NICE National Institute for Health and Care Excellence

Multiple sclerosis

Management of multiple sclerosis in primary and secondary care

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Contents

Multiple sclerosis

Multiple sclerosis (MS) is a disease of the central nervous system (brain and spinal cord). The disease process is one of episodes where white matter within the brain or spinal cord becomes inflamed and then destroyed by the person's own immune system. These inflamed areas become scarred, giving the disease its name: **multiple** areas of hardening (**sclerosis**) within the brain or spinal cord. Many of these episodes do not cause any symptoms, but when sudden symptoms occur the person is said to have had a relapse.

MS usually starts in early adult life. Once present the disease never goes; there is no cure and the person lives with the diagnosis for life. For many people with MS, the disease causes little trouble, but for others it causes problems that can affect all aspects of their own life and that of their family.

There are recognised ways of describing different patterns of MS.

- **Relapsing/remitting MS** – symptoms come and go. Periods of good health or remission are followed by sudden symptoms or relapses (80% of people at onset).
- **Secondary progressive MS** – follows on from relapsing/remitting MS. There are gradually more or worsening symptoms with fewer remissions (about 50% of those with relapsing/ remitting MS develop secondary progressive MS during the first 10 years of their illness).
- **Primary progressive MS** – from the beginning, symptoms gradually develop and worsen over time (10–15% of people at onset).

Between three and seven people per 100,000 population are diagnosed with MS each year and about 100 to 120 people per 100,000 population have MS. From these rates it is estimated that in England and Wales about 1800 to 3400 people are newly diagnosed with MS each year and that 52,000 to 62,000 people have MS.

Key priorities for implementation

The following recommendations have been identified as priorities for implementation.

Specialised services

- Specialist neurological and neurological rehabilitation services should be available to every person with MS, when they need them. This is usually when they develop any new symptom, sign, limitation on activities, or other problem, or when their circumstances change.

Rapid diagnosis

- An individual who is suspected of having multiple sclerosis should be referred to a specialist neurology service, and seen rapidly within an audited time. The individual should be seen again after all investigations necessary to confirm or refute the diagnosis have been completed (also rapidly within an audited time).[1]

Seamless services

- Every health commissioning organisation should ensure that all organisations in a local health area agree and publish protocols for sharing and transferring responsibility for and information about people with MS, so as to make the service seamless from the individual's perspective.

A responsive service

- All services and service personnel within the healthcare sector should recognise – and respond to – the varying and unique needs and expectations of each person with MS. The person with MS should be involved actively in all decisions and actions.

Sensitive but thorough problem assessment

- Health service professionals 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.

Self-referral after discharge

- Every person with MS who has been seen by a specialist neurological or neurological rehabilitation service should be informed about how to make contact with the service when he or she is no longer under regular treatment or review. The individual should be given guidance on when such contact is appropriate.

[1] The Guideline Development Group debated the meaning of the word 'rapidly'. In this context, it is taken to mean that the exact time will vary according to clinical need but should be, in the opinion of the development group, no longer than 6 weeks from referral to being seen by a neurologist, and a further 6 weeks until any necessary investigations are completed.

1 Guidance

1.1 General principles

1.1.1 Communication

1.1.1.1 All communication with all people with MS should comply with the general principles of good communication, shown in Appendix E, Table 1.

1.1.1.2 Some people with MS may not be able to follow everything fully or remember complex details. This includes people who have no obvious disability. So, when talking to the person with MS, the healthcare professional should:

- be straightforward
- check the person has understood
- back up what was said with written (and other) material
- reinforce as necessary.

1.1.2 Emotional support

1.1.2.1 A person with MS may benefit from emotional support; this should be considered by each individual and team in contact with the individual. Where possible, that emotional need should be met directly or through referral to a suitable resource.

1.1.3 Encouraging autonomy/self-management

1.1.3.1 People with MS should be enabled to play an active part in making informed decisions in all aspects of their MS healthcare by being given relevant and accurate information about each choice and decision.

1.1.3.2 As far as possible, people with MS should be helped to manage their own general health through the following.

- Information and advice provided in written, audio or other media on:

- specific activities that promote health maintenance and prevent complications
- changes in their health that may require them to take further action
- the condition and its management (including both local and sources of further information and support in clear and accessible language).

  This function could be fulfilled by working in conjunction with local voluntary organisations.

- And, through acquiring the skills needed to:
  - seek, evaluate and use advice and help available
  - communicate effectively with healthcare professionals (for example, through participation in the Expert Patient Programme).

1.1.4 Support to family and carers

1.1.4.1 Family members (including any schoolchildren) living in the same house as the person with MS, and any family members delivering substantial support even if living elsewhere, should be supported by:

- asking about their physical and emotional health and well-being, especially in the case of children aged 16 years or less, and offering advice and referring on for additional support if necessary
- providing them with general factual information about MS; this should only be extended to include more specific information related to the person with MS with the permission of that person
- ensuring that they are willing to undertake support of personal activities of daily living (such as dressing and toileting), are safe and competent at such tasks, and that the person with MS is happy for them to provide such assistance
- informing them about social services carer assessment and support procedures.

1.1.5 Assessment and measurement

1.1.5.1 The review checklist shown in Appendix E, Table 2 should be used each time a person with MS starts a new 'episode of care' (including initial diagnosis), and whether or not the presenting issues relate to the MS. The healthcare professional should:

- record the information for future comparison
- refer to the specific recommendations made in this document if any problem is identified.

1.1.5.2 Healthcare staff who frequently undertake MS-specific assessments or treatments should:

- be familiar with simple methods for detecting impairment and limitations on activities
- be trained in their use and interpretation (if used).

1.1.5.3 All healthcare staff within a local health community should use the same simple methods for common assessments.

1.1.5.4 When initially assessing an individual, and when undertaking any treatment, healthcare staff should consider the characteristics of a measure (see the resource pack) recognising that:

- formally evaluated measures may not exist or be practical
- personalised measures should be considered, including comparing the outcome against goals agreed (goal attainment scaling).

1.1.5.5 Before embarking on any course of treatment, the healthcare professional should be satisfied that the individual fully understands the implications of the treatment, and is able to participate in it as necessary.

Further guidance may be found at the Department of Health consent website.

1.2 Teamwork

1.2.1 Teams and goal setting

1.2.1.1 When several healthcare and other professionals are involved with a person with MS, they should work together with the person and his or her family, as a team:

- towards common agreed goals
- using an agreed common therapeutic approach.

1.2.1.2 The goals set should:

- be agreed as relevant and important by the person with MS
- cover both short-term specific actions and longer-term outcomes
- be challenging or ambitious but achievable
- be set both at the level of individuals and at the level of the team as a whole
- be formulated in such a way as to leave no doubt as to when they have been met.

1.2.1.3 Goal attainment scaling should be considered as one way of setting goals and evaluating progress.

1.2.2 Specialist services

1.2.2.1 Every healthcare commissioning authority should ensure that all people with MS have ready access to a specialist neurological service for:

- diagnosis of MS initially, and of subsequent symptoms as necessary
- provision of specific pharmacological treatments, especially disease-modifying drugs, and enacting the risk-sharing scheme for interferon beta and glatiramer acetate.

1.2.2.2 The healthcare commissioning authority should also ensure that its population has ready access to a specialist neurological rehabilitation service. This should

be available to all people with MS when the presenting problem is outside the competence of the first point of contact, for:

- undertaking assessment (that is, diagnosis) when the person has complex problems
- undertaking specific pharmacological or other therapies
- providing an integrated programme of rehabilitation when the person has complex problems
- monitoring change, especially when the person with MS has more severe impairments or limitations on activities
- giving advice to other services.

1.2.2.3 As a minimum, the specialist neurological rehabilitation service should have as integral members of its team, specialist:

- doctors
- nurses
- physiotherapists
- occupational therapists
- speech and language therapists
- clinical psychologists
- social workers.

The team should either have as team members, or through agreed mechanisms, ready access to other local relevant specialist services with expertise in treating neurologically disabled people, to cover:

- dietetics
- liaison psychiatry
- continence advisory and management services

- pain management services
- chiropody and podiatry
- ophthalmology services.

