NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline

Multiple sclerosis in adults: management

Draft for consultation, December 2021

This guideline covers diagnosing and managing multiple sclerosis in people aged 18 and over. It aims to improve the quality of life for adults with multiple sclerosis by promoting symptom management, comprehensive reviews and effective relapse treatment.

The guideline does not cover disease-modifying treatments. These are covered by the technology appraisals on NICE's webpage on multiple sclerosis.

This guideline will update NICE guideline CG186 (published October 2014).

Who is it for?

- Healthcare professionals
- Social care practitioners
- Commissioners and providers
- Adults with multiple sclerosis and their families and carers

What does it include?

- the recommendations
- recommendations for research
- rationale and impact sections that explain why the committee made the 2022 recommendations and how they might affect practice
- the guideline context.

Information about how the guideline was developed is on the guideline's webpage. This includes the evidence reviews, the scope, details of the committee and any declarations of interest.

New and updated recommendations

We have reviewed the evidence on diagnosis, information and support, symptom management and rehabilitation, coordination of care and the role of multiple sclerosis nurse specialists. You are invited to comment on the new and updated recommendations. These are marked as **[2022]**.

You are also invited to comment on recommendations that we propose to delete from the 2014 guideline.

We have not reviewed the evidence for the recommendations shaded in grey, and cannot accept comments on them. In some cases, we have made minor wording changes for clarification.

See update information for a full explanation of what is being updated.

Full details of the evidence and the committee's discussion on the 2022 recommendations are in the evidence reviews. Evidence for the 2014 recommendations is in the full version of the 2014 guideline.

Contents

Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in NICE's information on making decisions about your care.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

1.1 Diagnosing multiple sclerosis

Recognising multiple sclerosis

See also NICE's guideline on suspected neurological conditions: recognition and referral for advice for non-specialists on initial assessment of symptoms and signs that might indicate a neurological condition.

1.1.1 Be aware that people with multiple sclerosis (MS) may present with a wide range of symptoms affecting different parts of the body. The most common are:

- loss or reduction of vision in 1 eye with painful eye movements
- double vision
- ascending sensory disturbance and/or weakness
- problems with balance, unsteadiness or clumsiness
- altered sensation or pain travelling down the back and sometimes into the limbs when bending the neck forwards (Lhermitte's symptom).

[2022]

1.1.2 Be aware that usually people with MS present with neurological symptoms or signs as described in recommendation 1.1.1, and:

- are often aged under 50 **and**
- may have a history of previous neurological symptoms **and**

- have symptoms that have evolved over more than 24 hours **and**
- have symptoms that may persist over several days or weeks and then improve **and**
- do not have fever or infection. **[2022]**

1.1.3 Do not routinely suspect MS if a person's main symptoms are fatigue, depression, dizziness or vague sensory phenomena, unless they have a history or evidence of focal neurological symptoms or signs. **[2022]**

1.1.4 Before referring a person suspected of having MS to a neurologist, confirm that this is a neurological episode by taking a history, assessing the person and excluding alternative, more common diagnoses. **[2022]**

Referral and diagnosis

1.1.5 Refer people suspected of having MS to a consultant neurologist for confirmation of the diagnosis. Contact the consultant neurologist directly if you think a person needs to be seen urgently. **[2022]**

1.1.6 Diagnose MS using a combination of history, examination, MRI and laboratory findings, and by following the 2017 revised McDonald criteria, after:

- assessing that symptoms are consistent with an inflammatory demyelinating process; for example, headache is not suggestive of MS
- excluding alternative diagnoses (targeted laboratory tests to exclude MS mimics may be indicated if the history, examination or MRI findings are atypical)
- establishing that lesions on MRI scans have developed at different times and are in different anatomical locations for a diagnosis of relapsing–remitting MS
- looking for cerebrospinal fluid-specific oligoclonal bands if there is no clinical or radiological evidence of lesions developing at different times
- establishing progressive neurological deterioration over 1 year or more for a diagnosis of primary progressive MS. **[2022]**

1.1.7 If MS is suspected but the McDonald criteria are not completely met, plan a review to reassess the possibility of MS. Discuss the timing of this and future reviews with the person (for example, annually) and ensure that they know who to contact for advice if they develop further neurological symptoms or if current symptoms worsen. **[2022]**

1.1.8 Do not diagnose MS on the basis of MRI findings alone. **[2022]**

1.1.9 Offer people with confirmed MS information and advice on resources and support. For further details, see the section on information and support at the time of diagnosis. **[2022]**

For a short explanation of why the committee made the 2022 recommendation see the rationale and impact section on diagnosing multiple sclerosis.

Full details of the committee's discussion are in the committee discussion for diagnostic criteria.

Optic neuritis and neuromyelitis optica spectrum disorder

1.1.10 If a person has an episode of isolated, optic neuritis, confirmed by an ophthalmologist, refer them to a consultant neurologist for further assessment. **[2014]**

1.1.11 Diagnosis of neuromyelitis optica spectrum disorder should be made by an appropriate specialist based on established up-to-date criteria. **[2014]**

1.2 Providing information and support

For advice on communication and information follow the recommendations in NICE's guideline on patient experience in adult NHS services. For advice on shared decision making, follow the recommendations in NICE's guideline on shared decision making.

Information and support at the time of diagnosis

1.2.1 The consultant neurologist should ensure that people with MS, and with their agreement their family members or carers, are offered oral and

written information at the time of diagnosis. This should include, but not be limited to, information about:

- what MS is
- treatments, including disease-modifying therapies
- symptom management
- how support groups, local services, social services and national charities are organised and how to get in touch with them
- online resources
- legal requirements such as notifying the Driver and Vehicle Licensing Agency (DVLA) and legal rights including social care, employment rights and benefits. **[2014, amended 2021]**

1.2.2 Discuss with the person with MS and their family members or carers whether they have social care needs and if so refer them to social services for assessment. Ensure the needs of children of people with MS are addressed. **[2014]**

1.2.3 Offer the person with MS a face-to-face follow-up appointment with a healthcare professional with expertise in MS to take place within 6 weeks of diagnosis. **[2014]**

