

Multiple sclerosis

Understanding NICE guidance – information for people with multiple sclerosis, their families and carers, and the public

November 2003

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Issue date: November 2003

This booklet was produced in association with the MS Trust (01462 476700; www.mstrust.org.uk) and the Multiple Sclerosis Society (0208 438 0700; www.mssociety.org.uk)

To order copies

Copies of this booklet can be ordered from the NHS Response Line; telephone 0870 1555 455 and quote reference number N0368. A version in English only is also available, quote reference N0367. The NICE clinical guideline on which this information is based, *Multiple sclerosis: management in primary and secondary care*, is available from the NICE website (www.nice.org.uk). Copies can also be obtained from the NHS Response Line, reference number N0366.

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Web: www.nice.org.uk

ISBN: 1-84257-445-0

Published by the National Institute for Clinical Excellence
November 2003
Typeset by Icon Design, Eton
Printed by Abba Litho Sales Limited, London

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About this information

This information describes the guidance that the National Institute for Clinical Excellence (called NICE for short) has issued to the NHS on the management of multiple sclerosis (MS) in the community and in hospitals. It is based on *Multiple sclerosis: management in primary and secondary care*, which is a clinical guideline produced by NICE for doctors, nurses and others working in the NHS in England and Wales. Although this information has been written chiefly for people with MS, it may also be useful for family members, those who care for people with MS and anyone interested in MS or in healthcare in general.

Clinical guidelines

Clinical guidelines are recommendations for good practice. The recommendations in NICE guidelines are prepared by groups of health workers, lay representatives with experience or knowledge of the condition being discussed, and scientists. The groups look at the evidence available on the best way of treating or managing a condition and make recommendations based on this evidence.

There is more about NICE and the way that the NICE guidelines are developed on the NICE website (www.nice.org.uk). You can download the booklet

The guideline development process – information for the public and the NHS from the website, or you can order a copy by phoning the NHS Response Line on 0870 1555 455 (quote reference number N0038).

What the recommendations cover

NICE clinical guidelines can look at different areas of diagnosis, treatment, care, self-help or a combination of these. The areas that a guideline covers depend on the topic. They are laid out at the start of the development of the guideline in a document called the scope.

The recommendations in *Multiple sclerosis: management in primary and secondary care*, which are also described here, cover the full range of care that should be available from the NHS to adults of all ages with MS. They include how the diagnosis should be made, how people should be told they have MS and the treatments that should be offered. Treatments for MS may involve medicines but also include physiotherapy, rehabilitation, and psychological and emotional support.

The guideline describes what should happen when you need to see a health worker. Because of the way MS progresses, there may be long periods of time during which you do not need to see a health worker. It's important that, during these times, you know who

to contact if you have new symptoms or if your symptoms get worse.

Currently, not all the services outlined are available in all parts of the country. The NICE guideline has identified some areas that are priorities – these are shown as the key recommendations on pages 7–9.

The guideline does not include recommendations about care that should be provided by social services. However, NHS staff – particularly those working in the community – work closely with staff in social services. You should expect information about your needs to be shared (if you agree) with people in social services who have responsibility to assess and provide help (for example, with equipment or adaptations to your home) and with other agencies such as the job centre.

The guideline does not contain information on support offered by voluntary organisations, but specialist groups for people with MS or other organisations can help you with advice and practical support.

The information that follows tells you about the NICE guideline on MS. It doesn't attempt to explain MS or the treatments in detail. To find out more about MS, NHS Direct may be a good starting point and will be able to tell you about other support organisations you could contact. Phone NHS Direct on 0845 4647 or visit the website at www.nhsdirect.nhs.uk (see

www.nhsdirect.nhs.uk/enr.asp?TopicID=316&AreaID=291&LinkID=316 for links to other sources of information on MS).

If you have questions about the specific treatments and options covered, talk to your health worker (doctor, nurse, therapist or other person depending on what it is you want to know).

How guidelines are used in the NHS

In general, health workers in the NHS are expected to follow NICE's clinical guidelines. But there will be times when the recommendations won't be suitable for someone because of his or her specific medical condition, general health, wishes or a combination of these. Also, not all the recommendations in this guideline will apply for everyone with MS because the condition has different effects in different people. If you think that the treatment or care you receive does not match the treatment or care described in the pages that follow, you should talk to your doctor or the health worker you have most contact with.

If you want to read the other versions of this guideline

There are three versions of this guideline:

- this one
- the 'NICE guideline', *Multiple sclerosis: management in primary and secondary care*, which has been issued to people working in the NHS
- the full guideline, which contains all the details of the guideline recommendations, how they were developed and information about the evidence on which they were based.

All versions of the guideline are available from the NICE website (www.nice.org.uk). This version and the NICE guideline are also available from the NHS Response Line – phone 0870 1555 455 and give the reference number(s) of the booklets you want (N0368 for this version, N0367 for this version in English only, and N0366 for the NICE guideline).

Explanation of medical words and terms

An explanation of some of the medical words and terms is provided on pages 58–62.

Key messages for you and your health workers

The guideline that NICE has issued to the NHS contains many specific recommendations about the sort of care a person with MS should receive in the NHS and these are covered on the following pages. Some of the recommendations in the guideline are known as 'key priorities for implementation'. They are particularly important and should be put in place as a priority.

Key priorities for implementation

- Specialist neurological and neurological rehabilitation services should be available to every person with MS when they need them, usually when they develop any new symptom, sign, limitation on activities or other problem, or when their personal, family or social circumstances change. (Specialist neurological services are health services that are for people with conditions involving the nervous system, such as MS. Rehabilitation services aim to help people to live independently.)

- Every person who is suspected of having MS should be rapidly* referred to a specialist neurology service. Every person should be seen again after all investigations needed to make a diagnosis have been completed. People should be told how long they have to wait for the first referral and for the follow-up appointment. The extent to which these dates are kept to should be monitored.
- Local organisations that pay for local services (for example, primary care trusts in England and local health boards in Wales) should ensure that all organisations in a local health area agree and publish information about how they will provide services and share information so that services work smoothly for patients. This information should include agreement on how different organisations will share responsibility for the care of people with MS and how transfer of care between organisations will work.
- All services and people employed within the health sector should recognise and respond to the varying and unique needs and expectations of each person with MS and should involve them actively, if they wish, in all decisions and actions.

