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Managing multiple sclerosis in primary and secondary care

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

First draft for consultation – March 2003

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

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1 About this information

This booklet describes the guidance that the National Institute for Clinical Excellence (NICE for short) has issued to the NHS on multiple sclerosis. 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 booklet has been written chiefly for people with multiple sclerosis, it will also be useful for family members, those who care for people with multiple sclerosis and anyone with an interest in multiple sclerosis or in healthcare in general.

Clinical guidelines

Clinical guidelines aim to improve the care and treatment provided by the health service. The recommendations in NICE guidelines are prepared by groups of health professionals, patient representatives 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 covered by each guideline are laid out at the start of the development of the guideline in a document called the scope.

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The recommendations in *Multiple sclerosis: management in primary and secondary care* cover the full range of care that that should be available from the NHS to adults of all ages with MS. It includes how the diagnosis should be made, how it should be communicated, and the treatments that may be offered. Treatments for MS may involve medicines but also other treatments such as physiotherapy or rehabilitation, and psychological and emotional support. The guideline provides information about when you should expect to receive these different kinds of care or treatment, and how they should be given.

The guideline does not include recommendations about care that is provided by social services or voluntary groups.

If you want to find out more about multiple sclerosis, NHS Direct may be a good starting point and will be able to tell about other organisations you could contact. You can call NHS Direct on 0845 46 47 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).

If you have questions about the specific treatments and options mentioned in this booklet, 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. If you think that the treatment or care you receive does not match the treatment or care described in this booklet, you should discuss your concerns with your doctor or the health worker you have most contact with.

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If you want to read the other versions of this guideline

Multiple sclerosis: management in primary and secondary care and the full guideline (which contains all the details of the guideline recommendations and how they were developed) are both available from the NICE website (www.nice.org.uk). Copies are also available from the NHS Response Line; telephone 0870 1555 455 and give the reference number [to be added by NICE].

2 About multiple sclerosis

Multiple sclerosis (often shortened to MS) is a disease of the central nervous system (your brain and spinal cord) that usually starts in early adult life. When the disease is active, patches of the white matter around your brain and spinal cord become inflamed, and are damaged by your own immune system. These areas become scarred and hard – the name ‘sclerosis’ means hardening. It is not known what causes MS.

MS affects people very differently. It 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, while others find their symptoms get steadily worse over time. Having MS means living with uncertainty and adapting to changing situations. Symptoms can occur suddenly without warning and when they do this is called an ‘episode’ or a ‘relapse’ (see page x). These symptoms will often disappear or improve significantly with treatment. So the way MS affects you can range from causing you little or no trouble at all for many years, to affecting every aspect of your life.

MS can affect any part of the body and there are a whole range of symptoms you might experience at some time, but probably any one person will only experience a few of those described in this booklet.

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Symptoms can include tiredness, problems moving around, eye problems, incontinence and difficulty with thought processes. For more information on specific symptoms see page x.

You can still have a good quality of life regardless of any physical problems. Talking to other people with MS can help, and support and information are available from MS organisations – your healthcare team can tell you about these, or you can get details from NHS Direct (see page xx).

A 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. Not all of this guideline will apply to you all of the time. This guideline describes what the NHS should do to diagnose and help you cope with the condition. At this point in time not all the treatments outlined below are available in all parts of the country. This guideline will help services and health professionals to provide better treatment and care.

3 What you can expect from the NHS when you have MS

Structure of the NHS

Because MS is such a variable condition, each person with MS will need different sorts and levels of help from the NHS. It is difficult to have a single system that can apply to everyone

However in each local area there should be a specialist neurological service that leads to timely diagnosis of MS or confirmation that a relapse is present. A specialist rehabilitation service that co-ordinates the various treatments including specialist doctors, nurses,

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physiotherapists, occupational therapists, speech and language therapists, clinical psychologists and social workers should be available.

In addition local services should have written agreements (protocols) about how different organisations, such as the health service and social services, work together and share relevant information.

The guideline recommends that people with MS should have the opportunity to be actively involved in planning services and how they are delivered within their locality, especially neurology and rehabilitation services.

Encouraging independence and self help

Health workers should encourage you to be involved in all aspects of your care. 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**, and provide you with information about the benefits and risks (if any) of each, to help you decide what is best for you. They should take into account whether you have problems following, remembering or understanding complex 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 help line or support group. They should check that you have understood what they have said to you, reinforce information if necessary, and give you written material or tapes to take home where possible. Communication should take place in a quiet area and you should have the opportunity to have someone, who you choose, with you.