Ongoing information and support

1.2.4 Explain to people with MS that they should have a comprehensive review of their care at least once a year and what this should cover (see the

section on comprehensive review). Advise them to ask their healthcare professional for a review if it has not taken place. **[2022]**

1.2.5 Review information, support and social care needs regularly. Continue to offer information and support to people with MS or their family members or carers even if this has been declined previously. **[2014]**

1.2.6 Ensure people with MS and their family members or carers have a management plan that includes who to contact if their symptoms change significantly. **[2014]**

1.2.7 Explain to people with MS that the possible causes of symptom changes include:

- another illness such as an infection
- further relapse
- change of disease status (for example progression). **[2014]**

1.2.8 Talk to people with MS and their family members or carers about the possibility that the condition might lead to cognitive problems. **[2014]**

1.2.9 Provide ongoing information and support tailored to the person's changing needs or circumstances, for example, for people planning to have children or for people as their MS becomes more advanced. **[2022]**

1.2.10 Explain to carers (including young carers) about their right to a carer's assessment and tell them about other sources of information and support

that may be available (see NICE's guideline on supporting adult carers and the Young Carers [Needs Assessment] Regulations 2015). **[2022]**

Information and support for people planning to have children or who are pregnant

1.2.11 Ask the person with MS soon after diagnosis and at regular intervals if they have any plans for starting or extending their family now or in the future, either through pregnancy or adoption. **[2022]**

1.2.12 Explain to people with MS, and their partners if appropriate, that MS should not stop them from planning a family. Advise them that:

- fertility is not affected by MS
- pregnancy can be well managed in people with MS
- support may be available with caring for and supporting children. **[2022]**

1.2.13 Discuss caring for a child and the possible impact of MS symptoms, such as fatigue, and how these could be managed. **[2022]**

1.2.14 If a person with MS is thinking about or planning pregnancy, or is pregnant, offer the opportunity to talk with a healthcare professional with knowledge of MS to answer any questions they have. For example, this may include discussing the following, as appropriate:

- the risk of the child developing MS
- taking vitamin D supplements before and during pregnancy (see NICE's guideline on vitamin D)
- taking folic acid supplements before and during pregnancy (see NICE's guideline on maternal and child nutrition)
- possible changes to medicine use before and during pregnancy
- that pregnancy does not increase the risk of disease progression
- that relapses may decrease during pregnancy and may increase 3 to 6 months after childbirth before returning to pre-pregnancy rates

- that birth options and pain relief choices available (including epidurals) should not be affected by MS
- that breastfeeding is safe for people with MS. **[2022]**

Information and support for people as MS becomes more advanced, including those approaching the end of their life

1.2.15 Give people with MS that is becoming more advanced and their family members or carers information and support covering:

- social isolation and feelings of depression
- mobility aids and home adaptations
- other support available, such as legal rights including social care, employment rights and benefits, and the right to a carer's assessment (see recommendation 1.2.6). **[2022]**

1.2.16 Explain to people with advanced MS and their family members or carers about the services available (for example, occupational therapy, palliative care and social services) and give them support to access them if needed. **[2022]**

1.2.17 For advice on identifying people who may be approaching the end of their life and providing information and support, follow the recommendations in NICE's guideline on end of life care for adults. **[2022]**

1.2.18 When appropriate, explain to the person with MS (and their family members or carers if the person wishes) about advance care planning and power of attorney. Follow the recommendations on advance care planning in NICE's guideline on decision-making and mental capacity. **[2022]**

For a short explanation of why the committee made the 2022 recommendations see the rationale and impact section on providing information and support.

Full details of the evidence and the committee's discussion are in evidence review A: information and support for patients, their families and carers.

Full details of the committee's discussion on diagnostic criteria are in the committee discussion document.

1.3 Coordination of care

For general advice on continuity of care and relationships follow the recommendations in NICE's guideline on patient experience in adult NHS services.

1.3.1 Offer the person with MS an appropriate single point of contact with knowledge of MS services to coordinate care and help them access services. **[2022]**

1.3.2 Care for people with MS using a coordinated multidisciplinary approach. Involve professionals who can best meet the needs of the person with MS and who have expertise in managing MS including:

- MS nurses
- consultant neurologists
- neurological physiotherapists and occupational therapists
- speech and language therapists, psychologists, dietitians, social care, continence specialists and specialist neuropharmacists or specialist MS pharmacists
- consultants in rehabilitation medicine
- primary healthcare team. **[2014, amended 2022]**

For a short explanation of why the committee made the 2022 recommendation see the rationale and impact section on coordination of care.

Full details of the evidence and the committee's discussion are in evidence review B: coordination of care.

1.4 Modifiable risk factors for relapse or progression of MS

Exercise

1.4.1 Encourage people with MS to exercise. Advise them that regular exercise may have beneficial effects on their MS and does not have any harmful effects on their MS. **[2014]**

Smoking

1.4.2 Advise people with MS not to smoke and explain that it will increase the progression of disability. (See NICE's guideline on stop smoking interventions and services.) **[2014]**

Vaccinations

1.4.3 Offer vaccinations in line with advice from the Joint Committee on Vaccinations and Immunisation and the Green Book: Immunisation against infectious disease for people with MS and their carers. **[2014, amended 2022]**

1.5 MS symptom management and rehabilitation

The guideline does not make recommendations for all symptoms that occur in people with MS. Some symptoms are addressed in other NICE guidelines and these are referenced where relevant.