1.2.3 Working across organisations

1.2.3.1 All parts of the healthcare system, social services and other statutory services should have agreed protocols that specify:

- how responsibility for people with MS is shared with other groups or organisations
- what agreed descriptive information (that is, a common dataset) about the person with MS should always be shared
- the point of contact within any service or organisation, and how contact should be made.

1.2.3.2 People with MS should be able to identify and contact:

- a named person in their health area who is responsible for all NHS services for local people with MS (including co-ordination and collaboration with other statutory services)
- a named person in their health area with clinical expertise who is able to respond to any inquiry on clinical problems (and to guide the person to the most appropriate local service)
- a named person within any healthcare team with whom they are involved.

1.2.4 Timing of actions

To be useful (that is, to be effective and efficient) it is important that any intervention is timely.

1.2.4.1 Any action recommended within these guidelines should be undertaken within a time that takes into account:

- risk of direct harm associated with any delay

- distress or discomfort being experienced or likely to occur
- risk of secondary complications associated with delay
- risk of harm to others (for example, carers) associated with delay
- any nationally recommended targets for timing
- action being taken by any other person or service.

1.2.5 Within team communication – a conceptual framework

1.2.5.1 All individual clinicians, professional groups and organisations involved in the care of those with MS should use the World Health Organization's International Classification of Functioning (WHO ICF) model of illness, and its vocabulary.

1.2.6 Support over time

1.2.6.1 Services should cater for the varying needs of people with MS over time, by:

- responding in a timely and flexible way to the intermittent acute needs of people with MS, especially in the early phases
- identifying and reducing the risks of complications that might develop in the individual
- making fully available, to people with MS, population-based programmes of health promotion and/or disease prevention (such as screening for cervical carcinoma), specifically taking into account an individual's possible impairments and activity limitations.

1.2.6.2 When any 'episode of care' (medical or rehabilitation treatment programme) ends (that is, when no further benefit is anticipated), the healthcare team should:

- ensure that any necessary long-term support needs are met
- ensure that the person with MS knows who to contact and how to contact them, in the event that the person with MS experiences a change in his/her situation

- discuss with the person with MS whether they want a regular review of their situation and, if so, agree on a suitable and reasonable interval and method of review (for example, by phone or post or as an outpatient).

1.2.6.3 Health services should ensure that there are mechanisms to allow good communication between health and social services at all times.

1.2.6.4 Individuals who are severely impaired and markedly dependent should have their support needs reviewed at least yearly, and they should have these needs met as necessary and in accordance with their wishes, through one or more of the following:

- additional support in the home
- respite care in the home
- respite care in another age-appropriate setting
- moving into a residential or nursing home.

1.3 Diagnosis

1.3.1 Involving the individual in the diagnostic process

1.3.1.1 An individual should be informed of the potential diagnosis of MS, as soon as a diagnosis of MS is considered reasonably likely (unless there are overwhelming patient-centred reasons for not doing so). This should occur before undertaking further investigations to confirm or refute the diagnosis.

1.3.1.2 Throughout the process of investigating and making the diagnosis of MS, the healthcare professional should:

- find out what and how much information the individual wants to receive. (This should be reviewed on each occasion.)
- discuss the nature and purpose of all investigations, especially the likely outcomes and their implications for the individual.

1.3.1.3 If a diagnosis of MS is confirmed, the individual should be told by a doctor with specialist knowledge about MS. (This is usually a consultant or experienced specialist registrar.) See also the recommendations for good communication (Appendix E, Table 1).

1.3.1.4 After the diagnosis has been explained, the individual should be:

- offered in the near future[2] at least one more appointment to see wherever possible the doctor who gave the original diagnosis
- put in touch with, or introduced to, a skilled nurse or other support worker, ideally with specialist knowledge of MS and/or other neurological conditions and counselling experience
- offered written information about local and national disease-specific support organisations
  including details of local rehabilitation services
- offered information about the disease, preferably in the form of an information pack, specific to the newly diagnosed.

1.3.1.5 Within 6 months of diagnosis, the individual should be offered the opportunity to participate in an educational programme to cover all aspects of MS.

1.3.2 Making the diagnosis of MS

There is no single specific diagnostic test available, but in practice, the diagnosis can be made clinically in most people.

1.3.2.1 When an individual presents with a first episode of neurological symptoms or signs suggestive of demyelination (and there is no reasonable alternative diagnosis), a diagnosis of MS should be considered.

1.3.2.2 When an individual presents with a second or subsequent set of neurological symptoms, which are potentially attributable to inflammatory or demyelinating lesions in the central nervous system (and again, there is no reasonable alternative diagnosis), the individual should be referred to an appropriate expert for investigation.

1.3.2.3 A diagnosis of MS should be made clinically:

- by a doctor with specialist neurological experience
- on the basis of evidence of CNS lesions scattered in space and time
- primarily on the basis of the history and examination.

1.3.2.4 When doubt about the diagnosis remains, further investigation should:

- exclude an alternative diagnosis, or
- find evidence that supports the potential diagnosis of MS.
  - Dissemination in space should usually be confirmed, if necessary, using a magnetic resonance imaging (MRI) scan, interpreted by a neuro-radiologist if possible, using agreed criteria such as those described by McDonald and colleagues[3].
  - Dissemination in space may also be confirmed using evoked potential studies. Visual evoked potential studies should be the first choice.
  - Dissemination in time should be confirmed clinically, or using the MRI criteria described by McDonald and colleagues[3].

1.3.2.5 Other tests supportive of the diagnosis of MS, such as analysis of the cerebrospinal fluid (CSF), should only be used either when the investigation is being undertaken to exclude alternative diagnosis or when the situation is still clinically uncertain.

1.3.2.6 The diagnosis of MS is clinical and an MRI scan should not be used in isolation to make the diagnosis.

1.3.2.7 A computed tomography (CT) brain scan should only be used to exclude alternative diagnoses that can be diagnosed using that investigation.

1.3.2.8 Any CSF samples taken from individuals who might have MS should be tested for the presence of oligoclonal bands and should be compared with serum samples.

1.3.2.9 The evidence supporting the diagnosis and its degree of certainty should always be documented formally in the medical notes and letters discussing the diagnosis. This allows the diagnosis to be critically reviewed and reinvestigated if necessary.

1.3.3 Diagnosis of an acute episode

General diagnosis

1.3.3.1 If a person with MS has a relatively sudden (within 12–48 hours) increase in neurological symptoms or disability, or develops new neurological symptoms, a formal assessment should be made to determine the diagnosis (that is, the reason for the change). This should be recorded clearly.

1.3.3.2 This diagnostic assessment should:

- be undertaken within a time appropriate to the clinical presentation
- consider the presence of an acute infective cause
- involve a GP or acute medical/neurological services.

1.3.3.3 Further neurological investigation should not be undertaken unless the diagnosis of MS itself is in doubt.

Diagnosis of optic neuritis

Acute, sometimes painful, reduction or loss of vision in one eye, optic neuritis, is a relatively common presenting symptom of MS.

1.3.3.4 Every individual presenting with an acute decline in visual acuity, with or without associated pain, should be seen by an ophthalmologist for diagnosis.

1.3.3.5 If the diagnosis is confirmed as optic neuritis, without any other specific cause and possibly due to MS, the ophthalmologist should discuss the potential diagnosis with the individual (unless there are overwhelming patient-centred reasons for not doing so). A further referral to a neurologist for additional assessment should be offered.

Diagnosis of transverse myelitis

An acute episode of weakness or paralysis of both legs, with sensory loss and loss of control of bowels and bladder, is an emergency that may be due to transverse myelitis, and it may be a symptom of MS.

1.3.3.6 Every person presenting with symptoms and signs of acute spinal cord dysfunction should be investigated urgently, especially to exclude a surgically treatable compressive lesion.

1.3.3.7 If a diagnosis of transverse myelitis is made (and there is no previous history of neurological dysfunction), the individual should be informed that one of the possible causes is MS.

1.4 Treatment

1.4.1 Treatment of acute episodes

Acute episodes of neurological symptoms are thought to arise from a process whereby the cerebral white matter becomes inflamed as the individual's own immune system starts to damage the myelin sheaths of the nerves (part of the white matter). Treatment recommendations are independent of whether the symptoms arise from a first presentation or a subsequent relapse.