* The group that developed the guideline debated the meaning of the word "rapidly". In the opinion of the members of the group, someone suspected of having MS should be seen by a neurologist within 6 weeks of being referred and any necessary investigations should be completed within a further 6 weeks.

- Health service workers in regular contact with people with MS should consider in a systematic way whether the person with MS has a 'hidden' problem contributing to their clinical situation, such as fatigue, depression, cognitive impairment, impaired sexual function or reduced bladder control.
- Every person with MS who has been seen by a specialist neurological service or neurological rehabilitation service should be informed how to make contact with these services when they aren't under regular treatment or review. They should also be given guidance on when such contact is appropriate.

Multiple sclerosis (MS)

MS is a condition of the brain and spinal cord (which make up the central nervous system). MS affects people very differently. It usually, but not always, starts when people are young adults. When MS is active, areas of the brain and spinal cord become inflamed and are damaged by the body's own immune system. These areas become scarred and hard – the name 'sclerosis' means hardening. The cause is not known. The scarring and hardening of the central nervous system can affect different parts of the body, causing a number of symptoms (these

are known as neurological symptoms because they involve the nervous system). Not everyone with MS has the same symptoms – which ones a person gets depends on the areas of the central nervous system that have become damaged.

Different types of MS

MS is a life-long condition that progresses slowly in most people, but the pattern of change is very variable and cannot be predicted. Some people get just a few mild symptoms and, especially in the early stages of MS, have long periods of stability, whereas others find their symptoms get steadily worse over time.

When symptoms occur suddenly without warning, it is called an 'episode' or a 'relapse' (see page 23). These symptoms will often disappear or improve significantly. When symptoms disappear or improve for a period, the MS is said to be in remission.

There are recognised ways of describing the different patterns of MS that occur (see the list in the box that follows). They describe how MS has affected you so far but they do not tell you what is going to happen in the future.

Medical terms for the different patterns of MS

Relapsing/remitting MS – symptoms come and go. Periods of good health or remission are followed by sudden symptoms or relapses. About eight out of ten people with MS have relapsing/remitting MS at onset.

Secondary progressive MS – this stage can develop after a period of years in many people who initially have relapsing/remitting MS – there are gradually more or worsening symptoms with fewer remissions. About half the people with relapsing/remitting MS develop secondary progressive MS during the first 10 years of their illness.

Primary progressive MS – from the start, symptoms gradually develop and worsen over time. About two to three in 20 people with MS have primary progressive MS at onset.

Diagnosis

Diagnosing MS can be difficult. MS can cause many different symptoms, but all of them can also be caused by other medical conditions. Unfortunately there is no simple test that tells whether a symptom is due to MS.

To diagnose MS, doctors have to find evidence of damage that has occurred at different times in different parts of the central nervous system.

If you visit your GP or hospital doctor with neurological symptoms that they cannot explain, they should consider whether MS is a possibility. At this appointment, it is often not possible to make a firm diagnosis. If your symptoms are not too severe, your doctor may not take any action at this time. If you have another period of symptoms (an 'episode'), though, you should be referred to a doctor who specialises in conditions of the brain and spinal cord (a neurologist). As soon as the doctor thinks there's a reasonable chance that you might have MS, you should be told and your doctor should explain what will happen to you next.

When you see a neurologist, they should ask you about your symptoms. Often the neurologist can make a diagnosis by listening to how you describe your symptoms and from a physical examination.

If the neurologist is still unsure about the diagnosis, some further tests should be carried out. The most common tests are:

- an MRI scan of the brain and/or spinal cord (MRI is short for magnetic resonance imaging)

- monitoring how the brain responds to a pattern on a screen (this is called a visually evoked potential test)
- taking a sample of fluid from around the spinal cord for analysis if the diagnosis is still uncertain (this is known as a lumbar puncture).

Doctors should not just use MRI scans on their own to make a diagnosis of MS. And CT brain scans should only be used to rule out other possible reasons for symptoms. (CT stands for computed tomography.)

When the diagnosis has been made, your neurologist should tell you about the diagnosis, what it means and what is to happen next. They should give you as much information as you want, and they should do this in a sensitive manner and preferably in a quiet area or room. You may have your family or friends there if you want them, and the doctor should give you the opportunity to ask as many questions as you have.

You should also be offered written information about:

- MS
- the local and national support organisations that can offer independent advice and support
- the services that are available.

Your doctor should note the diagnosis in your medical notes, describing why they think you have MS and showing if there are any remaining doubts about the diagnosis.

Immediately after MS is diagnosed

Immediately after MS is diagnosed:

- you should be offered another appointment in the near future to talk to the same specialist doctor
- you should be put in touch with a skilled nurse or other support worker with knowledge of MS and with counselling experience
- you should be given the chance to take part in a course and learn about MS (this should happen soon after diagnosis, although it may not be immediately afterwards).

Help within the NHS

Who can help

If you visit your GP with a new problem or because you are finding a particular activity more difficult, your doctor should try to decide whether the new problem is happening because of your MS. If they think it is and that it might affect you for a while, they should refer you to a specialist neurological rehabilitation team for a full assessment. Details of this team can be found on page 19.

Because MS is such a variable condition, each person with MS will need different types and levels of help from the NHS. It is difficult to have a single system that can apply to everyone. The NICE guideline makes recommendations about how health services should be organised for people with MS.

Every person with MS should have a way of contacting the NHS team for MS in their local area. This could be by phoning an MS specialist nurse or it could be a contact within the local primary care team (GPs and health workers who work in the community) or within the specialist neurological rehabilitation team (the team of health workers who help you to live as independently as possible). The important thing is that each person should know who they can contact for information, help and advice about MS, as

well as having access to their GP. When a symptom that might be due to MS occurs, the health worker should discuss it in a straightforward way.

Also, local services should have written agreements (known as 'protocols') about how different organisations, such as the health service and social services, work together and share relevant information to ensure that the needs of people with MS are met.