1.5.1 Determine how often the person with MS will need to be seen based on:

- their needs, and those of their family and carers **and**
- the frequency of visits needed for different types of treatment (such as review of disease-modifying therapies, rehabilitation and symptom management). **[2014]**

Fatigue

Assessment and non-pharmacological management of fatigue

1.5.2 Ask people with MS if they have fatigue. **[2022]**

1.5.3 Do not assume that fatigue is caused by MS. Assess for other causes and manage these or refer the person for management if indicated. Other causes of fatigue may include:

- sleep problems
- symptoms of MS, such as pain, spasticity and bladder dysfunction
- side effects of medicines
- illnesses, such as infections, anaemia and thyroid dysfunction
- anxiety and depression (see NICE's guidelines on generalised anxiety disorder and panic disorder in adults and depression in adults with a chronic physical health problem). **[2022]**

1.5.4 Explain that MS-related fatigue may be brought on by heat or biological, physical and emotional stress. **[2022]**

1.5.5 Offer people with MS and fatigue a personalised discussion about how they can manage fatigue. This could include:

- identifying goals and priorities
- advice on conserving their energy
- reviewing lifestyle factors such as diet and exercise
- using stress management and wellbeing approaches such as mindfulness and cognitive behavioural techniques to help with day-to-day activities. **[2022]**

1.5.6 Advise people that aerobic, resistive and balance exercises, including yoga and pilates, may be helpful in treating MS-related fatigue. **[2022]**

1.5.7 Explain to people that there is no evidence that a specific diet will improve fatigue in people with MS, but that a healthy diet will benefit their general health. **[2022]**

1.5.8 For people with MS with moderately impaired mobility (an EDSS [Expanded Disability Status Scale] score of greater than or equal to 4), consider a combination of:

- a programme of supervised aerobic and moderate progressive resistance activity **and**
- cognitive behavioural techniques. [2022]

1.5.9 Do not use vitamin B12 injections to treat fatigue in people with MS. **[2014]**

1.5.10 Do not offer hyperbaric oxygen to treat fatigue in people with MS. **[2022]**

See also the recommendations in the section on non-pharmacological management of mobility problems and fatigue.

For a short explanation of why the committee made the 2022 recommendations see the rationale and impact section on assessment and non-pharmacological management of fatigue.

Full details of the evidence and the committee's discussion are in evidence review C: non-pharmacological management of fatigue.

Pharmacological management of fatigue

1.5.11 Discuss with the person with MS whether a medicine to treat fatigue might be an option for them. Explain the risks and benefits of the possible

treatments and use shared decision making to decide whether they wish to try a medicine, and which one would be most suitable for them. **[2022]**

1.5.12 If a person with MS wishes to try a medicine for fatigue, consider any of the following options, taking into account the person's needs and preferences:

- amantadine
- modafinil (except in pregnant women and those planning pregnancy)
- a selective serotonin reuptake inhibitor (SSRI).

See box 1 for recommended dosages. **[2022]**

In December 2021 this was an off-label use of amantadine, modafinil and SSRIs. See NICE's information on prescribing medicines. See also the 2020 Medicines and Healthcare products Regulatory Agency (MHRA) drug safety update on modafinil (Provigil): increased risk of congenital malformations if used during pregnancy.

Box 1 Dosages of amantadine, modafinil and SSRIs to treat MS-related fatigue

Amantadine:

- initial dose 100 mg taken in the morning
- increase to 100 mg in the morning and 100 mg at midday if needed and tolerated.

Modafinil:

- initial dose 100 mg once daily
- increase to 200 mg in the morning and up to 200 mg at midday if needed and tolerated.

SSRIs: use the lowest dose recommended for licensed indications.

Note: treatment response should be monitored to adjust the dose and to decide whether to continue or stop the medication.

For a short explanation of why the committee made these recommendations, see the rationale and impact section on pharmacological management of fatigue.

Full details of the evidence and the committee's discussion are in evidence review D: pharmacological management of fatigue.

Mobility problems

See also recommendation 1.4.1 for advice on encouraging exercise in people with MS.

1.5.13 Ensure people with MS and mobility problems have access to an assessment to establish individual goals and discuss ways to achieve them. This would usually involve rehabilitation specialists and physiotherapists with expertise in MS. **[2014]**

Pharmacological management of mobility problems

1.5.14 Do not offer fampridine to treat mobility problems in people with MS. Fampridine is a clinically effective treatment for some people, but it is not cost effective at the current list price. **[2022]**

This recommendation does not apply to people who have already started treatment with fampridine in the NHS who should be able to continue treatment until they and their NHS clinician think it appropriate to stop.

For a short explanation of why the committee made this recommendation see the rationale and impact section on pharmacological management of mobility problems.

Full details of the evidence and the committee's discussion are in evidence review E: pharmacological management of mobility.

Non-pharmacological management of mobility problems and fatigue

1.5.15 Consider vestibular rehabilitation for people with MS who have fatigue or mobility problems associated with limited standing balance. **[2014]**

1.5.16 Consider supervised exercise programmes involving moderate progressive resistance training and aerobic exercise to treat people with MS who have mobility problems or fatigue. **[2014]**

1.5.17 Help the person with MS continue to exercise, for example, by referring them to a physiotherapist or exercise referral schemes. **[2014, amended 2021]**

1.5.18 If more than 1 of the interventions recommended for mobility or fatigue are suitable, offer treatment based on which the person prefers and whether they can continue the activity after the treatment programme ends. **[2014]**

1.5.19 Encourage people with MS to keep exercising after treatment programmes end for longer term benefits (see NICE's guideline on behaviour change: individual approaches). **[2014]**

Spasticity

1.5.20 Suspect spasticity when a person with MS presents with any of the following:

- involuntary muscle movements (spasms)
- muscle stiffness
- pain and restriction with certain movements or positions causing difficulty in performing various activities
- a change in their mobility. **[2022]**

1.5.21 Assess people with MS and suspected spasticity for factors that might worsen spasticity, for example, pressure ulcers, bladder and bowel dysfunction and infections, poor posture or positioning, and pain. **[2022]**

1.5.22 Discuss with the person the balance between the benefits and harms of treating spasticity. In particular, explain that some people use their

spasticity to maintain their posture and ability to stand, walk or transfer, and that treatment with muscle relaxants may adversely affect this. **[2022]**

1.5.23 Consider oral baclofen as a first-line drug treatment to treat spasticity in people with MS who have specific treatment goals such as improving mobility or easing pain and discomfort. Take into account any contraindications, comorbidities and the person's preferences. **[2022]**

1.5.24 If oral baclofen is not tolerated or does not provide adequate relief, consider gabapentin as a second-line option to treat spasticity in people with MS. **[2022]**

In December 2021, this was an off-label use of gabapentin. See NICE's information on prescribing medicines. See also the 2019 MHRA drug safety update on pregabalin (Lyrica), gabapentin (Neurontin) and risk of abuse and dependence.