MS is a condition that remains with a person for life. Successful treatment depends not only on the health service but also on the individual taking an active part in their own care. There is much that people can do to help themselves and information on how to help

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yourself, including maintaining a healthy lifestyle, should be made available to you.

How you feel about the effect the disease is having 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 the disease. Their health and well-being should also be considered and reviewed over time.

Accessing the NHS

People with MS can have a wide range of problems. They may find they need to see a number of different health workers to get the right expertise to help with each problem. When this happens, the health workers should work together, and should agree common aims and approaches to treatment along with the person with MS. These aims will be different for each individual and should cover both the next few months and further ahead. You may wish your family to be involved in this process.

The NHS should ensure that each person with MS has a method for contacting the NHS for help, particularly when new or distressing symptoms arise. When a symptom that might be due to MS occurs, health workers should discuss it with the person in a straightforward way, and in each area there should be a system for them to rapidly make a referral to the most appropriate part of the NHS.

Record keeping

In order to develop aims or plans for treatment, health workers will need to collect and record information about your condition. Your health worker should ask you about and record your MS symptoms each time

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you see them, to chart your progress over time. Health workers will also need to take measurements to be able to monitor progress. By sharing relevant information with each other, different health workers should not need to ask you the same questions each time and provide you with consistent advice.

4 About the diagnosis

Diagnosing MS can be difficult. MS can cause many different neurological symptoms but all of them can also be caused by other conditions. There is no simple test that tells if a symptom is due to MS or not. The diagnosis of MS depends on the doctor finding evidence of damage located in different parts of the nervous system that have occurred at different times. It is often not possible to make the diagnosis firmly at the first visit. You may have to wait for a while without being sure whether you have MS or not. This can be frustrating but is unavoidable.

The first time you visit your GP or hospital doctor with neurological symptoms that they cannot find a cause for, they may consider whether MS is a possibility. At this point, it is often not possible to make a diagnosis of MS. Depending on the severity of your symptoms your doctor may not take any action at that time. If you suffer a second episode you should be referred to a neurologist (a doctor who specialises in how the brain and nerves work). You should be told if MS is suspected, and your doctor should explain what will happen to you next.

The neurologist will ask you about your symptoms. Usually, a diagnosis can be made on the basis of how you describe your symptoms and from a physical examination that the neurologist will carry out.

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If the neurologist is still unsure about the diagnosis, some further tests will be carried out. At this stage the doctor should explain that he suspects MS and why the tests are being done. The most common tests are:

- magnetic resonance imaging (called an MRI scan) of your brain and spinal cord
- small electrodes placed on your head to monitor how your brain responds to what you see (called a visual evoked potential test).
- less commonly, a lumbar puncture test (a needle into the back of the spine) to obtain a sample of the fluid from around your spinal cord to be analysed in the laboratory.

When the diagnosis has been made, your doctor (preferably the consultant) should tell you about the diagnosis, what it means, and what is to happen next. The guideline advises doctors to tell you 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.

The doctor (or someone in the team) should also offer you written information:

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

Your medical notes should record the diagnosis, describe why the doctor thinks you have MS, and also show if there are any remaining doubts.

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What should happen immediately after MS is diagnosed?

Immediately after MS is diagnosed:

- you should be offered another appointment to talk to the same specialist doctor within 1 month
- you should be put in touch with, or introduced to, a skilled nurse or other support worker with knowledge of MS and with counselling experience
- within 6 months of diagnosis you should be given the chance to take part in an educational programme that will inform you about all aspects of MS.

5 About relapse

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

Acute, or sudden, relapses are thought to happen when your immune system damages a small part of the white matter in your brain or spinal cord and it becomes inflamed. The symptoms will depend on which part of the white matter is affected. They may be quite minor – numbness in a hand or loss of coordination in a leg or more disabling and obvious.

Two of the more frightening and disabling symptoms are:

- loss of some or all of your vision (optic neuritis) – the nerve to the eye is inflamed.; if this happens, you will usually be referred to an eye specialist (ophthalmologist)
- leg weakness or paralysis, or loss of control of your bowels or bladder (transverse myelitis which is inflammation around the spinal cord in your back). These symptoms are always worrying and you should be referred for an urgent assessment to rule out other causes and usually to have some steroid treatment.