1.4.1.1 Any individual who experiences an acute episode (including optic neuritis) sufficient to cause distressing symptoms or an increased limitation on activities should be offered a course of high-dose corticosteroids. The course should be started as soon as possible after onset of the relapse and should be **either**:

- intravenous methylprednisolone, 500 mg–1 g daily, for between 3 and 5 days **or**
- high-dose oral methylprednisolone, 500 mg–2 g daily, for between 3 and 5 days.

1.4.1.2 An individual should be given a clear explanation of the risks and benefits involved in taking corticosteroids.

1.4.1.3 Frequent (more than three times a year) or prolonged (longer than 3 weeks) use of corticosteroids should be avoided.

1.4.1.4 Other medicines for the treatment of an acute relapse should not be used unless as part of a formal research protocol.

1.4.2 Rehabilitation for an acute episode

1.4.2.1 When a person with MS experiences a sudden increase in disability or dependence the individual should be:

- given support, as required and as soon as practical, both in terms of equipment and personal care
- referred to a specialist neurological rehabilitation service. The urgency of the referral should be judged at the time, and this referral should be in parallel with any other medical treatment required.

1.4.3 Interventions affecting disease progression

1.4.3.1 People with relapsing-remitting MS, and those with secondary progressive MS in which relapses are the dominant clinical feature, who meet the criteria developed by the Association of British Neurologists are eligible for treatment under the risk-sharing scheme. See Health Service Circular 2002/004 and Appendix E, Table 3.

1.4.3.2 People with MS should be advised that linoleic acid 17–23 g/day may reduce progression of disability.

Rich sources of linoleic acid include sunflower, corn, soya and safflower oils.

1.4.3.3 The following treatments should not be used except in specific circumstances, detailed below.

Circumstances:

- after full discussion and consideration of all the risks

- with formal evaluation, preferably in a randomised or other prospective study
- by an expert in the use of these medicines in MS with close monitoring for adverse events.

Treatments:

- azathioprine
- mitoxantrone
- intravenous immunoglobulin
- plasma exchange
- intermittent (4-monthly) short (1–9 days) courses of high-dose methylprednisolone.

1.4.3.4 The following treatments should not be used (because research evidence does not show beneficial effects on the course of the condition):

- cyclophosphamide
- anti-viral (for example, aciclovir, tuberculin)
- cladribine
- long-term treatment with corticosteroids
- hyperbaric oxygen
- linomide
- whole-body irradiation
- myelin basic protein (any type).

1.5 Altering the risk of relapses

1.5.1 Infections and immunisations

Infections may be associated with a worsening of disability, most often through indirect mechanisms such as an increased temperature. In some cases, infection may trigger a relapse.

1.5.1.1 People with MS should be offered immunisation against influenza.

1.5.1.2 People with MS should have any other immunisation they need, with advice that there is no known risk of causing a relapse of their MS.

1.5.2 Pregnancy

There is no evidence that pregnancy influences the overall course of the condition over time.

1.5.2.1 Women with MS who wish to become pregnant should be advised that the risk of relapse decreases during pregnancy, and increases transiently postpartum.

1.5.2.2 When giving birth, women with MS should have the analgesia that seems most appropriate and acceptable to them, without fear of its affecting their MS.

1.5.3 Stress (various types)

Putative stresses include emotional stress, trauma, and stresses caused by medical intervention. In the absence of conclusive evidence, it has only been possible to make a recommendation on stress relative to surgery.

1.5.3.1 People with MS should be encouraged to have any surgery they need, using whichever anaesthetic technique is appropriate. They should be informed that there is no known increase in the risk of relapse.

1.6 Rehabilitation and maintenance of functional activities and social participation

This section focuses on the ways in which health services can help people with MS to maximise their level of functional activities (that is, minimise disability and dependence) and help them maintain social roles. The general items addressed in this section should be looked at in conjunction with the specific recommendations given in Section 1.5.

1.6.1 General points

1.6.1.1 If a person with MS starts to experience a new limitation on his or her activities, the cause should be identified medically, and the following considered:

- is it due to an unrelated disease?
- is it due to an incidental infection?
- is it due to a relapse of the MS?
- is it part of a gradual progression?

1.6.1.2 If the limitation persists, despite treatment of any identified cause, the person with MS should be seen and assessed by a multidisciplinary service, specialised in neurologically based disability.

This service should implement a rehabilitation programme.

1.6.1.3 The components of the rehabilitation programme should include the following.

- Establishing the wishes and expectations of the person with MS.
- Assessing and, if necessary, measuring relevant factors, in order to identify and agree goals with the person; these might include one or more of the following:
  - identifying and treating any treatable underlying impairments
  - giving task-related practice of a specific activity or activities
  - providing suitable equipment (with training in its use)

- altering the environment as needed
- teaching others how to assist with (or take over) tasks.

- Monitoring progress against set goals; the goals should be reviewed and reset, until no further goals exist and no further interventions are needed.

1.6.1.4 Where possible, both assessment and task-related practice should take place in the environment most appropriate to the task (for example, home, work or leisure).

1.6.2 Vocational activities – employment and education

1.6.2.1 Any person with MS who is in work or education should be asked specifically whether they have any problems, for example motor, fatigue or cognitive difficulties.

1.6.2.2 Any individual who has problems that affect their work or education should be seen for further assessment of their difficulties, preferably by a specialist vocational rehabilitation service, or specialist neuro-rehabilitation service.

1.6.2.3 The results of the assessment should be used:

- to advise the person with MS on strategies, equipment, adaptations and services available to assist with vocational difficulties; and/or
- to advise the employer or others, with permission from the person with MS, on strategies, equipment and adaptations to assist; and/or
- to give information to the disability employment advisor, if involved (see recommendation 1.6.2.4).

1.6.2.4 The person should always be informed about available vocational support services (currently including Disability Employment Advisers and the Access to Work Scheme), and that there may be adjustments at work to which they are entitled under the Disability Discrimination Act.

1.6.2.5 Any individual who cannot stay in or find alternative employment should be advised about other options such as voluntary work and where to find information about these options.

1.6.3 Leisure and social interaction

1.6.3.1 Any person with MS whose participation in or enjoyment of a leisure or social activity becomes limited should be referred to a specialist neurological rehabilitation service which should:

- identify whether previous activities are still achievable and, if not, help the person consider new activities
- assess for, and then teach, the skills and techniques that could help achieve these activities
- if necessary refer the person to local services that might help them establish and continue leisure and social activities.

1.6.4 Mobility

1.6.4.1 Any person with MS who experiences reduced mobility (and it affects or threatens his or her activities) should be seen and assessed by a specialist neurological rehabilitation service. The assessment should determine which interventions are needed:

- identification and treatment of any underlying impairment, especially weakness, fatigue, spasticity, ataxia, sensory loss and loss of confidence
- task-related practice of a specific mobility activity or activities (for example, walking, transferring, using a wheelchair, climbing stairs)
- provision of suitable equipment, including wheelchairs, driving equipment and adaptive technology (with training in its use)
- alteration of the environment to increase independent mobility
- teaching others how to safely assist with (or take over) tasks such as walking, climbing stairs, moving in bed or transferring.

1.6.4.2 Physiotherapy treatments aimed at improving walking should be:

- offered to a person with MS who is, or could be, walking
- given at home or on an outpatient basis, depending on the preference of the person with MS and local resources.

1.6.5 Activities of daily living

Activities of daily living are usually divided into personal, domestic and community activities.

1.6.5.1 Any person with MS who experiences a limitation in personal, domestic or community activities should receive a comprehensive multidisciplinary assessment. This should be carried out by a team experienced in the treatment and management of MS, and should cover the person's previous and current functioning in the following areas:

- personal activities such as dressing, eating, using the toilet and washing
- domestic activities such as cooking, washing and ironing clothes, keeping the house clean and dealing with household bills
- community activities such as shopping, using public transport, negotiating the environment safely (for example, avoiding traffic) and accessing other public amenities
- any caring or support activities within the home, including caring for children.