1.5.25 When using oral baclofen or gabapentin to treat spasticity in people with MS, explain to the person that they should:

- increase the dose gradually in at least 2 week increments to optimise symptom improvement or until they reach the maximum dose they can tolerate
- stop taking the medicine if there is no benefit at the maximum tolerated dose (explain that baclofen can cause harm if stopped suddenly and that special precautions may be needed when stopping specific medicines)
- have their medicines reviewed at least annually once the optimal dose has been reached. **[2022]**

See the BNF and the summary of product characteristics for baclofen and gabapentin for advice on optimising dosage and stopping treatment and, if relevant, treating people with renal impairment and older people.

1.5.26 Consider a combination of oral baclofen and gabapentin for people with MS if:

- individual medicines do not provide adequate relief **or**
- side effects from individual medicines prevent the dose being increased. **[2022]**

See the BNF and summary of product characteristics for baclofen and gabapentin. Use caution when using these medicines in combination.

In December 2021, this was an off-label use of gabapentin. See NICE's information on prescribing medicines. See also the 2019 MHRA drug safety update on pregabalin (Lyrica), gabapentin (Neurontin) and risk of abuse and dependence.

1.5.27 If spasticity is causing significant impairments in mobility, posture or function and initial treatments are unsuccessful, refer to a multidisciplinary team experienced in the management of spasticity for assessment and treatment planning. **[2022]**

1.5.28 For guidance on THC:CBD spray for treating spasticity in people with MS, see NICE's guideline on cannabis-based medicinal products. **[2019]**

For a short explanation of why the committee made these recommendations see the rationale and impact section on spasticity.

Full details of the evidence and the committee's discussion are in evidence review F: pharmacological management of spasticity.

Oscillopsia

1.5.29 Consider gabapentin as a first-line drug to treat oscillopsia in people with MS. **[2014]**

In December 2021, this was an off-label use of gabapentin. See NICE's information on prescribing medicines and the 2019 MHRA drug safety

update on pregabalin (Lyrica), gabapentin (Neurontin) and risk of abuse and dependence.

1.5.30 Consider memantine as the second-line treatment for oscillopsia in people with MS. **[2014]**

In December 2021, this was an off-label use of memantine. See NICE's information on prescribing medicines.

1.5.31 Refer the person with MS for specialist advice if there is no improvement of oscillopsia after treatment with gabapentin and memantine or side effects prevent continued use. **[2014]**

Emotional lability

1.5.32 Consider amitriptyline to treat emotional lability (involuntary laughing and crying related to a frontal lobe lesion) in people with MS. **[2014]**

In December 2021, this was an off-label use of amitriptyline. See NICE's information on prescribing medicines.

Pain

1.5.33 Assess and investigate the cause of pain to establish a diagnosis and offer treatment specific to the cause of the pain. **[2022]**

1.5.34 Be mindful of the impact of pain on the mental wellbeing of people with MS, and provide advice and support. See NICE's guideline on depression in adults with a chronic physical problem. **[2022]**

1.5.35 Treat neuropathic pain in people with MS and refer people to pain services according to NICE's guideline on neuropathic pain in adults. **[2022]**

1.5.36 Be aware that musculoskeletal pain is common in people with MS and is usually secondary to problems with immobility, spasticity and posture. Assess musculoskeletal pain and offer treatment appropriate to the cause, for example see the sections on managing mobility problems and

spasticity, and NICE's guideline on low back pain and sciatica in over 16s. **[2022]**

For a short explanation of why the committee made the 2022 recommendations see the rationale and impact section on pain.

Full details of the evidence and the committee's discussion are in evidence review G: non-pharmacological management of pain.

Cognitive and memory problems

1.5.37 Be aware that the symptoms of MS can include cognitive problems, including memory problems that the person may not immediately recognise or associate with their MS. **[2022]**

1.5.38 Assess cognition as part of the person's comprehensive review. Tailor the assessment to the person's needs, for example, use a clinic interview or brief formal assessment, or consider referral for a full neuropsychological assessment if needed. **[2022]**

1.5.39 Be aware that anxiety, depression, difficulty sleeping, fatigue and medication can affect cognition. Assess for and offer management appropriate for these issues in people with MS and cognitive or memory problems (for example, see the section on fatigue and NICE's guidelines on generalised anxiety disorder and panic disorder in adults and depression in adults with a chronic physical health problem). **[2022]**

1.5.40 Consider referring people with MS and persisting cognitive impairments to an occupational therapist and/or a neuropsychologist to assess and manage these symptoms according to the person's needs. **[2022]**

For a short explanation of why the committee made these recommendations see the rationale and impact section on cognitive and memory problems.

Full details of the evidence and the committee's discussion are in evidence review H: non-pharmacological management of memory and cognitive problems.

Ataxia and tremor

The evidence was reviewed for the pharmacological management of ataxia and tremor, and the committee made a research recommendation.

For a short explanation of why the committee only made a research recommendation, see the rationale section on pharmacological management of ataxia and tremor.

Full details of the evidence and the committee's discussion are in evidence review I: pharmacological management of ataxia and tremor.

1.6 Comprehensive review

1.6.1 Ensure all people with MS have a comprehensive review of all aspects of their care at least once a year. **[2014]**

1.6.2 Ensure the comprehensive review is carried out by healthcare professionals with expertise in MS and its complications. Involve different healthcare professionals with expertise in specific areas of the review if needed. **[2014]**

1.6.3 Tailor the comprehensive review to the needs of the person with MS assessing:

- MS symptoms:
  - mobility and balance including falls
  - need for mobility aids including wheelchair assessment
  - use of arms and hands
  - muscle spasms and stiffness
  - tremor
  - bladder, bowel and sexual function (see NICE's guidelines on urinary incontinence in neurological disease and faecal incontinence in adults)
  - sensory symptoms and pain
  - speech and swallowing (see NICE's guideline on nutrition support for adults)