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These symptoms are usually temporary, with full or partial recovery after treatment.

How should relapses be treated?

When a person with MS gets sudden new or worsening symptoms the GP or hospital doctor should perform an examination of the nervous system and note the change on your records.

This assessment should take place within 48 hours of your reporting the problems. It is important to realise that new symptoms may not be due to a new episode of MS. Often a simple infection (for example common cold) may make it appear that there is a problem, so the doctor should first look for signs of infection that might be causing the symptoms and treat it if appropriate.

If the doctor decides that the symptoms are due to MS then you may be offered a course of steroid treatment. Steroids can reduce the inflammation causing the symptoms and so reduce their severity. Steroids can also have side effects. You should have the benefits and risks explained to you so you can decide whether or not to have the treatment. If your symptoms are minor then often no treatment will be required. The guidelines recommend that there is an overall benefit if they are used as follows.

- If the new symptoms are limiting your activities more than before, or causing you distress, you should be offered a short course of high dose steroids starting as soon as possible. This can be either as an intravenous infusion (that is in 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 take steroids more than three times a year and for no longer than 3 weeks at any one time.

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If the new symptoms make it difficult to carry on daily activities as normal:

- you should be referred to a specialised rehabilitation service (see page x) and/or given the extra support you need, for example special equipment or personal care as soon as possible.

If the relapse has affected your vision so that reading is difficult you should also be referred to an ophthalmologist or low vision clinic.

Different types of MS

There are recognised ways of describing the different patterns of MS that occur (see list in box). Some of these terms have some use in selection for treatment. They describe how MS has affected you in the past but they do not tell you what is going to happen in the future.

The term 'relapsing/remitting MS' describes a pattern of multiple bouts of symptoms that come and go. This is the pattern of MS that is most likely to benefit from interferon beta therapy (see section 6).

Types of MS

Relapsing/remitting MS – symptoms come and go. You have periods of good health followed by sudden symptom or relapses.

Secondary/progressive MS – You gradually get more or worsening symptoms with fewer remissions. Often a follow on from relapsing/remitting MS.

Primary progressive MS - your symptoms gradually develop and worsen over time.

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6 How can the NHS help reduce the impact of MS on my life?

Most people with MS visit their GP because they have a new problem or are finding a particular activity more difficult. It is important to realise that there may be ways round your difficulties.

Your GP or hospital doctor may be able to reassure you that the problem is unrelated to MS and treat it in the normal way. If however they feel the new problem is related to MS and is likely to persist then you should be referred to a specialist neurological rehabilitation team for a full assessment.

Each 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 GP team or within the specialist neuro-rehabilitation team. The important thing is that each person should know whom they can contact for information, help and advice about MS as well as having access to the GP.

Specialist neuro-rehabilitation services

Rehabilitation services aim to find practical ways around specific problems that might be limiting you, helping you to maximise your ability to lead as full and independent a life as possible.

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

They should advise you on how changes or alterations at home might help you and/or your family or carers. They should check you are getting the right personal support and respond if your needs change (you may get better, or worse).

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Rehabilitation services can help in the following areas of your life.

- **Work/employment and education** – they can give advice on equipment, adaptations and support services (such as disability employment advisers and access to work schemes) and talk to your employer (with your permission).
- **Leisure and social life** –they can help you get back into your old activities or to start new ones.
- **Moving around** – if you have problems walking, physiotherapy should be offered. If necessary you will be offered equipment such as, or driving aids or wheelchairs.
- **Daily living** – if you are finding daily living tasks difficult, you should be offered a programme to help you improve or maintain your independence in, for example, shopping, cooking, dressing and washing. Your care plan may be shared with social services if they are involved.
- **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 made to increase your independence or reduce the stress on your carers. You should be assessed to find out what is most useful to you, and your family/carers should be taught how to use equipment where relevant.
- **Help for carers** – your carer/s should be shown how to help you keep as much independence and dignity 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.

At the end of a period of rehabilitation, you should be told how and who to contact if something changes.

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7 About treating and managing MS

As has already been stated, MS is a very variable condition.

- If the condition is mild with no relapses, then no treatment is needed.
- When there is a relapse, acute steroid treatment may be needed (see section 5).
- If there are several relapses, drug treatment may be offered which attempt to reduce the frequency and severity of those relapses
- Any specific symptoms caused by an episode or relapse may need specific treatment.
- For those with more severe disease a much wider range of treatment and support will be needed. (These are described in section 8.)

