Many people with MS have fatigue. This is not ordinary tiredness, but a feeling of utter exhaustion that is not related to how much you have been doing. The fatigue can be brought on by heat, overexerting yourself or stress. Sometimes it can be related to the time of day. If you have problems with fatigue, your GP should first make sure that nothing else could be causing it, such as anxiety, depression, difficulty in sleeping or medical problems such as anaemia or thyroid disease. If you have any of these conditions you should be offered treatment for them first.

If your fatigue is caused by your MS, a drug called amantadine could help with this.

Training in mindfulness (paying attention to your present thoughts and feelings), cognitive behavioural therapy (a type of talking therapy that helps you change the way you think and behave) or special techniques to help you manage your fatigue may also help. Aerobic, balance and stretching exercises such as yoga may also help ease MS-related fatigue.

Mobility problems

If you are having problems with mobility you should be fully assessed so that you and your healthcare professional (usually a rehabilitation specialist or a physiotherapist with expertise in MS) can set some goals and plan how you can achieve them.
Problems with mobility and fatigue

Taking part in a supervised exercise class that combines some aerobic and strength training may help if you have problems with mobility or fatigue.

Continuing to exercise will keep helping your MS, so your healthcare professional should encourage you and help you to keep exercising. They may refer you to local exercise classes or to a scheme that offers gym membership at a reduced cost.

Your healthcare professional should explain what activities are available and ask which you prefer.

Problems with balance

If you find it hard to balance because of dizziness, special exercises to improve your balance may also be helpful.

Spasticity

Spasticity is a condition that affects the muscles, making them more stiff and rigid than usual. Other conditions can make spasticity worse such as constipation or an infection and these should be assessed and treated.

You may need to try several different drugs for spasticity taken at various doses until the right one is found for you. The drugs could include baclofen, gabapentin, tizanidine, dantrolene, and benzodiazepines. You may even need to try a combination of drugs. Drugs that don’t work for you should be stopped. Once you have found the best drug and dose for you, your neurologist should set up an appointment to review your treatment at least once a year.

You should also be encouraged to manage your own spasticity by varying the drug dose you take within agreed limits.

If the drugs above do not help your spasticity, you should be referred to a specialist spasticity service. The service should offer you a 4-week trial of a mouth spray containing cannabis-based medicines. If your symptoms improve enough, you should be able to continue treatment with this mouth spray after the 4-week trial. For more information, see NICE’s guideline on cannabis-based medicinal products.
Problems with eyesight

Some people with MS have a problem with their eyesight that makes it look as if objects are moving when they are not (you may hear this called 'oscillopsia'). If this affects you, drugs called gabapentin or memantine could help. If neither of the drugs work or the side effects mean that you can't take them, your doctor should refer you to a consultant neurologist or ophthalmologist.

Emotional lability

Some people with MS may have emotional lability, a difficulty with their emotions that means they may laugh or cry inappropriately without being able to control it. If this happens to you, talk to your GP who may consider with you whether a drug called amitriptyline may help.

Pain

People with MS may have neuropathic pain. Neuropathic pain happens when the nerves don't work properly and send the wrong signals to the brain. It can feel like stabbing, an electric shock, burning, tingling, prickling, itching, or a sensation of pins and needles anywhere in the body. If you have neuropathic pain, your GP should offer you treatment in line with NICE's guideline on neuropathic pain. They may also refer you to a pain specialist.

People with MS can also get pain in their muscles, joints and bone, and this is usually caused by problems with mobility or posture. If you have this type of pain your doctor should assess your symptoms and offer treatment or referral.

Other symptoms

If you have problems with your memory or thinking, or if you have anxiety, depression or difficulty in sleeping, your doctor should assess your symptoms and offer you treatment for these. They may suggest you see an occupational therapist or neuropsychologist (a psychologist who specialises in conditions that affect the nervous system), or that you attend a memory clinic if your problems relate to memory or thinking.

Off-label use

At the time of publication (October 2014), some of the drugs may be recommended for 'off-label' use in this guideline.
In the UK, medicines are licensed to show that they work well enough and are safe enough to be used for specific conditions and groups of people. Some medicines can also be helpful for conditions or people they are not specifically for. This is called 'off-label' use. Off-label use might also mean the medicine is taken at a different dose or in a different way to the licence, such as using a cream or taking a tablet. There is more information about licensing medicines on the NHS website.

Drugs being recommended off-label include gabapentin for spasticity and problems with your eyesight, memantine for problems with your eyesight, amantadine for fatigue and amitriptyline for emotional lability.

### Questions you might like to ask

- How long will I have to take the drugs for?
- Will I need to try another drug for spasticity if this one doesn’t work?
- Will I have to stop taking them gradually?
- Might I have problems when I stop taking them?
- Are there any side effects associated with this drug or combination of drugs?
- What will happen if I choose not to have the treatment you have offered?
- What should I do if I get any side effects?
- Are there any long-term effects of taking this treatment?
- Is there some other information (like a leaflet, DVD or a website I can go to) about the treatment that I can have?