  - vision
  - cognitive symptoms
  - fatigue
  - depression and anxiety (see NICE's guidelines on depression in adults with a chronic physical health problem and generalised anxiety disorder and panic disorder in adults)
  - sleep
  - respiratory function.
- MS disease course:
  - evidence of progression
  - evidence of active disease
  - relapses in past year
  - eligibility for disease modifying treatments (see the section on other treatments).
- General health:
  - weight
  - smoking, alcohol and recreational drugs
  - exercise
  - access to routine health screening and contraception
  - care of other chronic conditions.
- Social activity and participation:
  - family and social circumstances
  - driving and access to transport
  - employment
  - access to daily activities and leisure.
- Care and carers:
  - personal care needs
  - social care needs
  - access to adaptations and equipment at home. **[2014, amended 2022]**

1.6.4 Refer any issues identified during the comprehensive review of the person with MS to members of the MS multidisciplinary team and other appropriate teams so that they can be managed. **[2014]**

1.6.5 Ensure people with MS are offered a medicines review in line with NICE's guidelines on medicines adherence and medicines optimisation. **[2014]**

1.6.6 Ensure people with MS have their bone health regularly assessed and reviewed in line with NICE's guideline on osteoporosis. **[2014]**

1.6.7 Ensure people with MS and severely reduced mobility are regularly assessed and reviewed for risk of contractures (shortening of tendons, muscles or ligaments that limits joint movement). **[2014]**

1.6.8 Check people with MS and severely reduced mobility at every contact for areas at risk of pressure ulcers (see NICE's guideline on pressure ulcers). **[2014]**

1.6.9 Discuss the care provided by carers and care workers as part of the person's care plan. Ensure that carers (including young carers) know about their right to a carer's assessment (see NICE's guideline on supporting adult carers for recommendations on identifying, assessing and meeting the caring, physical and mental health needs of families and carers and the Young Carers [Needs Assessment] Regulations 2015). **[2014 amended 2022]**

1.6.10 Refer people with MS to palliative care services for symptom control and for end-of-life care when appropriate. **[2014]**

1.7 Relapse and exacerbation

Recognising a relapse

1.7.1 Diagnose a relapse of MS if the person:

- develops new symptoms **or**
- has worsening of existing symptoms

and these last for more than 24 hours in the absence of infection or any other cause after a stable period of at least 1 month. **[2014]**

1.7.2 Before diagnosing a relapse of MS:

- rule out infection – particularly urinary tract and respiratory infections **and**
- discriminate between the relapse and fluctuations in disease or progression. **[2014]**

1.7.3 Do not routinely diagnose a relapse of MS if symptoms are present for more than 3 months. **[2014]**

Treating acute relapse of MS

1.7.4 Develop local guidance and pathways for timely treatment of relapses of MS. Ensure follow-up is included in the guidance and pathway. **[2014]**

1.7.5 Assess and offer treatment for relapses of MS that affect the person's ability to perform their usual tasks, as early as possible and within 14 days of onset of symptoms. **[2014]**

1.7.6 Non-specialists should discuss a person's diagnosis of relapse and whether to offer steroids with a healthcare professional with expertise in MS because not all relapses need treating with steroids. **[2014]**

1.7.7 Offer treatment for relapse of MS with oral methylprednisolone 0.5 g daily for 5 days. **[2014]**

1.7.8 Consider intravenous methylprednisolone 1 g daily for 3 to 5 days as an alternative for people with MS:

- in whom oral steroids have failed or not been tolerated **or**
- who need admitting to hospital for a severe relapse or monitoring of medical or psychological conditions such as diabetes or depression. **[2014]**

1.7.9 Do not prescribe steroids at lower doses than methylprednisolone 0.5 g daily for 5 days to treat an acute relapse of MS. **[2014]**

1.7.10 Do not give people with MS a supply of steroids to self-administer at home for future relapses. **[2014]**

Information about treating a relapse with steroids

1.7.11 Discuss the benefits and risks of steroids with the person with MS, taking into account the effect of the relapse on the person's ability to perform their usual tasks and their wellbeing. **[2014]**

1.7.12 Explain the potential complications of high-dose steroids, for example temporary effects on mental health (such as insomnia, depression, confusion and agitation) and worsening of blood glucose control in people with diabetes. **[2014]**

1.7.13 Give the person with MS and their family members or carers (as appropriate) information that they can take away about side effects of high-dose steroids in a format that is appropriate for them. **[2014]**

1.7.14 Ensure that the MS multidisciplinary team is told that the person is having a relapse, because relapse frequency may influence which

disease-modifying therapies are chosen and whether they need to be changed. **[2014]**

Medical, therapy and social care needs at time of relapse or exacerbation

1.7.15 Identify whether the person having a relapse of MS or their family members or carers have social care needs and if so refer them to social services for assessment. **[2014]**

1.7.16 Offer inpatient treatment to the person having a relapse of MS if their relapse is severe or if it is difficult to meet their medical and social care needs at home. **[2014]**

1.7.17 Explain that a relapse of MS may have short-term effects on cognitive function. **[2014]**

1.7.18 Identify whether the person with MS having a relapse or exacerbation needs additional symptom management, rehabilitation or consideration for disease-modifying treatments. **[2014 amended 2022]**

1.8 Other treatments

Disease-modifying treatments

NICE has published technology appraisal guidance on disease-modifying treatments for MS. For full details, see NICE's technology appraisal guidance on multiple sclerosis.

Vitamin D

1.8.1 Do not offer vitamin D solely for the purpose of treating MS. **[2014]**

Omega fatty acids compounds

1.8.2 Do not offer omega-3 or omega-6 fatty acid compounds to treat MS. Explain that there is no evidence that they affect relapse frequency or progression of MS. **[2014]**

Terms used in this guideline

This section defines terms that have been used in a particular way for this guideline.

Advanced MS

MS is described as 'advanced' when it has progressed to the point where a person is severely affected by their symptoms and has significant ongoing physical or cognitive impairment. People with advanced MS are unable to carry out most of their usual activities of daily living independently and need other people to assist them. The term is used to describe the level of burden rather than the type or duration of the MS.

Recommendations for research

The guideline committee has made the following recommendations for research.

Key recommendations for research

1 Coordination of care

What is the clinical and cost effectiveness of processes of care, including the role of MS specialist nurses and other healthcare professionals, to improve care coordination and health outcomes in adults with MS? **[2022]**

For a short explanation of why the committee made this recommendation see the rationale section on coordination of care.