So the treatment you will be offered depends on the type of MS you have and on your specific symptoms. It will be different for each person. Health workers should offer you information, advice and help in acquiring the skills to enable you to help yourself as much as possible.

Managing MS is a partnership between the health workers and the person with MS. There are often choices to be made that you should be part of, for example when to use high-dose steroids for a relapse. The support the NHS offers should help you to acquire the skills to find and make use of information to prevent complications, how to stay fit and healthy and how to communicate effectively with health workers.

Treatment with medicines to slow disease progression

There are two types of medicine that can reduce the number and the severity of your MS attacks or relapses. These are:

- interferon beta (brand names Avonex, Rebif and Betaferon)
- glatiramer acetate (brand name Copaxone).

These medicines are injected in the muscle or under the skin.

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The medicines are not suitable for everybody with MS and like most medicines they can have side effects. They are available under a special scheme set up by the Department of Health. Under this scheme they are available in only a limited number of hospitals and can only be prescribed by specialist neurologists. Full details of this scheme can be found on <http://www.info.doh.gov/doh/coin4.nsf/page/HSC-2002-004?OpenDocument>. If you are offered either medicine, your neurologist should talk to you about their expected benefits and their side effects or risks. You should have regular check-ups to see if they are helping you.

Who can benefit?

People with relapsing/remitting MS and those with secondary/progressive MS can benefit from these medicines. (See box on page x.) At present there is no medicine that helps people with primary progressive MS or other types of MS, but research is ongoing.

If you have either relapsing/remitting or secondary progressive MS

You should be offered interferon beta or glatiramer acetate, but only if you are aged 18 or over, can walk on your own for at least 10 metres (that is, without hands on support from another person), and you have had at least two relapses in the last 2 years.

Continuing or stopping medicines

You will need regular check-ups with the neurologist to assess if the medicines are helping you or not. If they seem to be working and you are well then the medicines will be continued. But if either you or the doctor is concerned that they are not helping, or if they are causing side effects, then the doctor should talk to you about stopping your medicines. You might need to stop for other reasons such as if you are pregnant or trying to get pregnant.

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If you have a relapse while taking these medicines, they will not necessarily be stopped, but you may be given a high dose of steroid treatment for the relapse as well. If you have two major relapses within a year you may be taken off these medicines because that would be a sign that they are not working.

Other medicines

You may be given other medicines or other treatments in specific circumstances. This will usually be because your neurologist thinks they will help your particular situation. Again the doctor should explain the possible risks and benefits to you and the effects should be monitored closely.

Some medicines are being tested in clinical trials to see if they can help people with MS. You may be asked to take part in one of these trials. It is your decision whether to take part or not and you should be given enough information to make up your mind.

Linoleic acid (17–23 g a day) may reduce the progression of MS associated disability. It can be taken in capsule form or as part of a diet rich in sunflower seed oil products.

Many other treatments have been tried to stop the MS progressing. Some are known not to work. Others are only recommended as part of a formal clinical trial as their benefit is not yet known.

Complementary therapies

Some people with MS try alternative or complementary treatments to help with troublesome symptoms. Some treatments can simply make you feel better because they treat you as a whole person – mind, body and spirit.

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Many people consult alternative or complementary practitioners privately, but in some areas it is possible to see somebody on the NHS. Ask your GP if it is possible to refer you.

If you go to see a private practitioner, make sure they are registered with the appropriate registration body, which has lists of trained practitioners (see section 8, page x for details). Treatment can be costly.

Do tell your doctor or other health worker 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 and fish oils may be helpful for people with MS.

Other things affecting your MS

Immunisation

You should be offered a flu jab and be given any other immunisations you need. There is some evidence that getting an infection can either bring on symptoms or worsen the MS. There is no evidence that an immunisation itself will cause a relapse of your MS.

Pregnancy

Having MS is no reason not to have a baby. Your risk of relapse is actually less when you are pregnant. It goes up 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 won't. If you are taking medicines for MS you may need to stop taking them up to 6 months in advance of trying to get pregnant

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Stress

Although many people believe that stress can make MS worse, the evidence for this is weak. Stress is unpleasant for most people regardless of any medical condition they may have. However it is likely that stress, whether emotional or due to trauma or the stress of surgery, has no effect on your MS.