Specialist neurological services

In each local area there should be a specialist neurological service that can diagnose MS and confirm that someone is having a relapse. (A specialist neurological service has health workers who are experts in conditions involving the central nervous system.)

Providing healthcare to people with severe symptoms

Health workers can provide many services to people with MS in their own home. This becomes more important if you have severe difficulty attending your GP surgery or neurology clinic, or if you need nursing care several times a week. People who have severe symptoms and who depend quite heavily on others

for help should have their need for support assessed at least every year. The needs identified through this process should be met according to the wishes of the person.

Encouraging independence and self-help

Managing MS is a partnership between health workers and the person with MS taking an active part in their own care. You should, as far as possible, be helped to manage your own general health.

There are often decisions to be made, and you should be part of the discussions around these decisions. Any health worker you are in contact with should be clear about the options and choices open to you **for the aspects of care they are dealing with**. They should provide information about the benefits and risks (if any) of different options, to help you decide what is best for you. They should take into account whether you have problems following, remembering or understanding complicated details. You should be given as much information as you want, including details of others who can help, such as a specialist nurse, GP, a national helpline or support group. Health workers should check that they have given you information in a way you can understand, and give you written materials or tapes to take home where possible.

Communication should take place in a quiet area and you should have the opportunity to have someone (such as a friend or family member) with you if you choose.

As well as providing treatment, you should also get advice on how to maintain a healthy lifestyle, stay fit, prevent complications and how to make the best use of NHS services. This package of activities is sometimes called a 'self-management programme'.

The effect MS has on your life will vary over time. Services should be flexible, so you get the right help when you need it. Support for you and your family, including your children, should be available, and your needs should be reviewed over time. Family members should be provided with information about MS and the support available from social services. Their health and well-being should also be considered and reviewed over time, particularly if they are 16 or younger. If a member of your family is to help with some of your daily routine (such as helping you get dressed), it's important that they and you are happy with the arrangement and that they can do it safely and properly.

Specialist neurological rehabilitation team

A specialist neurological rehabilitation team that co-ordinates the various treatments should be available. This should include specialist doctors, nurses, physiotherapists, occupational therapists, speech and language therapists, clinical psychologists and social workers.

The team aims to find practical ways around specific problems that might be limiting your activities, helping you to maximise your ability to lead as full and independent a life as possible.

The team should look at your whole situation, taking into account your own priorities and interests, and agree a programme with you and your carers.

They should advise you on how changes or alterations at home might help. They should check you are getting the right personal support and respond if your needs change.

The team can help directly or by referring you to someone who can advise you on the following.

- **Work, benefits and education** – you should be able to get advice on equipment, adaptations and support services (such as Disability Employment Advisers, Access to Work Scheme, and benefits advice) to help you overcome any barriers to

staying in work; they can also talk to your employer (with your permission). If you cannot stay in your job or find other work, you should be given advice about other options, such as voluntary work, and how to find out more about them.

- **Leisure, social life and relationships** – the team can help you get back into your old activities or to start new ones, and can help with any lack of confidence, depression, and social and sexual problems.
- **Moving around** – if you have problems walking or would be able to walk if you had some physiotherapy, you should be offered physiotherapy. If necessary, you should be offered equipment such as sticks, driving aids or a wheelchair.
- **Daily living** – if you are finding daily living tasks difficult, your needs should be assessed (this should take place over several visits and in more than one place). You should then be offered a programme to help you improve or maintain your independence in, for example, shopping, cooking, dressing and washing. Your programme should be checked regularly to make sure that it is helping. After the programme has ended, you should be told how to go about getting another assessment if your situation changes again.

- **Equipment and adaptations** – if you depend on someone else for any of your daily activities, especially for moving around, there may be equipment or adaptations that can be provided to increase your independence or reduce the help you need from family members or carers. You should be assessed to find out what is most useful to you, and your family or carers should be taught how to use equipment where relevant. After a time, there should be a check that you, your family and/or carers are using the equipment properly and safely. From time to time the equipment should be checked to make sure it is still suitable for you and that it is still safe.
- **Help for family members and carers** – members of your family and carers should be shown how to help you keep as much independence as possible (if they are willing and able to do this). They should also get support and practical help; for example, they should be taught how to move and lift you safely. If you have more than 1 hour of help a day, the amount of support you get should be monitored at least once a year – the person doing this should also check whether it's the right support for you. A similar check should be made if something major happens that might affect your condition (for example, if you have an infection or a relapse).

Once you have worked with the rehabilitation team and are able to use their techniques or equipment, you should be told how and who to contact if something changes.

Medical notes

Your health workers should collect and record information about your condition so that they can develop aims or plans for treatment, and assess your progress. To do this, your health worker should ask you about, monitor and record your MS symptoms at each visit. By sharing relevant information with each other, different health workers should not need to ask the same questions each time and they should find it easier to provide you with consistent advice.

Treating and managing MS and its symptoms

As has already been said, MS is a very variable condition. The treatment you should be offered will depend on the type of MS you have and on your specific symptoms. It will be different for each person. Health workers should also offer information and advice on, and help in acquiring, the skills to enable you to help yourself as much as possible.

The approach that should be followed for managing MS can be summarised as follows.

- If the person's MS is mild with no relapses, then no treatment is needed. (See the next section for a description of a relapse.)
- If the person has a relapse, steroid treatment may be needed (see the next section).
- If a person has several relapses, medicines may be offered to try to reduce the frequency and severity of the relapses (see pages 26–31).
- Any specific symptoms caused by MS may need specific treatment (see pages 32–53).
- For people whose MS is more severe, a much wider range of treatment and support should be offered. (These are described on pages 19–22.)

Sudden (or 'acute') relapse

One of the features of MS, especially in the early stages, can be periods of stability or recovery (known as remissions) followed by sudden episodes of symptoms or disability (known as relapses).

Sudden relapses are thought to happen when the immune system damages a small part of the brain or spinal cord and it becomes inflamed. The symptoms will depend on which part of the brain or spinal cord is affected. They may be relatively minor – for example, numbness in a hand – or more disabling and obvious. Two of the more dramatic symptoms are described below. Sometimes having one of these symptoms is the first sign a person has MS.