Full details of the evidence and the committee's discussion are in evidence review B: coordination of care.

2 Cognitive rehabilitation

For adults with MS, including people receiving palliative care, what is the clinical and cost effectiveness of non-pharmacological interventions for memory and cognitive problems? **[2022]**

For a short explanation of why the committee made this recommendation see the rationale section on cognitive and memory problems.

Full details of the evidence and the committee's discussion are in evidence review H: non-pharmacological management of memory and cognitive problems.

3 Outcome measures for cognitive rehabilitation

What core outcome measures should be used for studies assessing memory and cognition in people with MS?

For a short explanation of why the committee made this recommendation see the rationale section on cognitive and memory problems.

Full details of the evidence and the committee's discussion are in evidence review H: non-pharmacological management of memory and cognitive problems.

4 Continued relapses

Is intravenous methylprednisolone more clinically and cost effective than oral methylprednisolone in people with relapsing–remitting MS and people with secondary progressive MS with continued relapses? **[2014]**

5 Mobility

What is the optimal frequency, intensity and form of rehabilitation for mobility problems in people with MS? **[2014]**

6 Spasticity

For adults with MS, including people receiving palliative care, what is the clinical and cost effectiveness of pharmacological interventions for generalised spasticity? **[2022]**

For a short explanation of why the committee made this recommendation see the rationale section on spasticity.

Full details of the evidence and the committee's discussion are in evidence review F: pharmacological management of spasticity.

7 Vitamin D

Can vitamin D slow down the progression of disability in MS? **[2014]**

Other recommendations for research

Information and support

What information, education and support do adults with clinically isolated syndrome and their families and carers find most useful? **[2022]**

For a short explanation of why the committee made this recommendation see the rationale section on providing information and support.

Full details of the evidence and the committee's discussion are in evidence review A: information and support for patients, their families and carers.

Non-pharmacological management of fatigue

For adults with MS, including people receiving palliative care, what is the clinical and cost effectiveness of non-pharmacological interventions for fatigue? **[2022]**

For a short explanation of why the committee made this recommendation see the rationale section on assessment and non-pharmacological management of fatigue.

Full details of the evidence and the committee's discussion are in evidence review C: non-pharmacological management of fatigue.

Pharmacological management of fatigue

For adults with MS, including people receiving palliative care, what is the clinical and cost effectiveness of pharmacological interventions for fatigue? **[2022]**

For a short explanation of why the committee made this recommendation see the rationale section on pharmacological management of fatigue.

Full details of the evidence and the committee's discussion are in evidence review D: pharmacological management of fatigue.

Pain

For adults with MS, including people receiving palliative care, what is the clinical and cost effectiveness of non-pharmacological interventions for pain? **[2022]**

For a short explanation of why the committee made this recommendation see the rationale section on pain.

Full details of the evidence and the committee's discussion are in evidence review G: non-pharmacological management of pain.

Ataxia and tremor

For adults with MS, what is the clinical and cost effectiveness of pharmacological interventions for ataxia and tremor? **[2022]**

For a short explanation of why the committee made this recommendation see the rationale section on pharmacological management of ataxia and tremor.

Full details of the evidence and the committee's discussion are in evidence review I: pharmacological management of ataxia and tremor.

Rationale and impact

These sections briefly explain why the committee made the recommendations and how they might affect practice.

Diagnosing multiple sclerosis

Recommendations 1.1.1 to 1.1.9

Why the committee made the recommendation

The recommendations were updated to reflect changes to the McDonald criteria (revised 2017), which are expected to speed up diagnosis and reduce the chance of misdiagnosis. The committee agreed that the previous recommendations on diagnosis are still relevant, but made some updates based on their experience and changes to practice since 2014.

The committee retained the recommendations on symptoms and features of MS, highlighting that symptoms can be wide-ranging and listing the most common symptoms and those that would make a diagnosis unlikely.

The committee removed the recommendation on performing blood tests to exclude alternative diagnosis and instead highlighted that these need to be tailored to the individual and their presenting symptoms.

The committee agreed that a consultant neurologist should be responsible for the diagnosis of MS, using the history, examination, MRI and other test findings, and by following the revised McDonald criteria. To meet the updated criteria, dissemination of lesions in the nervous system in space and time needs to be demonstrated, and all lesions visible on an MRI scan can contribute to the criteria, irrespective of whether they have caused symptoms (symptomatic lesions) or have not caused symptoms (asymptomatic lesions). A positive finding of cerebrospinal fluid oligoclonal bands can now be used in place of dissemination of lesions in some circumstances. The criteria have been developed for people experiencing clinically isolated syndrome, which means that they must present with symptoms suggestive of an inflammatory demyelinating condition.

The committee agreed to retain the previous recommendation on reviewing people with suspected MS who do not meet the McDonald criteria, but added the example of reviewing people annually, which is in line with current practice.

The committee supported the importance of providing details of support groups and reliable internet sites at the time of diagnosis.

How the recommendation might affect practice

The recommendations are expected to help to reduce variation between services and clinicians. The recommendations reflect current clinical practice and are not expected to increase the number of referrals or the cost of making a diagnosis and therefore will not have a resource impact.

Return to recommendations

Providing information and support

Recommendations 1.2.4 and 1.2.9 to 1.2.18

Why the committee made the recommendations

Ongoing information and support

The committee noted that people who were diagnosed with MS a long time ago may not be offered an annual review. They highlighted the importance of informing people with MS and their carers that they should have a regular comprehensive review so that they can ensure that this takes place at least once year and covers all of their needs.

The evidence showed that MS has a significant impact on carers and that information and support for them was often lacking. Carers are not always aware of the support available to them and often do not have the information they need as circumstances change for the person with MS. The committee agreed that carers should be aware of their right to a carer's assessment, and highlighted that this should include assessments for young carers.

The committee also noted that the timing of information was important and agreed that information and support should be provided according to the changing needs or circumstances of the person with MS. Considering pregnancy and approaching more advanced disease were identified as particular situations in which information and support needs should be reviewed. The committee made specific recommendations for these groups.

No evidence was identified on the information and support needs for people diagnosed with clinically isolated syndrome, and the committee therefore made a

research recommendation on information and support for people with clinically isolated syndrome.