1.6.5.2 A comprehensive assessment of this type should:

- actively involve the person with MS, encouraging them to think about and define what they need to continue to achieve their goals and aspirations
- take place on more than one occasion and in different environments
- take into account the individual's priorities, interests, goals and potential
- consider environmental factors, and the support available from family and carers
- take into account both current and future needs.

1.6.5.3 After the assessment, a programme of interventions should be developed for the person with MS, with the aim of increasing and maintaining independence wherever possible. The programme of interventions should be agreed by the individual. The interventions specified should be goal-directed, and designed to meet the individual's priorities, interests and potential.

1.6.5.4 If the individual agrees, the programme of interventions should be shared with social services, and this must occur if social services are to be responsible for maintenance interventions.

1.6.5.5 There should be regular monitoring to check how effective the interventions are, with a view to changing them if necessary.

1.6.5.6 At the end of the planned programme, the person should know how to obtain a re-assessment if their situation changes.

1.6.6 Equipment, adaptations and personal support

1.6.6.1 Every person with MS whose activities are persistently affected should be assessed by a specialist neurological rehabilitation service to determine how their environment might be improved, enabling for example:

- an increase in the person's independence
- the impact on their activities to be minimised
- a reduction in risk to the person or their carers.

The environmental changes considered should include the following:

- provision of (or changes in) equipment
- alterations in the structure of the building
- provision of (or change in) the personal support provided.

Equipment and adaptations

1.6.6.2 If a person with MS depends on someone else for an activity (especially in mobility), an expert should assess whether an aid or adaptation, including an environmental control system, could be of benefit. For example, it may increase the independence of the person with MS, and/or minimise the stress on, or risk for, the person who assists them. The person with MS or, if necessary, their family and/or carers, should be taught how to use the equipment. Ability and safety in using the equipment should be checked at least once, after a suitable interval.

1.6.6.3 The service providing or recommending the equipment should ensure the equipment's continuing appropriateness and safety, at appropriate intervals.

Personal support

1.6.6.4 If a person with MS receives support or supervision from someone, for any particular activity, an assessment should be made to determine whether a greater level of independence could be achieved.

1.6.6.5 If personal support is provided by family, friends or paid carers, an expert should offer knowledge and skills to help the carer(s) provide assistance in ways that maintain the dignity and utmost independence of the person with MS, while also not threatening the health or well-being of the carers.

1.6.6.6 If support is given on a daily basis for more than 1 hour, then the level and appropriateness of the support offered should be monitored, at a minimum, on a yearly basis. It should also be reviewed after any significant medical event (for example, infection, relapse, complication, departure of family member). Any person involved in hands-on activities, especially physical moving and handling, should be taught appropriate safe techniques for the individual situation, and should be able to seek further tuition or advice when they need it.

1.7 Managing specific impairments

The range of potential symptoms is vast; only the more common ones are covered in these guidelines. In most people there will be several if not many symptoms, and although this section

is subdivided by symptom, in practice the overall situation of the individual must always be borne in mind before acting. Thus for each impairment there is an unwritten first recommendation – do not start or modify treatment until all aspects of the individual's clinical situation have been established and understood, and the wishes and expectations of the person with MS have been established.

1.7.1 Fatigue

1.7.1.1 Each professional in contact with a person with MS should consider whether fatigue is a significant problem or a contributing factor to their current clinical state.

If fatigue is disrupting the individual's life, then the following recommendations apply.

1.7.1.2 The presence of significant depression should be considered; if significant depression is present, it should be treated.

1.7.1.3 Other factors causing fatigue, such as disturbed sleep, chronic pain and poor nutrition, should be identified and treated if possible.

1.7.1.4 Some medicines may exaggerate fatigue, thus any medication being taken should be reviewed.

1.7.1.5 General advice and training on how to manage fatigue should be given, including encouragement to undertake aerobic exercise and to use energy-conservation techniques.

1.7.1.6 At present, no medicines targeted at fatigue should be used routinely, although people with fatigue should be informed that a small clinical benefit might be gained from taking amantadine 200 mg daily.

1.7.2 Bladder problems

Bladder dysfunction

1.7.2.1 Each professional in contact with a person with MS should consider whether the person has any problems controlling bladder function. Problems may include frequency or urgency of micturition, sleep disturbance from nocturia (awaking with need to empty bladder), difficulty in passing urine or incontinence of urine.

1.7.2.2 Any person with MS who has bladder symptoms should:

- have their post-micturition residual bladder volume measured using a simple measure such as ultra-sonography of the bladder
- be assessed for the presence of a urinary tract infection clinically and, if necessary, using an appropriate dipstick for nitrites and leucocyte esterase. Treatment should be provided, if necessary. (See also Section 1.7.3.)

1.7.2.3 Urgency or urge incontinence sufficient to be bothersome or cause incontinence should be treated in the first instance using:

- advice on changes to clothing and/or toilet arrangements (for example, provision of a commode downstairs)
- intermittent self-catheterisation if there is a high residual volume, and the person is able and willing
- anticholinergic medicines such as:
  - oxybutynin or
  - tolterodine
- checking for an increased post-voiding residual volume if symptoms recur.

1.7.2.4 Any person who has nocturia should be offered desmopressin (100–400 µg orally or 10–40 µg intranasally) at night, to control the symptom.

1.7.2.5 Any person who wishes to control urinary frequency during the day (for example, when travelling), and who has failed with other measures, should be offered desmopressin (100–400 µg orally or 10–40 µg intranasally), but **desmopressin should never be used more than once in 24 hours.**

1.7.2.6 Any person with MS who, despite treatment, has incontinence more than once a week should:

- be referred to a specialist continence service for further assessment and advice
- be considered for a course of pelvic floor exercises preceded by a course of electrical stimulation of the pelvic floor muscles (if such a course is available).

1.7.2.7 Any person with MS who experiences persistent incontinence should be offered a convene drain (for men) or pads (for women).

1.7.2.8 Any person who has continued bladder symptoms despite pharmacological and other treatments should be considered:

- for intermittent self-catheterisation taught by a suitably trained specialist, or
- for longer-term urethral catheterisation as a means of control, with suprapubic catheterisation being considered especially when active sexual function is still wanted. **See recommendations below on use of catheters.**

1.7.2.9 Intravesical botulinum toxin should only be used by suitably trained doctors in the context of clinical research.

1.7.3 Urinary tract infections

1.7.3.1 Any person with MS at risk of urinary tract infections should not be recommended prophylactic use of antibiotics or cranberry juice.

1.7.3.2 If a person with MS experiences new urinary tract symptoms, or develops general malaise and/or worsening of existing symptoms with a raised temperature, they should:

- be given a urine dipstick test for infection, and culture, if necessary
- be offered treatment with an appropriate antibiotic.

1.7.3.3 Any person with MS with more than three confirmed episodes of urinary tract infection in a period of 1 year should be assessed by a continence specialist

for residual urine and other evidence of risk factors, and offered appropriate treatment and guidance.

1.7.3.4 The general principles of care for people with long-term urinary catheters, as described in the NICE guideline on prevention of healthcare-associated infection in primary and community care (see Section 6) should be followed. Of particular note in treating a person with MS are:

Long-term indwelling catheters should:

- be used only after all reasonable non-invasive methods have been tried
- be reviewed regularly, to check whether alternative less invasive methods can be used.

Drainage systems from the catheter should:

- be emptied regularly, before the bag is over-full
- bladder installations and wash-outs should not be routinely used.

1.7.4 Bowel problems

1.7.4.1 Each professional in contact with a person with MS should consider whether the person has any problems controlling bowel function. Potential problems include urgency, difficulty, pain, constipation or incontinence.

1.7.4.2 Any person with MS who has apparent constipation (pain on or difficulty with defecation, bowels open less than twice a week) should be offered advice on fluid intake and dietary changes that might help, and then be considered for oral laxatives.

1.7.4.3 Any individual with faecal incontinence should be assessed for constipation with overflow, possibly exacerbated by laxative use.

1.7.4.4 If a person with MS has apparent constipation (pain on or difficulty with defecation, bowels open less than twice a week) despite treatment with oral

laxatives, he or she should be considered for the routine use of suppositories or enemas.

1.7.5 Weakness and cardio-respiratory fitness

1.7.5.1 Each professional in contact with a person with MS should consider whether muscular weakness is a significant problem, or contributing factor, to the person's current clinical state. If so, the person should be assessed to determine the nature and cause of the weakness.