Loss of some or all vision in one eye

A sudden loss or reduction in vision in one eye happens when the nerve to the eye becomes inflamed (known as 'optic neuritis'). If you have this symptom, you should be referred to an eye specialist (ophthalmologist) for a diagnosis.

If a person has not been diagnosed with MS, but the eye specialist thinks their optic neuritis could be a sign of MS, the person should be offered the chance to see a neurologist for assessment.

Leg weakness or paralysis, or loss of control of the bowel or bladder

These symptoms are caused by inflammation around the spinal cord, which is known as transverse myelitis. If you have one of these symptoms, you

should be referred for an urgent assessment to rule out causes other than MS and usually to have some steroid treatment (see below).

Optic neuritis and transverse myelitis are usually temporary, and the person usually recovers (fully or partly) after treatment.

Treatment

If you suddenly get new symptoms or your symptoms suddenly get worse, your GP or hospital doctor should assess your condition and write the changes on your medical notes.

It is important to realise that new symptoms may not be due to a new episode of MS. Often an infection (for example, a common cold) may be the cause of the symptoms. So, as part of their assessment, the doctor should look for signs of an infection that might be causing the symptoms and treat it if necessary.

If your symptoms are due to MS and are severe enough to be causing you distress or limiting what you can do, you should be offered a course of a steroid at high doses. The common name of the steroid is methylprednisolone. It can reduce the inflammation and make the relapses shorter and/or less severe. But it can also have side effects. The benefits and risks should be explained so you can decide whether or not to have the treatment.

The steroid can be given either as an intravenous infusion (that is, through a drip into your arm, which is usually done in hospital) or as tablets to be taken each day for several days. You should not have more than three courses of steroids in a year, and you should not take steroids for more than 3 weeks at a time.

You should not be given other medicines to treat your symptoms unless they are being given to you as part of a research study (in this case, your doctor should explain the situation to you and ask for your agreement to take part).

If the new or worsened symptoms make it difficult to carry on your normal daily activities, you should be referred to a specialised neurological rehabilitation service (see page 19) and given the extra support you need – for example, special equipment or personal care, as soon as possible.

Treatment with medicines to reduce the frequency and severity of relapses

People with relapsing/remitting MS and those with secondary progressive MS who are experiencing relapses may benefit from beta interferon or glatiramer acetate. These medicines are injected into the muscle or under the skin. They are not suitable for everybody with MS and, like all medicines, they can have side effects.

These medicines are available in the NHS to some people with MS under a special scheme set up by the Department of Health and the Welsh Assembly Government. Under this scheme they are available from a limited number of hospitals and can only be prescribed by specialist neurologists. Full details of the scheme can be found on the Internet at www.info.doh.gov/doh/coin4.nsf/page/HSC-2002-004?OpenDocument.

If you have relapsing/remitting MS, you should be offered beta interferon or glatiramer acetate if:

- you are 18 or over, and
- you can walk for at least 100 metres without assistance (without assistance means without physical support from another person), and
- you have had at least two relapses in the past 2 years, and
- there aren't any reasons why you shouldn't take the medicine (such as certain other medical conditions).

If you have secondary progressive MS with relapses, you should be offered beta interferon if:

- you are 18 or over, and
- you can walk on your own for 10 metres without assistance, and
- you have had at least two relapses in the past 2 years, and
- your MS is getting worse only at a very slow rate (any increase in disability has been minimal over the past 2 years), and
- there aren't any reasons why you shouldn't take the medicine (such as certain other medical conditions).

If you are offered either medicine, your neurologist should talk to you about the possible benefits and side effects or risks and you should be given training on using the medicines. You should have regular check-ups to see if the medicine is helping you.

Continuing or stopping medicines

Regular check-ups with the neurologist are needed to check if a medicine is helping you. If a medicine seems to be working and you are well, then the

medicine should be continued. But if either you or the doctor is concerned that it is not helping, or if it is causing unacceptable side effects, then the doctor should talk to you about stopping your medicine. You might need to stop for other reasons such as if you are pregnant or trying to get pregnant.

If you have a relapse while taking a medicine for MS, the medicine will not necessarily be stopped, but you may be given steroid treatment for the relapse as well. If you have two major relapses within a year, you may be taken off the medicine because this would be a sign that it is not working.

Other treatments to help to slow down MS

Linoleic acid in the diet may help to slow the disabling effects of MS. Linoleic acid is present in sunflower, corn, soya and safflower oils and is also available in capsules. Benefits have been shown in some people who had 17–23 g a day.

There are some other treatments that might be used to try to slow down the progression of a person's MS. These are shown in the box on the next page. These should only be used:

- if the person has been told and has thought about all the possible risks involved, and

- the effects of the treatment and any side effects or other problems are being closely monitored and reported (for example, as part of a research study), and
- they are being given by an expert who has experience of using the medicine for people with MS.

If you are asked to take part in a research study, it is up to you whether to take part or not and you should be given enough information to let you make up your mind. Deciding not to take part in a trial will not affect the care you receive.

Treatments that should only be used under certain conditions (the general names of medicines are shown, not the brand names)

- Azathioprine
- Mitoxantrone
- Intravenous immunoglobulin
- Plasma exchange
- Intermittent (4-monthly) short (1–9 days) courses of high-dose methylprednisolone

There are also some treatments that should not be used because there's no evidence that they work. These include the treatments shown in the box below.

**Treatments that should not be used
(the general names of medicines are shown, not
the brand names)**

- Cyclophosphamide
- Anti-viral treatments (for example, aciclovir, tuberculin)
- Cladribine
- Long-term treatment with steroids
- Hyperbaric oxygen
- Linomide
- Whole-body irradiation
- Myelin basic protein (any type)

At present, there are no medicines similar to beta interferon or glatiramer acetate for people with primary progressive MS, but research is being carried out in this area.

Complementary therapies

Some people with MS try complementary treatments to help with the management of MS. If you decide to try a complementary therapy, you should look into the costs and any risks involved. Do also tell your doctor or other health workers you are in contact with if you are considering, or having, any alternative or complementary therapy.