Having surgery

People with MS who need operations or anaesthetics may have them without any concern that it will worsen their MS. So there is no need for you to avoid surgery.

8 About MS 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 listed below. It is a daunting list – but remember it's most unlikely they'll all be experienced by you!

Before agreeing with you on treatment your doctor and other health workers should ask and talk to you about aspects of your health (for example the things in the following section) when you see them in order to find out what you want or need. You need to make sure you tell them if and how these symptoms are affecting your life.

Tiredness (fatigue)

About half of all people with MS report that they feel abnormally tired. The first thing your doctor should do is to consider any possible reasons for your tiredness apart from MS, for example the effects of the drugs you are taking. The tiredness could be caused by being depressed, pain, disturbed sleep or poor nutrition in which case, each should be treated in its own right. You should be given general advice on helping

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yourself to prevent or manage fatigue such as taking exercise and also learning ways to conserve your energy when necessary.

If the fatigue persists then unfortunately there are no clear answers. Medicine called amantadine may help a little but the benefits are likely to be small.

Bladder problems

MS can sometimes affect your bladder control. This may lead to a need to pass water (urinate) more often than usual, or to a difficulty urinating, or a loss of control so that you may wet yourself. These are 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 urine has become infected which can be treated with antibiotics. Or it may be that the muscles that make the bladder work are not functioning and that treatment with medicines can successfully stimulate them to work properly again.

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 you develop new symptoms that might be due to urinary tract infection (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.

The long-term use of antibiotics or drinking cranberry juice do not help to prevent infections.

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Bladder control problems

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, you may be given medicines such as oxybutynin or tolterodine. These help by stimulating the muscles that control the release of urine. If this is not successful it may be suggested that you should try the use of a catheter, which you insert into your bladder at intervals during the day to drain the urine. By preventing the bladder from becoming overfull, you can control the symptoms. If your symptoms are that you need to get up at night to urinate or if you need to urinate frequently during the day, you may be given drug 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 are having difficulty getting to the toilet in time, you may be offered advice on clothing that is easier to manage or arrangements to make a toilet easier to reach.

So whenever bladder problems are reported the doctor or health worker should check what might be causing the problem before offering treatment and should test your urine. They may send you to have some tests at hospital.

If the problems persist despite treatment, or if you have more than three urinary tract infections in 1 year, you should be referred to a continence specialist for tests, treatment and advice.

The continence service may offer you, or refer you for a course of exercises or electrical treatment for the muscles controlling the bladder.

Sometimes if the bladder cannot be controlled despite all other treatments it may be necessary to have long-term catheterisation (putting a tube into the bladder to drain off urine).

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Bowel problems

MS can affect the nerves that control the bowels and so too can some of the medicines. Patients with MS may have difficulty controlling their bowels, such as an urgent need to empty them, pain, constipation or incontinence.

Your doctor or health worker should ask you about your bowels and when a problem is noted should be able to help you improve the control of the symptoms. This may be as simple as advice on diet or it may be with one or more of laxatives, suppositories or enemas. The treatment may only be needed as a one-off, or the treatments may be needed on a regular basis to prevent the symptoms returning.

Muscle weakness

Keeping fit is just as important for people with MS as for the rest of the population. From the time of your diagnosis your health worker should encourage you to take plenty of exercise. However many patients will notice that their muscles appear weak and feel that it is limiting activities. If this occurs, a health worker should assess you and check for any possible causes other than your MS. If none is found, you may be given a programme of aerobic exercises or other specific exercises to help develop your strength and endurance.

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

Spasms and stiffness (muscle spasms and spasticity)

MS can cause muscles to develop uncontrolled contractions (spasms) and the stiff or rigid muscles make movement difficult (sometimes called

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spasticity). Loss of control over your muscles in this way can be distressing and can be painful.

Your doctor or health worker should look for and treat any pain or infection which may be causing or making the symptoms worse. If your problems continue, you should be referred to a specialist physiotherapist. You will learn techniques such as stretching, which can help to prevent stiffness developing in the joints or muscles. If your family or others help you do these exercises they too should be shown what to do. Your progress with these should be monitored.

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

In a small number of people whose spasms are not controlled with the above the specialist neuro-rehabilitation team may assess the possibility of more direct treatments which may include the use of special splints, the provision of special seating, the injection of drugs into the spinal cord or the injection of botulinum toxin into the affected muscles. These are specialist treatments and it is not recommended that they are used outside the specialist services.