1.7.5.2 People with a limitation of their activities should be assessed for weakness of voluntary motor control using a valid technique.

People with motor weakness should be shown and advised to undertake exercises and techniques to maximise strength and endurance appropriate to their circumstances, including aerobic training.

Usually, specific exercises should be selected and explained by a neuro-physiotherapist.

1.7.5.3 People with motor weakness should be taught techniques and given equipment, such as orthoses, needed to optimise performance of activities appropriate to their circumstances.

1.7.5.4 People with weakness sufficient to cause postural abnormalities should be assessed for specialist supportive equipment, including but not limited to seating.

1.7.6 Spasticity and spasms

1.7.6.1 Each professional in contact with a person with MS who has any muscle weakness should consider whether spasticity or spasms are a significant problem, or a contributing factor, to the person's current clinical state.

1.7.6.2 If spasticity or spasms are present, then simple causative or aggravating factors such as pain and infection should be sought and treated.

1.7.6.3 Every person with MS who has persistent spasticity and/or spasms should be seen by a neuro-physiotherapist to assess and advise on physical techniques, such as passive stretching and other physical techniques, to reduce spasticity and especially to avoid the development of contractures. Families and carers should be taught how to prevent problems worsening, and a monitoring system should be put in place.

1.7.6.4 More active specific measures should be considered only if the spasms or spasticity are causing pain or distress, or are limiting (further) the individual's dependence and activities. In this case, both benefits and risks should be considered carefully. A specific goal (or goals) should be set, but will rarely include improved performance in activities.

1.7.6.5 Initial specific pharmacological treatment for bothersome regional or global spasticity or spasms should be with baclofen or gabapentin. The following should be given only if treatment with baclofen or gabapentin is unsuccessful or side effects are intolerable:

- tizanidine
- diazepam
- clonazepam, or
- dantrolene.

Combinations of medicines, and other medicines such as anticonvulsants, should only be used after seeking further specialist advice.

1.7.6.6 People with MS who have troublesome spasticity and spasms unresponsive to simpler treatments should be seen by a team specialising in the assessment and management of spasticity. The team should consider using one or more of the following:

- standing and weight-bearing through legs
- splints

- serial casting
- special or customised seating, such as tilt-in-space chairs
- intrathecal baclofen
- phenol injections to motor points or intrathecally.

1.7.6.7 Intramuscular botulinum toxin should not be used routinely, but can be considered for relatively localised hypertonia or spasticity that is not responding to other treatments. It should be used when specific goals can be identified, and:

- in the context of a specialist service that can consider all aspects of rehabilitation (for example, seating)
- by someone with appropriate experience and expertise
- followed by active input from a neuro-physiotherapist.

1.7.7 Contractures at joints

1.7.7.1 Any person with MS who has weakness and/or spasticity sufficient to limit the regular daily range of movement around a joint should be considered at risk of developing a contracture at that joint, and should be considered for preventative measures.

1.7.7.2 Any person with MS at risk of developing contractures should have the underlying impairments assessed and ameliorated if possible (see sections on weakness [1.7.5] and spasticity [1.7.6]).

1.7.7.3 Any person with MS at risk of developing contractures should be informed; the individual, and or carer(s) should be taught how to undertake preventative measures, such as regular passive stretching of the joint(s) at risk and appropriate positioning of limbs at rest. In more severe instances, specialist advice should be obtained on seating and positioning, including positioning in bed.

1.7.7.4 Any person with MS who develops a contracture should be assessed by a suitable specialist for specific treatment; the assessment should take into account the problems caused by the contracture, the discomfort and risk of any treatment and the wishes of the person. At the same time, renewed efforts should be made to reduce the underlying causes and to prevent further contracture.

1.7.7.5 Specific treatment modalities to be considered should include prolonged stretching using:

- serial plaster casts
- other similar methods, such as standing in a standing frame and using removable splints.

These are usually combined with:

- local botulinum toxin injection, and
- surgery when necessary.

1.7.8 Ataxia and tremor

1.7.8.1 Any person with MS who experiences a limitation of activities due to tremor should be assessed:

- by a specialist rehabilitation team for medicines, treatment techniques and equipment (using the general principles of goal setting and evaluation recommended) and, if problems remain severe and intractable, the person should be assessed:
- by a neurosurgical team from a specialist centre, for suitability for an operation to reduce ataxia (after being given a full explanation of its major risks and possible benefits).

1.7.9 Sensory losses

1.7.9.1 Any person with MS who experiences a limitation of activities not otherwise explained should be assessed for sensory losses.

1.7.9.2 Any person with sensory disturbance sufficient to limit activities should be seen and assessed by a specialist rehabilitation team; the individual should be given advice on techniques and equipment to ameliorate their limitations, and advice on personal safety.

1.7.10 Visual problems

Difficulty in reading or seeing television is not uncommon, and the usual reason (other than the lack of glasses) is that the control over eye movement is poor. Actual loss of visual function due to optic neuritis is rare.

1.7.10.1 Each professional in contact with a person with MS should consider whether the individual's vision is disturbed, by considering, for example, the individual's ability to read the text of a newspaper, book or other written material and to see the television.

1.7.10.2 Any person with MS who is unable to read normal print or to see the television should be assessed for glasses by an optometrist.

1.7.10.3 Any individual who experiences reduced visual acuity, despite using suitable glasses, should be assessed in a specialist ophthalmology clinic.

1.7.10.4 Any person with MS who has nystagmus that causes reduced visual acuity or other visual symptoms should be offered a time-limited trial of treatment with oral gabapentin. This should be initiated and monitored by a suitable specialist.

1.7.10.5 Any person with MS who is unable to read (due to low visual acuity) or to see television, despite all available treatment, should be:

- assessed for low-vision equipment and adaptive technology
- referred to the appropriate specialist social services team
- registered as partially sighted.

1.7.11 Pain

Pain may arise either directly from the neurological damage (neuropathic pain) or from musculoskeletal problems due to reduced mobility. People with MS may also have pain from unrelated causes.

1.7.11.1 Each professional in contact with a person with MS should ask whether pain is a significant problem for the person, or whether it is a contributing factor to their current clinical state.

1.7.11.2 All pain, including hypersensitivity and spontaneous sharp pain, suffered by a person with MS should be subject to full clinical diagnosis, including a referral to an appropriate specialist service if needed.

Musculoskeletal pain

1.7.11.3 Every person with MS who has musculoskeletal pain secondary to reduced or abnormal movement should be assessed by specialist therapists to see whether exercise, passive movement, better seating or other procedures might be of benefit.

1.7.11.4 If non-pharmacological means are proving unsuccessful in managing the musculoskeletal pain (arising from reduced movement and/or abnormal posture), the individual should be offered appropriate analgesic medicines.

1.7.11.5 Any person with MS who has continuing unresolved secondary musculoskeletal pain should be considered for transcutaneous nerve stimulation or antidepressant medication.

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

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

Neuropathic pain

1.7.11.8 Neuropathic pain, characterised by its sharp and often shooting nature, and any painful hypersensitivity, should be treated using anticonvulsants such as carbamazepine or gabapentin, or using antidepressants such as amitriptyline.

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

1.7.12 Cognitive losses

About half of all people with MS may have impaired ability to learn and remember, to plan, to concentrate and to handle information quickly. The relatively high frequency of these losses is often not appreciated by clinicians, but equally must not be assumed.

1.7.12.1 Healthcare staff should always consider whether the person with MS has any impairment of attention, memory and executive functions sufficient to be a problem, or to be a contributing factor to their current clinical status.

1.7.12.2 When a person with MS is being involved in making a complex medical decision, or is starting a course of complex treatment that requires their active participation, they should have their cognition sensitively assessed to ascertain their ability to understand and participate adequately, and to determine what support they may need.

1.7.12.3 Any person with MS experiencing problems due to cognitive impairment should:

- have their medication reviewed, to minimise iatrogenic cognitive losses
- be assessed for depression, and treated if appropriate.