Information and support for people planning to have children

Recommendations from the previous version of the guideline were updated and new recommendations added, based on qualitative evidence and the committee's experience. The committee agreed that the recommendations should apply to both women and men planning to start a family, where appropriate, and to people considering adoption as well as those planning pregnancy.

The committee agreed that discussions about starting or extending a family should happen early to ensure that people with MS have time to make decisions and plan for the future. They agreed that healthcare professionals should proactively ask about and discuss the person's plans for having children. The committee noted that some people with MS assume that they cannot have children and do not ask for advice. Although there was limited evidence supporting early information giving, the committee agreed that, based on their experience, it is important to start these discussions soon after diagnosis.

The evidence showed that people with MS often have concerns about the impact of MS on having a family. The committee agreed that MS should not be a barrier to planning a family, because pregnancies can be well managed and additional support may be available. Many people with MS may feel like they are not able to have children, so the committee agreed that people with MS should be able to discuss the possibilities before making these decisions.

The evidence highlighted issues of particular concern to people with MS, such as how MS and treatments can affect pregnancy, whether they can pass MS on to their children and the impact of MS on their labour, birth options and breastfeeding. People also wanted more information on the possible impact that caring for a child might have on their symptoms, such as fatigue, and advice on how to manage this. The committee updated the existing recommendations based on the evidence. Based on their experience, the committee also included a reference to advice on folic acid in the NICE guideline on maternal and child nutrition because they agreed that this would also apply to people with MS.

Information and support for people as MS becomes advanced, including those approaching the end of their life

The qualitative evidence showed that feelings of social isolation and depression are common in people with MS, but they often lack information about available services and support. It also showed that people were not always aware of the availability and suitability of home adaptations and mobility aids, and how to obtain them. These are important for maintaining independence as MS progresses. Other areas were also identified where better information and support could improve the care of people with MS and carers, including legal rights, employment rights, benefits and carer's assessments.

Based on the evidence and their experience, the committee agreed that people with advanced MS and their carers need information and support to navigate services so that they can access extra support as their needs change.

The committee noted that NICE's guideline on end-of-life care for adults includes recommendations on providing information and support for people who may be approaching the end of their life. They also agreed that an existing recommendation on advance care planning and power of attorney should be retained because it is still supported by the evidence and important to help people plan for their future care. It was updated to include a cross reference to NICE's guideline on decision-making and mental capacity.

How the recommendations might affect practice

The recommendations are in line with current good practice. Overall, the committee did not think these recommendations would have a significant resource impact.

Return to recommendations

Coordination of care

Recommendation 1.3.1

Why the committee made the recommendations

The committee updated the 2014 recommendation to emphasise that the point of contact should have knowledge of MS services to coordinate the person's care and

help them access relevant healthcare professionals. The available clinical and health economic evidence was limited, so the committee were not able to specify that the point of contact should have knowledge of MS because this may represent a change in practice and a resource impact. Instead, a point of contact with access to appropriate healthcare services was specified to allow for different service configurations, for example, the point of contact would be able to access a healthcare professional who can contact the person with MS and respond to their concerns. The committee acknowledged the lack of evidence in this area and made a research recommendation on coordination of care for people with MS to support future guidance in this area.

How the recommendations might affect practice

The recommendation emphasises that the point of contact should have knowledge of MS services. This should not result in a large change in practice and therefore will not have a significant resource impact.

Return to recommendations

Assessment and non-pharmacological management of fatigue

Recommendations 1.5.2 to 1.5.8 and 1.5.10

Why the committee made the recommendations

Although a large number of studies have been published since the previous version of the guideline, the committee agreed that the new evidence was too limited in quality to change most of the existing recommendations. However, the new evidence did further support the 2014 recommendations on managing MS-related fatigue.

Fatigue may not always be identified and treated, so the committee agreed by informal consensus that people with MS should be asked about the presence of fatigue. Causes of fatigue other than MS may sometimes be missed, so the committee highlighted the importance of checking for other possible causes to ensure appropriate management.

There was some evidence that fatigue or energy management interventions and wellbeing techniques, such as cognitive behavioural therapy (CBT) and mindfulness,

are beneficial. However, the committee agreed that the evidence was not sufficient to recommend formal programmes because of limitations in the studies. Instead, the committee recognised that using elements of these approaches could be helpful and included in discussions about management options.

Based on their experience, the committee agreed that a fatigue management discussion should be offered, which is routinely provided in current practice. This would be a tailored discussion that could include goals and priorities for each the person, advice on energy conservation, review of lifestyle factors and the use of stress reduction and wellbeing techniques, including cognitive behavioural principles for managing day-to-day activities and mindfulness-based techniques.

The committee agreed that the previous recommendation on advice about the possible benefits of aerobic, balance and stretching exercises, including yoga, was still supported by the evidence. In addition, there was some evidence of benefit for resistive exercises and pilates.

There was a lack of evidence on specific diets, but a recommendation was made to highlight the benefits of following a healthy diet. Diet was also included in the discussion of fatigue management.

The committee agreed that the evidence still supported the previous recommendation on considering a programme of aerobic and moderate progressive resistance activity combined with cognitive behavioural techniques to treat fatigue in people with significantly impaired mobility (EDSS score of at least 4). This was based on clinical evidence, modest economic evidence (covering the ExIMS study, 2013) and the original economic analysis from the previous version of the guideline supporting the cost effectiveness of combined exercise programmes. The committee noted that this should be a supervised programme provided to the person with MS, rather than self-directed exercise, and that it should be tailored to the needs and abilities of the person.

No randomised controlled trial evidence was identified for hyperbaric oxygen to treat MS-related fatigue in people with MS. The committee were concerned that this intervention is being used despite the lack of evidence, sometimes at the expense of

the person with MS or through charities. They agreed that it should not be used based on the lack of evidence, their clinical experience and the high cost involved.

A research recommendation on identifying clinically and cost-effective interventions for the non-pharmacological management of fatigue was developed to encourage further research in this area.