Reduced movement in the joints (contractures)

If a joint is not moved through its full range of movement, whether due to muscle weakness or to spasticity or stiffness, the tissues around the joint will tighten up (contract) and lead to movement becoming limited and often painful. Contractures generally only occur in severe MS, but

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because the best treatment is to prevent them happening, anyone with MS who has weakness or spasticity should be assessed and advised on the options for maintaining best mobility or offered treatment for the spasticity or weakness (see above). The assessment should be by health workers with specialist experience in this area and will usually mean referral to a neurological rehabilitation service.

You and/or your carers should be taught how to prevent contractures. This may include regular stretching of the joints (moving the limb as far as the joint will allow) and specific positioning of the limbs and rest of the body while sitting in a chair or lying in bed.

When a contracture does develop, then a variety of treatments including the use of splints, special seating or special equipment to help in standing upright, and less often injections or surgery, may be useful.

Tremor and ataxia

People with MS can sometimes develop uncoordinated and clumsy movements called ataxia, or rapid, rhythmical and uncontrolled movements called tremor.

If you are affected by ataxia or tremor, you should be referred to a specialist team, including an occupational therapist, a physiotherapist and a doctor. You may be given medicines, exercises or equipment to help you carry out your usual activities. Less commonly if you have severe problems you may be offered an operation to reduce ataxia.

Sensory losses (loss of, oversensitive or other unusual feeling in the skin)

Many people with MS will notice feelings of pins and needles or numbness, or of oversensitivity of an area of skin. There is not usually any specific treatment for this but you should be referred to a specialist

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rehabilitation team for assessment and advice on techniques or equipment you can use to reduce the effects of the symptoms

Eye problems

Many people with MS have problems reading newspapers or watching television. The first thing to do if this happens is to have an eye test in case you need glasses. If reading is still difficult then, you should be referred to an ophthalmologist (a doctor who specialises in the diagnosis and treatment of eye diseases) who may be able to prescribe more powerful devices to help you see.

Sometimes the vision problem is because the eyes develop abnormal rapid movements (nystagmus), which makes it difficult to focus. This should be assessed in a specialist clinic because a drug called gabapentin can help some people.

Unfortunately in a few cases, despite treatment, vision will deteriorate so that reading, watching television and other activities become difficult or impossible. However even then there are a range of devices that can help people manage in spite of the poor vision. You should be referred to a specialist social services team for this and also be registered as partially sighted.

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 (neuropathic pain) or by being unable to move around (musculo-skeletal pain).

Any person with MS who experiences pain should have it properly assessed to see if it is due to the MS or to some other cause. If it is due to the MS then assessment by the specialist neuro-rehabilitation team

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will usually be necessary to sort out the nature of the pain and the most appropriate management for it:

Musculoskeletal pain (pain in the muscles and bones)

This is often due to lack of mobility, which in turn has been caused by weakness or by spasticity (see above). 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 then painkillers (analgesics) and other medicines can help, and techniques such as transcutaneous nerve stimulation (TENS) with a machine that stimulates nerve endings are of proven value. Other methods of pain control such as ultrasound, laser treatments and anti-epilepsy medicines have been shown not to work.

Psychological support using techniques such as 'cognitive behavioural therapy' and 'visual imagery' are also of proven value in some but not all situations.

Neuropathic pain (pain arising from the nervous system)

This type of pain is often sharp and shooting, and can include painful hypersensitivity (the skin, for example, being more sensitive to touch than usual). It can be treated with the anti-epilepsy medicines carbamazepine or gabapentin, or an antidepressant such as amitriptyline. If you are still in pain after treatment, you should be referred to a specialist pain service.

Problems with your thought processes (cognitive problems)

People with MS can have problems learning, remembering, planning and concentrating. This can affect your work and your home life.

The guideline advises all healthcare workers that they need to be aware that people with MS may not have understood all that is said to them

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first time. They should take particular care to make sure that you have understood what they are telling you.

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 a formal cognitive assessment by a psychologist may be helpful. Thought problems can be a very sensitive area for the individual affected and for those they live with. Specialist clinical psychologist support can help to either advise you on how to avoid difficulties for example in financial matters, or difficulties in relationships that may arise if a person is not 'thinking properly'. It can also help others that you live with help you.