There is some evidence that reflexology, massage, t'ai chi, magnetic field therapy, neural therapy, fish oils, and the combination of some forms of complementary therapy (known as multi-modal therapy) may be helpful for people with MS in terms of their general sense of well-being.

Managing specific symptoms

People with MS can experience a wide range of problems or symptoms during their life with MS – some minor and others more serious. Some will last for a short time and others may continue or develop over a lifetime. The most common ones are detailed below. It is a daunting list – but remember it's unlikely that one person would have all the symptoms described.

Before considering any specific treatment your doctor and other health workers should ask about all aspects of your health (for example, by checking if you have any of the symptoms in the following section) in order to find out what you want or need. Make sure you tell them if and how these symptoms are affecting your life.

Fatigue

Fatigue is an overwhelming feeling of tiredness and weariness. If you have fatigue, the first thing your doctor should do is consider any possible reasons for the fatigue apart from MS. For example, it may be that one of the medicines you are taking brings on fatigue. Being depressed, in pain, having disturbed sleep or a poor diet could cause fatigue. Each potential cause should be treated in its own right. You should also be given general advice on helping to prevent or manage fatigue, such as taking exercise and saving energy using special techniques.

At the moment, there are no medicines for fatigue that can be used routinely. A medicine called amantadine may help a little at a dose of 200 mg a day, but the benefits are likely to be small.

Bladder problems

MS can sometimes affect bladder control. This may lead to a need to pass urine (urinate) more often than usual, or to difficulty urinating, or to a loss of control about when you urinate. These may be difficult problems to talk about but it is important to do so because there is much that can be done to help. For example, a common cause is that the urinary system ('urinary tract') has become infected – this can be treated with antibiotics. Or it may be that the controlling mechanism that makes the bladder work has become oversensitive – there are medicines that can help to reduce this oversensitivity.

If you have a bladder symptom, you should be offered a test to measure the amount of urine that stays in your bladder after you've urinated. This may mean having an ultrasound scan of your bladder (similar to the type of scan a woman has during pregnancy) or some other simple test. You should also be tested to see if you've got a urinary tract infection.

Bladder control

If you need to urinate urgently, or if you cannot stop your flow of urine once it starts, or if there is leakage of urine that you cannot control, your healthcare worker should try one of the following.

- A medicine such as oxybutynin or tolterodine. These can help by making the contraction of the bladder muscle that controls the release of urine more predictable.
- If your bladder is not emptying fully, your healthcare worker may suggest trying a catheter, which you insert into your bladder at intervals during the day to drain the urine. By preventing the bladder from becoming overfull, your symptoms may be controlled.
- If your symptoms are that you often need to get up at night to urinate, you should be offered a medicine called desmopressin. This is an effective medicine but it must never be taken more than once in 24 hours because of the risk of side effects.
- If you need to urinate frequently during the day and you have tried other treatments, you should be offered desmopressin. Again, it is important that you do not take desmopressin more than once in 24 hours because of the risk of side effects.

If you are having difficulty getting to the toilet in time, you should be offered advice on clothing that is easier to manage or arrangements to make a toilet easier to reach.

If, despite treatment, you have urinary incontinence more than once a week, you should be referred to a continence specialist for tests and advice. The continence service may offer you a course of exercises or electrical treatment for the muscles controlling the bladder. If you continue to have incontinence, you should be offered some drainage equipment (sheath, tube and bag) if you are a man, or pads if you are a woman.

Sometimes, if the bladder cannot be controlled despite all other treatments it may be necessary to have long-term catheterisation. If you have this, you may be interested to know that NICE has issued some guidance that includes advice on the use of long-term catheters. See page 57 for the details.

A treatment called intra-vesical botulinum toxin should only be offered by suitably trained doctors as part of a clinical research study.

Urinary tract infections

People with MS often get urinary tract infections, but it can be difficult to separate the symptoms of an infection from the symptoms of MS itself.

If new symptoms develop that might be due to urinary tract infection (such as passing urine more often, burning or discomfort on passing urine or developing a temperature), your doctor should:

- test your urine for infection
- offer you antibiotic treatment if there's an infection.

If you have more than three (confirmed) urinary tract infections in a year, you should be referred to a continence specialist for tests, treatment and advice.

Using antibiotics or drinking cranberry juice does not help to **prevent** urinary tract infections.

Bowel problems

MS can affect the nerves that control the bowels, as can some of the medicines used for MS. This can cause difficulties with bowel control including an urgent need to empty bowels, pain or constipation.

Your doctor or health worker should ask you about your bowels and if there is a problem they should be able to help you to improve the situation. This may be as simple as giving you advice on diet or trying laxatives. If you remain constipated despite trying

laxatives, your doctor may discuss using suppositories or enemas. The treatment may only be needed as a one-off, or on a regular basis to prevent the symptoms returning.

Muscle spasms and stiffness

MS can cause muscles to jerk uncontrollably ('spasm') and to become stiff or rigid (known as 'spasticity'). These symptoms can make moving difficult.

If this is a problem for you, your doctor or health worker should look for and treat any pain or infection that may be causing or making the symptoms worse. If problems continue, you should be referred to a specialist physiotherapist who can advise on techniques such as stretching, which can help to prevent stiffness developing. Your progress should be monitored. If your family or others help you do the exercises they too should be shown what to do.

If your spasms or spasticity are causing you pain or distress, or are stopping you from doing things that you would otherwise be able to do, you and your doctor may decide to try a different approach (see below). If you do, you should consider the benefits and disadvantages carefully. You and your doctor should agree a goal to aim for.

There are medicines that can help relax the muscles and reduce the spasms. The most common are baclofen and gabapentin. But if these do not help, or if you develop problematic side effects, you should be offered tizanidine, diazepam, clonazepam or dantrolene. All these may have side effects and so they are usually prescribed and monitored by the specialist neurological rehabilitation service and you should have the chance to discuss the choice of medicine and be informed about its use.

A small number of people may find that their spasms are not controlled by these treatments. If so, the specialist neurological rehabilitation team should assess your condition and needs and discuss with you the possibility of more direct treatments. These include the use of special splints, standing and weight-bearing through the legs or the provision of special seating, and the infusion of medicines into the spinal fluid. These are specialist treatments and should be given and monitored by specialists.