1.7.12.4 Any person with MS complaining of cognitive problems, and any person where this is suspected clinically, should be:

- offered a formal cognitive assessment, coupled with specialist advice on the implications of the results
- advised, if necessary, about any vulnerability to financial or other abuse that may arise, and how to reduce the risk

- asked whether the results can be communicated to other people.

1.7.12.5 Any person with MS whose level of dependence or whose social behaviour cannot be easily understood in terms of other known impairments or factors should be offered a formal neuro-psychological assessment by a specialist clinical psychologist (and speech and language therapist if appropriate); it should be investigated whether cognitive or communicative losses are a contributing factor and, if so, appropriate management should be recommended.

1.7.13 Emotionalism

1.7.13.1 A person with MS may comment (or it may be noticed) that they may cry or laugh with minimal provocation and with little control; the individual should be offered a full assessment of their emotional state by someone with suitable expertise.

1.7.13.2 If the emotionalism is sufficient to cause concern or distress to the person with MS, or their family, then treatment with an antidepressant should be offered:

- usually a tricyclic antidepressant, or
- a selective serotonin re-uptake inhibitor.

1.7.13.3 If the person with MS still has uncontrolled emotionalism, is unwilling or unable to take antidepressants or is not responsive to antidepressants, then advice on behavioural management strategies should be offered by a suitable expert.

1.7.14 Depression

1.7.14.1 If depression is suspected, the person with MS should be assessed:

- by asking "Do you feel depressed?", or using a similar screening method
- clinically if necessary
- by a liaison psychiatrist if severe depression is present.

1.7.14.2 In any person with MS who is depressed, a list of possible contributing factors (such as chronic pain and social isolation) should be drawn up.

1.7.14.3 Assessment and interventions should be undertaken to ameliorate those contributing factors, where possible.

1.7.14.4 Specific antidepressant medication, or psychological treatments such as cognitive behavioural therapy, should be considered, but only as part of an overall programme of depression management.

1.7.14.5 Other concurrent psychological diagnoses, especially anxiety, should be considered.

1.7.15 Anxiety

1.7.15.1 Any person with MS whose function or happiness is being adversely affected by anxiety should be offered specialist assessment and management.

1.7.15.2 In people with MS with marked anxiety, psychologically based treatment should be offered.

1.7.15.3 Pharmacological treatment of anxiety should be through using antidepressants or benzodiazepines. The Committee on Safety of Medicines (CSM) guidelines on the use of benzodiazepines (reproduced in the *British National Formulary*) should be used.

1.7.16 Swallowing difficulties

Dysphagia (disturbance of swallowing) may lead to choking and aspiration of food or liquid into the lungs. It is more common in those with severe impairment. Facilities for the insertion of percutaneous endoscopic gastrostomy (PEG) tubes are widely available.

1.7.16.1 Any person with MS who is unable to transfer from bed to chair independently or who has any symptoms or signs of bulbar dysfunction such as any abnormality of eye movements, slurring of speech or ataxia, should be asked whether they have difficulties with chewing, or swallowing food or fluids (for

example, coughing), also whether they have altered their diet because of previous problems.

1.7.16.2 Any person with MS with any bulbar symptoms or signs, and any person with MS who has a chest infection, should have their swallowing assessed by a competent person (using a standardised swallowing test).

1.7.16.3 People with MS who, on formal assessment, have an abnormality of swallowing should be further assessed by a specialist speech and language therapist. Advice should be given on specific swallowing techniques, and on adapting food consistencies and dietary intake. Further diagnostic assessment (for example, by videofluoroscopy) should be undertaken if:

- first-line therapy and advice are ineffective
- a specific objective of the investigation can be identified.

1.7.16.4 Any person with MS who has difficulty swallowing for more than a few days should be assessed by a neurological rehabilitation team, to review the need for:

- adjustments to or provision of seating that will increase ease and safety of swallowing and feeding
- chest physiotherapy
- short-term use of nasogastric tube, especially if recovery is anticipated.

1.7.16.5 Any person with MS who has swallowing difficulties for more than 1 month should have his or her weight or nutritional status checked on a monthly basis (using a validated nutritional measure if needed). Dietary intake should be reviewed if there is continuing weight loss or evidence of malnutrition.

1.7.16.6 If PEG feeding is anticipated as being a likely future option, discussions with the person with MS should be commenced at an early stage and their wishes documented.

1.7.16.7 If swallowing difficulties persist, a PEG tube should be considered if any of the following occur:

- recurrent chest infections
- inadequate food and/or fluid intake
- prolonged or distressing feeding
- nasogastric tube in situ for over 1 month.

1.7.16.8 If PEG placement is indicated and agreed, the PEG tube should be inserted by a suitable specialist. Before the person with MS is discharged from hospital, full training should be given to any family members and carers who are going to be involved in feeding.

1.7.17 Speech difficulties

1.7.17.1 Any person with MS who has dysarthria sufficient to affect communication with people outside the home or over the phone, and any person who is concerned about their speech sound or clarity, should be assessed and given advice by a specialist speech and language therapist.

1.7.17.2 Any person with MS whose ability to communicate is affected significantly by dysarthria should be taught techniques to improve and maintain speech production and clarity; tuition should be provided by a specialist speech and language therapist, working with any other members of the neurological rehabilitation service who are involved.

1.7.17.3 Any person who continues to have difficulties in communication should be considered for, and if appropriate taught the use of, alternative non-verbal means of assisting with or replacing speech.

1.7.17.4 Any person with MS who cannot communicate effectively should be assessed by a specialist speech and language therapist for an augmentative aid to communication, which should then be provided as soon as possible. The family members, carers and other frequent communicators with any person with MS who has significant communication difficulties should have

discussions with the speech and language therapist on how best to help the person communicate.

1.7.18 Sexual dysfunction

MS may disturb the normal sexual physiology, and it may result in other impairments (such as spasms) that make normal sexual behaviour difficult. These may make it difficult for the person to establish or maintain partnership relations. Both aspects are important and should be considered together.

Male sexual function

1.7.18.1 Men with MS:

- should be asked whether they experience erectile dysfunction (relative or absolute) and, if so, whether it is of concern
- who have persisting erectile dysfunction and who do not have contraindications should be offered sildenafil 25–100 mg
- who do not respond to sildenafil should be assessed for the general and specific factors that might cause or worsen erectile dysfunction and that are amenable to treatment (such as depression, anxiety, vascular disease, diabetes and taking medicines that may cause erectile dysfunction). Other specific treatments such as alprostadil or intra-cavernosal papaverine should then be considered.

Female sexual function

1.7.18.2 Women with MS should be asked whether they experience sexual dysfunction (such as failure of arousal or lubrication or anorgasmia) and, if so, whether it is of concern.

1.7.18.3 Women with sexual dysfunction should be assessed for the general and specific factors that might cause or worsen sexual dysfunction and that are amenable to treatment (such as depression, anxiety, vascular disease, diabetes and taking medicines that may cause sexual dysfunction).

Partnership relations

1.7.18.4 Every person (or couple) with MS should be asked sensitively about, or given the opportunity to remark upon, any difficulties they may be having in establishing and/or maintaining wanted sexual and personal relationships; they should be offered information about locally available counselling and supportive services.

1.7.18.5 Every person (or couple) with persisting sexual dysfunction should be offered the opportunity to see a specialist (with particular expertise in sexual problems associated with neurological disease) and offered, as appropriate, advice on lubricants and the use of sexual aids, and other advice to ameliorate their sexual dysfunction.

1.7.19 Pressure ulcers

A pressure ulcer (decubitus ulcer or pressure sore) is an area of broken skin that is secondary to unrelieved pressure on the skin, often exacerbated by slight trauma – for example, when being moved. Pressure ulcers may range from minor breaks to very large deep areas of dead tissues extending over many square centimetres and down to bone. Once present they can be difficult to heal, and can cause general malaise and worsening of most impairments, and they carry a risk of generalised or localised infections. Many people with MS are at high risk of developing pressure ulcers because they may have, for example, limited mobility, impairment of sensory functioning and reduced cognitive function. Most pressure ulcers can be avoided by good anticipatory management. (See also the NICE Clinical Guideline on prevention of pressure ulcers [referenced in Section 6].)

1.7.19.1 Every person with MS who uses a wheelchair should be assessed for their risk of developing a pressure ulcer. The individual should be informed of the risk, and offered appropriate advice.