Emotional outbursts

Some people with MS find they cry (and more rarely, laugh) more often than other people, sometimes uncontrollably. If this problem is upsetting you or your family, specialist advice should be offered to you about how to manage the situation. Occasionally anti-depressants may be helpful.

Depression

Many people with MS get depressed, or low. Your doctor or health worker should take your depression seriously, and help you identify and change anything you can, which may be making it worse.

Depression should be treated just as for anyone with depression and this may include being referred to a psychiatrist if it is severe. Anti depressant medicines and psychological treatments are both effective but should be part of an overall program of depression management.

Anxiety

This is another common symptom in people with MS. Doctors and health workers should ask about it regularly and should be willing to

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offer advice and help. Psychological treatments and some medicines are both known to work and one or both may be offered to you.

Swallowing difficulties

Sometimes MS can affect the nerves that control swallowing and this is important because if food or drinks cause you to choke and 'go down the wrong way' it may lead to chest infections. If a person with MS notices difficulty chewing, swallowing or choking on food or fluids then a swallowing assessment by a speech and language therapist and a dietician should be done. They should advise you on specific swallowing techniques and on adapting your diet or food consistency, which may provide sufficient relief. Adjustments to your seating may be suggested to make swallowing easier.

In a few people, these measures may not be enough, especially if they get a lot of chest infections, and 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. Both of these ways of tube feeding can be done at home, and there should be training for you and those who live with you or help you at home.

Speech problems

People with MS may find they cannot speak as clearly as before and that their voice sounds different. If your speech problems are affecting your ability to communicate with people, you should be referred to a speech and language therapist for advice and help. This may include learning special techniques to help your speech or ways of communicating without speech or with limited speech or you may be offered special equipment to help you. The speech and language therapist should discuss with your family members and others you communicate with a lot how best to help you communicate.

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Sexual problems

MS can affect people's sex life by damaging the nerves that supply that area of the body. Health service staff should ask sensitively about this, but people who experience difficulty should not be afraid to raise the matter. It is possible to help in many cases.

There are many causes of poor sexual function including depression, anxiety, vascular disease (disease affecting the blood vessels), diabetes and some medicines (for example some medicines for blood pressure) that apply in MS as for any other condition. Local counselling and support services can often help and may be especially useful in helping couples to understand what is happening to their relationship. In addition the use of sildenafil (Viagra) for men and other treatments that can maintain an erection are of value.

Women should be asked about any sexual problems such as lack of arousal or lubrication and if so, whether it is of concern, and advised accordingly.

If problems persist then you, or you and your partner, should be referred to a specialist in sexual problems, who can advise on other treatments or help that may be available, if you want them.

Pressure sores (pressure ulcers)

When MS is severe and leads to limited movement or the need for a wheelchair, then there is an increased risk of a pressure sores.

Pressure sores are also known as ulcers or bedsores; they start as painful red areas that become purple before the skin breaks down. They often become infected and are slow to heal. If they do occur then treatment is the same as for anyone without MS.

The best treatment is to prevent them occurring in the first place, and anyone with MS who is limited in their movement should be assessed

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and advised about their risks. The assessment will usually be done by the rehabilitation service and should be able to give specific advice on what to do to avoid a sore developing. Sometimes this will be advice on diet or providing pressure-relieving devices and sometimes it will be advice on modifying the wheelchair or on use of a special mattress in bed.

If you are a wheelchair user and are admitted to hospital, a suitably trained person should advise you and the staff caring for you on pressure-relieving devices that should be used and procedures required to prevent pressure sores such as agreed ways to move or transfer you.

9 Glossary

[to be completed]

Acute – sudden as opposed to chronic (long term)

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.

Consultant – specialist doctor (for people with MS, normally a neurologist)

Incontinence -

Neurology – the study of the nervous system and its disorders

Neurologist – a doctor who is a specialist in disorders of the nervous system (brain and spinal cord)

Occupational therapist

Ophthalmologist – a doctor who is an eye specialist

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Physiotherapist

Progressive –becoming more severe or extensive over time

Rehabilitation – treatment aimed at helping you live independently

Relapse – the return of symptoms after a remission or recovery

Remission – a temporary disappearance or reduction in symptoms

Urinary tract – includes the kidneys, the ureters, the bladder and the urethra. Infections of the urinary tract include cystitis, urethritis and pyelonephritis.