It is not recommended that injections of botulinum toxin into the affected muscles are used routinely. They can be considered if a person has spasticity or rigidity that has not improved with other treatments and which affects only a relatively small area. In this instance, the injections should be given by someone with knowledge and experience of the technique and MS. A specialist physiotherapist should also be involved.

Clumsiness and shaking

People with MS can sometimes develop uncoordinated and clumsy movements (ataxia), or shaking movements (tremor).

If you are affected by ataxia or tremor, you should be referred to a specialist neurological rehabilitation team. The team should assess your needs and offer medicines, exercises and/or equipment to help you carry out your usual activities.

If you have severe problems, your suitability for an operation to reduce the ataxia should be assessed (the risks and benefits of the operation should be explained to you in full).

Muscle weakness

Keeping fit is just as important for people with MS as for the rest of the population. However, many people with MS notice that their muscles appear weak and feel that this is limiting activity. If this occurs, a health worker should make an assessment to check for any possible causes other than MS. If none is found, you should be given a programme of exercises to help develop strength and endurance.

If the weakness is more severe, then equipment may be provided that will help you get round the problems caused by the weakness and so continue to carry out your normal activities. If the weakness becomes very severe so that it affects your posture, the way you sit or your breathing, then there are devices that can help this, including special seating.

Reduced movement in the joints

If a joint is not moved through its full range of movement, whether because of muscle weakness or spasticity or stiffness, the tissues around the joint will tighten up (contract) and lead to movement becoming limited and often painful. The tightening is known as a contracture.

Contractures generally only occur in severe MS. The best treatment is prevention. So anyone with MS who has weakness or spasticity should be assessed and advised on how to keep their joints moving or offered treatment for the spasticity or weakness (see pages 38 and 40). This may be through regular stretching of the joints (moving the limb as far as the joint will allow) and/or specific positioning of the limbs and the rest of the body while sitting in a chair or lying in bed. Family members or carers should also be advised about the techniques.

If you get a contracture, you should be assessed for specific treatment. This could include periods of stretching, such as with long-term plaster casts, removable splints or by standing in a standing frame. This is usually combined with injections of botulinum toxin into the area and, where necessary, an operation. The assessment should be by a health worker with specialist experience in this area. Effort should also be made to reduce the underlying cause of the contracture.

Pressure sores

If MS leads to limited movement, loss of feeling or the need for a wheelchair, then there is an increased risk of pressure sores (also known as pressure ulcers and bedsores); they start as red areas that become purple before the skin breaks down.

The best approach is to prevent them occurring in the first place. Anyone with MS who is a wheelchair user should be assessed and given specific advice on what to do to prevent a sore developing.

If you use a wheelchair and are admitted to hospital, a suitably trained person should assess your risk of getting pressure sores – this assessment should take your MS into account. They should advise you and the staff caring for you on pressure-relieving devices that should be used and the procedures that should

be followed. This advice should cover your diet, special equipment and ways of moving you.

If your wheelchair is provided by the NHS or social services, or if your wheelchair seat is being reassessed, your needs in terms of preventing pressure sores should be considered. This shouldn't be limited to things for your wheelchair, but should cover all your activities, such as sleeping.

If you are thought to be at risk of getting pressure sores while in bed (in hospital or somewhere else), you should be given a mattress designed to reduce the chance of pressure sores for wherever you are lying. The areas where the sores would be most likely to develop should be checked. Health workers should not rely on turning you to stop pressure sores.

If you get a pressure sore, your health worker should get specialist advice. You should be given a special mattress and your sore should be dressed properly.

Changes in skin sensation

Many people with MS notice feelings of pins and needles or numbness, or that an area of skin feels particularly sensitive. There is not usually any specific treatment for this but you should be referred to the specialist rehabilitation team for assessment and

advice on techniques or equipment that could reduce the effects of the symptoms. You should also be given advice on how to avoid hurting yourself as a result of the changes in sensation.

Problems with memory and thought processes

MS can cause problems with learning, remembering, planning and concentrating – the medical term for this is cognitive losses.

All health workers should be aware that people with MS may not take in all that is said to them first time, or they may understand but then forget. They should take particular care to make sure that they have explained things clearly to you, check that you understand and back this up with written information if available.

If a person with MS is involved in making a decision about their care or is about to start a new complicated treatment, their health worker should sensitively assess their ability to understand and participate and consider any help they may need.

Common reasons for problems with thought are medicines you may be taking (that could be stopped or changed) or depression (which is treatable). If both are ruled out then you should be offered a formal assessment and specialist advice. This could

cover how to avoid difficulties in, for example, money matters or relationships. You should be asked whether the results of your assessment can be told to anyone else.

If a person's behaviour or level of dependence isn't easily explained by something other than MS, the person should be offered a formal assessment by a specialist clinical psychologist. A speech and language therapist may also be involved. The clinical psychologist can look at problems with thought and communication and can recommend how to manage them.

Emotional outbursts

Some people with MS find they cry (or more rarely, laugh) more often than other people, sometimes uncontrollably. This may not be related to feeling depressed (or happy). If this is the case, you should be offered a full assessment of your emotional state by someone with expertise in the area. If it is upsetting you or your family, you should be offered treatment with an antidepressant. This will usually be a tricyclic antidepressant or one of the SSRIs (which stands for selective serotonin reuptake inhibitors).

If you do not want to take antidepressants or if they do not work, you should be offered the opportunity to learn some strategies for controlling the emotions.

Depression

If you feel depressed, your health workers should take it seriously. They should work with you to identify and change anything that might be making the depression worse. They should also consider whether there might be other related things affecting your quality of life, such as anxiety (see below).

Depression should be treated just as for anyone with depression and this may include, if it is severe, being referred to a psychiatrist. Antidepressant medicines and psychological treatments may be recommended. If they are, they should form part of an overall programme for managing your depression.

Anxiety

If you are feeling anxious or are worrying to such a degree that it's affecting your normal day-to-day living or is making you unhappy, you should have the opportunity to see a specialist for assessment and help. If your anxiety is having quite a severe effect on your life, you should be offered a psychologically based treatment. The specialist may also discuss using medicines for a period of time (antidepressants or benzodiazepines).