1.7.19.2 Every person with MS who uses a wheelchair daily should be assessed by a suitably trained person, whenever they are admitted to hospital (for whatever reason), for their need for pressure-relieving devices and procedures. The assessment should be clinical, specifically taking into account the risk features associated with MS, and not simply the recording of a pressure ulcer risk score; it should lead to the development and documentation of an action plan to minimise risk, including:

- optimisation of nutritional status
- provision of suitable equipment
- documentation of agreed manual handling techniques.

1.7.19.3 Every person with MS who is provided with a wheelchair by a statutory organisation (NHS or social services), or whose wheelchair seating is being reassessed, should specifically be considered for pressure-relieving procedures and devices – not only in the wheelchair, but in all other activities, especially transfers and sleeping.

1.7.19.4 For every person with MS considered to be at risk on their bed (in hospital or in the community):

- an appropriate specialist mattress should be provided wherever they are lying down
- regular turning should not be depended upon as a policy for preventing pressure ulcers
- the skin areas at risk should be inspected to ensure that adequate protection is being provided.

1.7.19.5 If a pressure ulcer occurs, it should be considered an adverse event worthy of investigation, and advice should be sought from a specialist service.

1.7.19.6 Any person with MS who develops a pressure ulcer should be nursed on a low-loss mattress (while in bed). The ulcer should be dressed according to appropriate local guidelines.

1.7.20 Complementary therapies

1.7.20.1 People with MS should be informed that there is some evidence to suggest that the following items might be of benefit, although there is insufficient evidence to give more firm recommendations:

- reflexology and massage
- fish oils

- magnetic field therapy
- neural therapy
- massage plus body work
- t'ai chi
- multi-modal therapy.

1.7.20.2 A person with MS who wishes to consider or try an alternative therapy should be recommended to evaluate any alternative therapy themselves, including the risks and the costs (financial and inconvenience).

1.7.20.3 A person with MS should be encouraged to discuss any alternative treatments they are considering, and to inform their doctors and other professionals if they decide to use any.

[2] The Guideline Development Group debated the meaning of the words "in the near future". In this context, it is taken to mean that the exact time will vary according to clinical need but should be, in the opinion of the development group, no longer than 4 weeks.

[3] McDonald et al. (2001) Recommended diagnostic criteria for MS. *Annals of Neurology*; 50: 121–7

2 Notes on the scope of the guidance

All NICE guidelines are developed in accordance with a scope document that defines what the guideline will and will not cover. The scope of this guideline was established at the start of the development of this guideline, following a period of consultation.

In summary, the aim was to develop a guideline that is relevant to adults of all ages with MS, and considers the full range of care that should be routinely available from the NHS, including appropriate use of mainstream pharmacological therapy, physical therapy, rehabilitation and psychosocial treatments.

The guideline was developed for the NHS and, although it comments on the interface with other sectors, it does not consider them in detail.

3 Implementation in the NHS

3.1 In general

Local health communities should review their existing practice for multiple sclerosis against this guideline as they develop their Local Delivery Plans. The review should consider the resources required to implement the recommendations set out in Section 1, the people and processes involved, and the timing over which full implementation is envisaged. Priorities for implementation are set out at the start of this document. It is in the interests of people with MS that the implementation timeline is as rapid as possible.

Relevant local clinical guidelines, care pathways and protocols should be reviewed in the light of this guidance and revised accordingly.

This guideline should be used in conjunction with the developing National Service Framework for long-term neurological conditions, which will define the broader context of neurological services.

3.2 Audit

Suggested audit criteria are listed in Appendix D.

4 Research recommendations

The following research recommendations have been identified for this NICE guideline, not as the most important research recommendations, but as those that are most representative of the full range of recommendations. The Guideline Development Group's full set of research recommendations is detailed in the full guideline produced by the National Collaborating Centre for Chronic Conditions (see Section 5).

4.1 Epidemiology of relapses, impairments and activity limitations

4.1.1 There should be a prospective study on an epidemiologically sound defined population to establish reasonable estimates of:

- the frequency of relapses sufficient to cause increased limitation on activities
- the prevalence and yearly incidence of the most common impairments described in this guideline document
- the prevalence and yearly incidence of the most common limitations on activity including work described in this document
- the direct and indirect costs of the condition and how they relate to levels of limitation on activity, including not only NHS direct costs but all direct costs.

4.2 Diagnosing MS

4.2.1 There should be a prospective study on an epidemiologically sound population to investigate the most cost-effective protocols for investigating people presenting with (potential) MS to establish:

- the sensitivity and specificity of MRI scanning in people with different levels of clinical diagnostic certainty
- the role of other investigations in confirming or positively excluding the diagnosis of MS

- the prognostic value of MRI scan information over 5 years.

4.3 Rehabilitation assessment protocols

4.3.1 There should be a programme of research to develop and evaluate protocols, procedures or data-collection tools that can be used by any profession to:

- identify the probable presence of most common impairments
- quantify approximately activity performance in personal and household activities of daily living
- identify areas of activity limitation that are present in people with MS.

4.4 Specialist neurological rehabilitation services

4.4.1 A programme of research into the relative costs (direct and indirect) and benefits (direct and indirect) should be undertaken comparing:

- current rehabilitation practice with rehabilitation given by a specialist neurological rehabilitation service
- primarily inpatient with primarily outpatient or homebased neurological rehabilitation.

4.5 Acute relapse management – methylprednisolone and rehabilitation

4.5.1 A programme of research should investigate the management of acute relapse including comparing the costs and benefits associated with policies of:

- oral methylprednisilone against intravenous methylprednisolone
- hospital admission with early discharge once rehabilitation has started and support has been arranged against home care with rapid response care and rehabilitation input (with steroids if indicated).

4.6 Disease-modifying drugs

4.6.1 A programme of research into disease-modifying treatments sponsored and run by an organisation independent of either health purchasers or pharmaceutical companies should be set up to investigate interferon beta, glatiramer acetate, linoleic acid and azathiaprine (and any other newly licensed medicines) in terms of:

- benefits, specifically in terms of activity performance
- costs, including the medicines and all associated monitoring, etc.
- dis-benefits, both immediate side effects and longer-term rates of withdrawal and side effects
- effects of stopping treatment after 2 and 4 years.

4.7 Relationship between impairments and limitations in activities

4.7.1 A programme of research extending over many years should be instigated to investigate the nature and extent of relationships between impairments and activities and how they change over time.

5 Full guideline

NICE originally commissioned the Royal College of Physicians (RCP) and the Chartered Society of Physiotherapy (CSP) to develop this guideline. When the National Collaborating Centre for Chronic Conditions was formed in April 2001, it assumed the management responsibility, but with continuing leadership from the executive leads from the RCP and CSP. The Centre established a Guideline Development Group, which reviewed the evidence and developed the recommendations. The full guideline, Multiple Sclerosis – National Clinical Guidelines for NHS Management in Primary and Secondary Care, is published by the National Collaborating Centre for Chronic Conditions. The members of the Guideline Development Group are listed in Appendix B. Information about the Institute's Guideline Review Panel is given in Appendix C.

There is more information about how NICE clinical guidelines are developed on the NICE website. A booklet, 'How NICE clinical guidelines are developed: an overview for stakeholders, the public and the NHS' is available.

6 Related NICE guidance

National Institute for Clinical Excellence (2002) Multiple sclerosis – beta interferon and glatiramer acetate for the treatment of multiple sclerosis. NICE Technology Appraisal Guidance 32.

National Institute for Clinical Excellence (2002) Guidance on the use of computerised cognitive behavioural therapy for anxiety and depression. *NICE Technology Appraisal Guidance* No. 51. [Replaced by NICE technology appraisal guidance 97]

National Institute for Clinical Excellence (2003) Infection control. Prevention of healthcare-associated infection in primary and community care. NICE Clinical Guideline 2.