### Treatments you should not be offered

Fampridine for mobility problems is not recommended for use in the NHS because it does not provide enough benefit to patients to justify its cost. If you are already taking this drug you should be able to continue taking it until you and your doctor decide it is the right time to stop.

You should not be offered the following because there is not enough evidence that they work:

- vitamin B₁₂ injections for fatigue
omega-3 fatty acid or omega-6 fatty acid or vitamin D to treat MS. (You may need to take vitamin D if your doctor finds that you do not have enough in your body.)

What should happen if you have a relapse

Recognising a relapse

If you develop new symptoms or your symptoms get worse and last for more than a day, you may be having a relapse. Your healthcare professional should check that nothing else could be causing these symptoms, such as an infection, and confirm your diagnosis with a health professional with expertise in MS. Your symptoms should be assessed and you should be offered treatment for the relapse as early as possible, and within 14 days of your symptoms starting. Symptoms of relapse usually last a few weeks and improve within 3 months. If your symptoms don't improve your healthcare professional may discuss other possible causes with you.

Treating a relapse

Steroids can be used to treat MS symptoms or relapses but they should not be offered to you unless a health professional with expertise in MS agrees that they might help. Steroids are usually taken by mouth for 5 days but sometimes they may be given in hospital through a drip. It is not recommended for you to be given steroids to keep at home to use if you have a relapse in the future.

Your GP should make sure that other healthcare professionals looking after you know about your relapse, because it may affect which drugs you are given for your MS.

You may be referred to social services if you or your family and carers need support because of your relapse. If it is difficult to meet your needs at home, or your relapse is severe, you should be offered treatment in hospital as an inpatient.

You may need rehabilitation or extra treatment to manage your symptoms.

Information you should be given

Your healthcare professional should talk with you about the benefits and risks of steroids. They should explain that at high doses they can temporarily affect a person's mental health (for example, causing depression, confusion or agitation) and worsen blood sugar control in people with diabetes. You should also be given information to take away with you about these side effects in a format that
is right for you so you can refer to it in your own time.

Relapses may cause temporary problems with your memory and thinking.

**Questions you might like to ask**

- How do I know if I am having a relapse?
- Who should I contact if I am having a relapse?
- Can you tell me why you have decided to offer me this particular type of treatment for relapse?
- What will it involve?
- How will it help me? What effect will it have on my symptoms and everyday life? What sort of improvements might I expect?
- How long will it take to have an effect?
- Are there any risks associated with this treatment?
- What are my options for taking treatments other than the one you have offered me?
- Is there some other information (like a leaflet, DVD or a website I can go to) about the treatment that I can have?

**Reviewing your MS**

You should ideally have a full review at least once a year. The review should be carried out by healthcare professionals with expertise in MS, but they may decide to involve other people too, depending on your needs. They should ask not only about your MS symptoms, but also about your overall health and wellbeing and your ability to take part in family life, work and activities. They should ask about whether you feel fatigue or have problems with walking. You should be asked if you have any problems with pain, your bladder or bowel or with swallowing and if you ever feel depressed or anxious (see other NICE guidance for information on these conditions). They should also ask you about your care needs, and ask about the needs of your family and carers, and refer you to other teams if needed. Your medicines should also be reviewed (see 'other NICE guidance' for information on medicines adherence).
Everyone with MS should regularly have the health of their bones checked. If you have mobility problems you should also have your muscles and joints checked, and also be examined for pressure ulcers (sometimes called ‘bedsores’ or ‘pressure sores’). See other NICE guidance for details of our guidance on pressure ulcers. Your need for mobility aids should also be reviewed.

If in the future your MS gets worse, it may help to be seen by palliative care, who can help better control your symptoms and improve your quality of life.

**Questions you might like to ask**

- When is my next review appointment?
- How do I arrange an earlier appointment if I need one?

**Sources of advice and support**

- [MS Society](http://www.mssociety.org.uk), free helpline 0808 800 8000, [helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk)
- [MS Trust](http://www.mstrust.org.uk), 0800 032 38 39

You can also go to [NHS website](http://www.nhs.uk) for more information.

NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

**Other NICE guidance**

- [Stop smoking interventions and services](https://www.nice.org.uk/guidance/ng92) (2018) NICE guideline NG92
- [Pressure ulcers](https://www.nice.org.uk/guidance/cg179) (2014) NICE guideline CG179
- [Patient experience in adult NHS services](https://www.nice.org.uk/guidance/cg138) (2012) NICE guideline CG138
- [Generalised anxiety disorder and panic disorder in adults](https://www.nice.org.uk/guidance/cg113) (2011) NICE guideline CG113
Accreditation

Health & care information you can trust

The Information Standard Certified Member

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