Pain

Some people with MS have pain. This can be shooting, sharp pain or aching, dull pain. It may be caused by damage to the nerves (this is called neuropathic pain) or by reduced movement (this is known as musculoskeletal pain).

If you are in pain, you should be properly assessed to see if it is due to MS or to some other cause. If it is due to MS, then you should have a full assessment to find the nature of the pain and the most appropriate management for it. Often this will have to be done by the specialist neurological rehabilitation team.

Nerve pain (neuropathic pain)

Nerve pain is often sharp and shooting, and can include painful oversensitivity (for example, the skin is more sensitive to touch than usual). It should be treated with the medicines carbamazepine or gabapentin, or with an antidepressant such as amitriptyline. If you are still in pain despite treatment, you should be referred to a health team that specialises in helping people with pain.

Pain in the muscles and bones (musculoskeletal pain)

This is often due to a change in your movement or posture because of weakness or spasticity (see pages 38 and 40). If you have this type of pain, you should be assessed by a specialist therapist to see if exercise, better seating or other procedures can help.

If the measures have not worked, you should be offered painkillers ('analgesics'). If you are still in pain, antidepressants (which can also help with pain) should be considered, as should transcutaneous nerve stimulation (TENS for short), which uses a machine to stimulate nerve endings. Other methods of pain control such as ultrasound, laser treatments and anti-epilepsy medicines should not be used routinely for people with MS and this type of pain.

Your health worker may also discuss psychological techniques that could help, such as 'cognitive behavioural therapy' and 'visual imagery'.

Sexual problems

MS can affect people's sex life, both as a result of its impact on the central nervous system, and the emotional and social consequences of living with the condition. Some medicines for MS can also affect a person's sex life.

People with MS may be reluctant to seek help and health workers should ask sensitively about this as a routine part of the overall assessment of your needs. If you do experience difficulty you should not be afraid to raise the matter, as there is help available in many cases. You should be offered information about counselling available locally and other services that would offer support.

If you are a man and are having problems getting an erection, you should be offered the medicine sildenafil (providing there are no medical reasons why you shouldn't take it). If this doesn't help, you should be assessed to try to find the causes of the problem. If the cause is treatable, it should be treated. If there is still a problem, other treatments aimed at restoring erections should be considered, such as the medicines alprostadil or papaverine (which is injected into the penis).

If you are a woman and are having problems with sexual arousal or lack of orgasms, you should be assessed to try to find the causes of the problem. If the cause is treatable, it should be treated.

If your problem persists, you should be offered the opportunity to see a health worker who has specialist knowledge in this area who can advise you on things that may help.

Eye problems

Some people with MS have problems reading newspapers or watching television. This might not be due to MS, so the first step is to have a normal sight test in case you need glasses. If reading is still difficult despite glasses, you should be referred to a doctor who specialises in the diagnosis and treatment of eye problems (an ophthalmologist) who may be able to prescribe more powerful devices to help you.

Sometimes the vision problem is because the eyes develop abnormal movements that make it difficult to focus (this is known as 'nystagmus'). If your sight problem is related to nystagmus, you should be assessed by a specialist and offered a trial of a medicine called gabapentin under his or her supervision.

Unfortunately in a few cases, despite treatment, vision will deteriorate so that reading, watching television and other activities become difficult or impossible. If this happens, you should be assessed to see whether there is any equipment that might help you. You should also be referred to a specialist social services team and should register as being partially sighted.

Swallowing difficulties

Sometimes MS can affect the nerves that control swallowing. This is important because if food or drinks go down 'the wrong way' and cause choking it may lead to chest infections.

People who have a problem with swallowing that lasts for more than a few days should be referred to a neurological rehabilitation team for an assessment. This should involve assessing the person's need for:

- changes to the person's seating while eating
- physiotherapy on the chest
- a tube that runs from the nose to the stomach (to be used for a short period).

If you are unable to move from the bed to a chair by yourself, or if you have signs that the part of the brain that controls swallowing might not be working properly, such as abnormal eye movements or slurred speech, you should be asked whether you have problems chewing or swallowing food or drink. You should also be asked if you've altered what you eat or drink because of previous problems.

Where there are any of the signs described above or you have a chest infection, you should have a swallowing test.

If there's a problem with your swallowing, you should see a speech and language therapist for further assessment. You should be given advice on specific swallowing techniques and how to make changes to your diet or the consistency of your food.

If you are still having problems despite following the specialist's advice, and there's a clear reason for having them, you should be offered further tests.

Where swallowing difficulties last for more than a month, you should have your weight and nutrition level checked each month. If you lose weight or appear to be malnourished, your diet should be looked at.

In a few people, these measures may not be enough, especially if they get a lot of chest infections. Tube feeding may be needed. This may be through a tube placed in the nose or by a tube directly through the skin into the stomach. If this seems like a possibility for you, your health workers should discuss it at an early stage. They should write your wishes down in your medical notes. If a tube is recommended, and you agree, the tube should be put in by a specialist. Before you leave hospital, the family members or carers who will be involved in feeding you should be trained in what to do.

Speech problems

If speech problems are affecting your ability to communicate with people, or you are concerned about the sound or clarity of your speech, you should be assessed and given advice by a speech and language therapist.

If your speech is affected significantly, you should be taught special techniques to improve your speech by a specialist speech and language therapist.

People who continue to have problems may be offered training in other forms of communication to help with or replace speech. If you can't communicate effectively, you should be assessed by a specialist speech and language therapist for a communication aid. If one is suitable, you should get it as soon as possible.

If you have significant problems communicating, the speech and language therapist should talk to members of your family, your carers and anyone else who has to communicate with you regularly on how best to help.

Healthcare issues

Immunisation

Because there is some evidence that getting an infection can either bring on symptoms or worsen MS, people with MS should be offered a flu jab and any other immunisations against infection that may be necessary. There is no evidence that an immunisation itself will cause a relapse.

Pregnancy

Having MS is no reason for a woman not to have a baby. The risk of relapse is actually less during pregnancy. It increases in the months straight after the birth, but after a year the risk is back to normal.