National Institute for Clinical Excellence (2003) Pressure ulcer prevention. Pressure ulcer risk assessment and prevention, including the use of pressure-relieving devices (beds, mattresses and overlays) for the prevention of pressure ulcers in primary and secondary care. *NICE Clinical Guideline 6*. [Replaced by NICE clinical guideline 62]

Anxiety. NICE clinical guideline 113. (2011)

Depression in adults. NICE clinical guideline 90 (2009)

Pressure ulcer management. NICE clinical guideline 29 (2005)

7 Review date

The process of reviewing the evidence is expected to begin 4 years after the date of issue of this guideline. Reviewing may begin earlier than 4 years if significant evidence that affects the guideline recommendations is identified sooner. The updated guideline will be available within 2 years of the start of the review process.

Appendix A: Grading scheme

The recommendations in this guideline were graded according to the quality of the evidence they were based on. The gradings are available in the full guideline and are not shown in this web version.

Appendix B: The Guideline Development Group

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Consensus Reference Group

To support the development of this guideline, a Consensus Reference Group (CRG) was formed. The CRG met early in the development process to ensure that the aims and the clinical questions addressed by the guideline were appropriate. The CRG met again at the end of the process to review the recommendations drafted by the Guideline Development Group. The group used formal consensus techniques in their consideration of clinically important areas where there was insufficient evidence or disagreement over the interpretation of the evidence.

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Appendix C: The Guideline Review Panel

The Guideline Review Panel is an independent panel that oversees the development of the guideline and takes responsibility for monitoring its quality. The Panel includes experts on guideline methodology, health professionals and people with experience of the issues affecting patients and carers. The members of the Guideline Review Panel were as follows.

Dr Bernard Higgins (Chair)
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Dr Robert Higgins
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Dr Marcia Kelson
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Dame Helena Shovelton
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Fiona Wise
Acting Director of Modernisation Bedfordshire and Hertfordshire Strategic Health Authority

Dr John Young
Medical Director MSD Limited

Appendix D: Technical detail on the criteria for audit

The full guideline contains the technical detail on the criteria for audit.

Appendix E: Supplementary information

Table 1 Principles of good communication in healthcare

Principle	Comment
In any communication the healthcare professional should:	
Communicate in a suitable environment, usually a quiet area or room free from distraction or interruption	Privacy and quiet are important
Seek agreement from the person with MS that anyone present can be there and ensure that as far as possible anyone she or he wants present is there	Consider especially students and family
Start by asking what the person knows or believes already	Establishes expectations
Establish the nature and extent of the information that the person wishes to receive	Establishes expectations
Consider carefully the balance between the benefits and the risks associated with giving each item of information	Once given, information cannot be withdrawn
Tailor the communication to the person's: • specific situation • communicative and cognitive abilities • culture	Makes information relevant
Limit information given to that within their own knowledge, referring on to others as necessary for more detailed information	Do not give information if uncertain about it
Clarify specifically any options and choices the person may need to choose, specifying: • likely outcomes of each choice • benefits and risks of each choice	Both in diagnosis and treatment

Offer back-up with information being given: • in different ways (e.g. written leaflets, tapes) • by different people (e.g. specialist nurse) • at another time (e.g. follow-up appointment)	Information is often forgotten
Inform the person with MS about any recommended local or national sources of further information, including employment and voluntary sector sources	Allows person with MS to follow up and take more control
Consider need for emotional support during process especially if the information might be stressful, and arrange emotional support if needed.	Should be considered an intrinsic part of the process. (See 1.1.2.1)
Document in notes and inform other healthcare staff closely involved what has been communicated, especially the general practitioner.	Ensures consistency over time and across settings

Table 2: review checklist

This is not a list of questions to be asked of every person with MS on every occasion. It is a list to remind clinicians of the wide range of potential problems that people with MS may face, and which should be actively considered as appropriate. A positive answer should lead to more detailed assessment and management. (See Sections 1.6 and 1.7.)

Initial question
It is best to start by asking an open-ended question such as: "Since you were last seen or assessed has any activity you used to undertake been limited, stopped or affected?"

Activity domains

Then, especially if nothing has been identified, it is worth asking questions directly, choosing from the list below those appropriate to the situation based on your knowledge of the person with MS:

"Are you still able to undertake, as far as you wish:

- vocational activities (work, education, other occupation)?
- leisure activities?
- family roles?
- shopping and other community activities?
- household and domestic activities?
- washing, dressing, using toilet?
- getting about (either by walking or in other ways) and getting in and out of your house?
- controlling your environment (opening doors, switching things on and off, using the phone)?"

If restrictions are identified, then the reasons for these should be identified as far as possible considering impairments (see below), and social and physical factors (contexts).

Common impairments

It is worth asking about specific impairments from the list below, again adapting to the situation and what you already know:

"Since you were last seen have you developed any new problems with:

- fatigue, endurance, being overtired?
- speech and communication?
- balance and falling?
- chewing and swallowing food and drink?
- unintended change in weight?
- pain or painful abnormal sensations?
- control over your bladder or bowels?
- control over your movement?
- vision and your eyes?
- thinking, remembering?
- your mood?
- your sexual function or partnership relations?
- how you get on in social situations?"

Final question

Finally, it is always worth finishing with a further open-ended question:

"Are there any other new problems that you think might be due to MS that concern you?"

Table 3 Summary of the criteria suggested by the Association of British Neurologists and agreed by the Department of Health to determine eligibility for treatment using interferon beta and glatiramer acetate for people with MS within the 'risk-sharing scheme'

A. People with **relapsing/remitting MS** should be offered **interferon beta** (any type) provided that the following four conditions are met:

- can walk 100 metres or more without assistance
- have had at least two clinically significant relapses in the past 2 years
- are aged 18 years or older
- do not have contraindications (see specific Summary of Product Characteristics [SPC] for details)

B. People with **relapsing/remitting MS** should be offered **glatiramer acetate** provided that the following four conditions are met:

- can walk 100 metres or more without assistance
- have had at least two clinically significant relapses in the past 2 years
- are aged 18 years or older
- do not have contraindications (see SPC for details)

C. People with **secondary progressive MS** should be offered **interferon beta** (any type licensed for this use) provided the following conditions are met:

- can walk 10 metres or more with or without assistance
- have had at least two disabling relapses in the past 2 years
- have had minimal increase in disability due to gradual progression over the past 2 years
- are aged over 18 years
- do not have contraindications (see specific SPC for details)

D. People with MS offered treatment with **interferon beta** should have the following **stopping criteria** discussed and agreed before starting treatment:

- intolerable side effects
- becoming or trying to become pregnant
- occurrence of two disabling relapses within a 12-month period
- secondary progression with an observable increase in disability over a 6-month period
- loss of ability to walk, with or without assistance, that has persisted for longer than 6 months

E. People with relapsing–remitting MS offered treatment with **glatiramer acetate** should have the following **stopping criteria** discussed and agreed before starting treatment:

- intolerable side effects
- being pregnant or planning pregnancy
- occurrence of two disabling relapses within a 12-month period
- development of secondary progressive MS
- loss of ability to walk, with or without assistance, that has persisted for longer than 6 months.

Appendix F: Diagnosis of multiple sclerosis

The full guideline contains this information.

About this guideline

NICE clinical guidelines are recommendations about the treatment and care of people with specific diseases and conditions in the NHS in England and Wales.

The guideline was developed by the National Collaborating Centre for Chronic Conditions. The Collaborating Centre worked with a group of healthcare professionals (including consultants, GPs and nurses), patients and carers, and technical staff, who reviewed the evidence and drafted the recommendations. The recommendations were finalised after public consultation.

The methods and processes for developing NICE clinical guidelines are described in The guidelines manual.

We have produced information for the public explaining this guideline. Tools to help you put the guideline into practice and information about the evidence it is based on are also available.

Changes after publication

March 2012: minor maintenance.

December 2013: minor maintenance.

Your responsibility

This guidance represents the view of NICE, which was arrived at after careful consideration of the evidence available. Healthcare professionals are expected to take it fully into account when exercising their clinical judgement. However, the guidance does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer, and informed by the summary of product characteristics of any drugs they are considering.

Implementation of this guidance is the responsibility of local commissioners and/or providers. Commissioners and providers are reminded that it is their responsibility to implement the guidance, in their local context, in light of their duties to avoid unlawful discrimination and to have regard to promoting equality of opportunity. Nothing in this guidance should be interpreted in a way that would be inconsistent with compliance with those duties.

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