Women with MS can have a normal pregnancy and birth and can breastfeed afterwards. You should have the pain relief you want during childbirth, without worrying whether it will affect your MS – it will not.

Stress, including surgery

Stress is unpleasant for most people, regardless of any medical condition they may have. It is unclear whether stress, either emotional or due to trauma, has an effect on your MS.

People with MS who need operations or anaesthetics may have them without any concern that it will worsen their MS.

Where you can find more information

If you need further information about any aspects of MS or the care that you are receiving, please ask your doctor or other health worker. You can discuss this guideline with them if you wish, especially if you aren't sure about anything in this booklet. They will be able to explain things to you. NHS Direct may also be helpful – phone 0845 4647 or visit the NHS Direct website at www.nhsdirect.nhs.uk (see www.nhsdirect.nhs.uk/innerpage2.asp?Code=FM&Topic=276 for links to other sources of information on MS).

For further information about the National Institute for Clinical Excellence (NICE), the Clinical Guidelines Programme or other versions of this guideline (including the sources of evidence used to inform the recommendations for care), you can visit the NICE website at www.nice.org.uk. At the NICE website you can also find information for the public about other guidance in the following areas. These can also be ordered from the NHS Response Line (phone 0870 1555 455):

- beta interferon and glatiramer acetate for the treatment of multiple sclerosis, reference number N0053 (based on *NICE Technology Appraisal Guidance No. 32*)

- the use of computerised cognitive behavioural therapy for anxiety and depression, reference number N0158 (based on *NICE Technology Appraisal Guidance* No. 51)
- pressure ulcer risk assessment and prevention (including the use of pressure-relieving devices), reference number N0331 (based on *NICE Clinical Guideline 7*)
- the prevention and control of healthcare-associated infection in primary and community care, which includes advice on catheters, reference number N0219 (based on *NICE Clinical Guideline 2*) .

NICE is also currently developing:

- a guideline on the management of depression in primary and secondary care
- a guideline on the management of generalised anxiety disorder and panic disorder (with or without agoraphobia) in primary, secondary and community care
- an appraisal of the use of cannabinoids (cannabis derivatives) for the treatment of the symptoms of multiple sclerosis.

Details on the progress of these can be found on the NICE website.

Explanation of medical words and terms

Acute: when illness or symptoms come on suddenly.

Analgesic: a painkiller.

Ataxia: uncoordinated and clumsy movements that can be caused by MS.

Carers: usually family members, friends and neighbours who provide support to people with MS. The support they provide can be both physical – assistance in the tasks of daily living – and emotional. It should not be assumed that such carers will be able or will want to provide all the necessary assistance for people with MS, nor that people with MS will want them to. Personal assistants (PAs) are individuals, usually paid, who are employed by a person with a disability to assist them in routine functions of daily living. For many people with MS, they enable them to live independent lives. In this guideline the term ‘carer’ is used to cover both categories.

Catheter: a thin tube used to drain urine from the bladder. Intermittent catheters can be inserted by the person themselves when needed; indwelling catheters stay in place all the time.

Central nervous system: the brain and the spinal cord.

Chronic: long-lasting – MS is a chronic condition.

Clinical psychologist: a specialist health worker who is able to assess and help with problems such as depression, anxiety and cognition.

Clinical trial: a research study conducted with patients that tests out a medicine or other intervention to assess how well it works and/or its safety. Each trial is designed to answer scientific questions and to find better ways to treat individuals with a specific condition.

Cognition: the process of thinking and perceiving.

Consultant: specialist doctor (for people with MS, normally a neurologist or neurorehabilitationist, see below).

Contracture: when a muscle is permanently contracted (or tightened).

Incontinence: a lack of control over passing urine or faeces.

Musculoskeletal pain: pain in the muscles or bones which may happen because of problems with movement.

Neurologist: a doctor who has specialised in diagnosing and treating conditions involving the nervous system.

Neurology: the study and treatment of diseases of the nervous system.

Neuropathic pain: pain in the nerves.

Neurorehabilitationist: a healthcare worker who has specialised in helping people with conditions involving the nervous system live as normal a life as possible.

Nystagmus: these are uncontrollable jerky movements of the eye that can be caused by MS.

Occupational therapist: a health worker who is trained to assess patients' needs and help them carry out their normal daily activities by showing them special techniques and/or giving them equipment or adapting the equipment they have.

Ophthalmologist: a doctor who is an eye specialist.

Optic neuritis: an eye condition that results in a sudden loss or reduction in vision in one eye. It happens when the nerve to the eye becomes inflamed, which can be caused by MS.

Physiotherapist: a health worker who is trained to assess and help with mobility and movements. Physiotherapists use a broad range of techniques to help muscles and joints work to their full potential. They can also provide support and advice to carers as well as patients.

Pressure sore: an area of skin damage caused by pressure.

Primary care: healthcare delivered to patients in the community (that is, outside hospitals). Primary care covers a range of services provided by GPs, nurses and other health workers, such as dentists, pharmacists and opticians.

Progression: used to describe the worsening of a condition such as MS over time.

Psychiatrist: a doctor who has specialised in diagnosing and treating conditions affecting the mind.

Rehabilitation: treatment aimed at helping people live as independently as possible.

Relapse: when symptoms happen after a remission or recovery.

Remission: a disappearance or reduction in symptoms.

Secondary care: healthcare provided in hospitals.

Spasm: when a muscle jerks uncontrollably.

Spasticity: when a muscle tightens and becomes rigid.

Specialist neurological rehabilitation team: a team of health and social workers that coordinates the various treatments for people with neurological conditions, such as MS. The team should include specialist doctors, nurses, physiotherapists, occupational therapists, speech and language therapists, clinical psychologists and social workers.

Speech and language therapist: a health worker who is trained to assess and help with communicating.

Transverse myelitis: a condition where a leg becomes weak or paralysed, or there's loss of control of the bowel or bladder. It's caused by inflammation around the spinal cord, which can happen with MS.

Tremor: shaking that cannot be controlled.

Urinary tract: the urinary system – it includes the kidneys, the bladder and the tubes that connect them. Infections of the urinary tract include cystitis, urethritis and pyelonephritis.