How the recommendations might affect practice

The recommendations on assessment and offering people a personal tailored discussion about fatigue management do not represent a change in practice. Discussion of fatigue management is provided routinely in current practice by occupational therapists, MS nurses or physiotherapists. It does not involve a specific, structured fatigue management programme but includes some elements of fatigue management, such as advice on energy conservation. Similarly, the inclusion of stress and wellbeing techniques does not refer to structured interventions but allows the opportunity to use some elements of these techniques as part of the fatigue management discussion, which the committee agreed are used as part of fatigue management discussions in current practice.

Supervised aerobic and moderate progressive resistance programmes with cognitive behavioural techniques for people with an EDSS of at least 4 was recommended in the 2014 guideline based on clinical- and cost-effectiveness analysis. Physiotherapists and occupational therapists typically apply CBT principles like goal setting as part of exercise interventions in current practice, and this does not need to be a formal CBT intervention delivered by a psychologist. The committee agreed that this would not represent a change in practice.

Recommendations covering advice on exercises for MS-related fatigue (which would be self-directed exercise rather than supervised programmes provided to the person with MS) and following the principles of a healthy diet are consistent with current good practice, as is the recommendation not to offer hyperbaric oxygen.

As none of the recommendations represent a change in current practice these recommendations are not expected to have a resource impact.

Return to recommendations

Pharmacological management of fatigue

Recommendations 1.5.11 and 1.5.12

Why the committee made the recommendations

The evidence for treating fatigue with amantadine, modafinil or selective serotonin reuptake inhibitors (SSRIs) in people with MS was limited but showed some benefit for each medicine. The lack of good evidence comparing the different treatments meant that the committee were unable to recommend one in preference to the others or an order in which these treatments should be considered. The committee noted the safety concerns for modafinil, including that it should not be used during pregnancy and that precautions should be taken if prescribing it for women able to have children, in line with the 2020 MHRA safety advice on modafinil (Provigil). The committee noted additional advice on monitoring, stopping treatment and cautions for use in the 2014 MHRA safety advice on modafinil (Provigil).

Pharmacological interventions may be tried before non-pharmacological interventions, especially if a rapid response is a priority. The decision to try a medicine and which one to try should be made using shared decision making, taking into account the person's preferences and clinical factors. These medicines are off label for this indication and are typically prescribed in secondary care. The doses recommended are based on the committee's knowledge of current clinical practice.

A research recommendation on the pharmacological management of fatigue was made to support future research in this area.

How the recommendations might affect practice

Amantadine is currently prescribed as the first-line pharmacological treatment, alongside non-pharmacological management options, as a part of a multidisciplinary approach to fatigue. Other treatments, such as modafinil, are less commonly prescribed, usually under the guidance of secondary care specialists. Therefore, these recommendations may represent a change from current practice for primary care providers and a resource impact from the increased use of modafinil in a broader range of clinical settings, including primary care.

The recommendations may result in a decrease in the use of amantadine and an increase in the use of modafinil and SSRIs. Given that the unit cost of amantadine is greater than that of modafinil and SSRIs, the overall resource impact of this recommendation is unlikely to be significant.

Return to recommendations

Pharmacological management of mobility problems

Recommendation 1.5.14

Why the committee made the recommendations

Fampridine was shown to be effective in treating lack of mobility in some people with MS, but not all. A health economic analysis was carried out for this guideline update, which included modelling an initial 4-week assessment to identify which people with MS respond to and would then continue fampridine treatment. Based on the current list price, fampridine was not found to be a cost-effective treatment and so the committee made a recommendation to not offer fampridine for the management of mobility problems.

How the recommendations might affect practice

This recommendation does not represent a change in practice and therefore will not have a resource impact.

Return to recommendations

Spasticity

Recommendations 1.5.20 to 1.5.28

Why the committee made the recommendations

No new evidence was identified for the pharmacological management of spasticity in people with MS. However, the committee updated the 2014 recommendations based on their experience and knowledge of current practice.

The committee agreed that it is important to raise awareness of spasticity and its presentation to ensure that people with MS receive appropriate treatment. They also highlighted that it is important to emphasise that the management of spasticity in MS

should be tailored to the needs of the person and their specific treatment goals because spasticity can vary significantly in people with MS and change at different stages in the course of their disease. The committee agreed that the previous recommendation on assessing for and treating factors that may exacerbate symptomatic spasticity should be retained.

The committee were aware that some people with MS use their spasticity to support them in maintaining posture when transferring or standing, and they agreed that the treatment of spasticity can have the potential to cause greater levels of disability. It was, therefore, agreed that the balance of risks and harms of treatment need to be fully discussed with the person before agreeing treatment.

Although there was no new evidence on specific pharmacological treatments for spasticity, the committee took into account safety concerns for the use of gabapentin (see the 2019 MHRA drug safety update on pregabalin [Lyrica], gabapentin [Neurontin] and risk of abuse and dependence) and agreed that it should no longer be recommended as a first-line option. The combination of baclofen and gabapentin is offered when neither agent by itself manages to control symptoms, but this needs to be balanced against the possible side effects. The committee noted that the BNF states that both gabapentin and baclofen can have central nervous system (CNS) depressant effects, which might affect the ability to perform skilled tasks. There is also a potential increased risk of respiratory depression (as advised by the MHRA) when using gabapentin in combination with other CNS depressants and people with neurological disease (such as MS) may be at higher risk of this. The committee discussed the safety issues for gabapentin, and agreed that illegal diversion and misuse are of particular concern. However, they agreed that gabapentin can be an effective treatment and should still be an option for treating spasticity in MS if oral baclofen is not tolerated or unsuccessful. Prescribers should follow the MHRA safety advice on evaluating people for a history of drug abuse and checking for misuse and dependence. The committee noted that gabapentin is now a class C controlled substance and prescribers will need to follow the statutory requirements for its use.

Based on their experience, the committee agreed that information should be added to the previous recommendation on using these medicines to clarify the importance of gradually increasing the doses of medicine to reach the optimal dosage.

The committee agreed that if a person's treatment goals are not being met by treatment with baclofen or gabapentin (alone or in combination), and appropriate physical assessments and precipitating or prolonging factors have been addressed, other treatment approaches should be considered, which may be delivered by a service dedicated to the more specialist management of spasticity. The committee updated the recommendation in the 2014 guideline on referral to specialist services to include multidisciplinary teams, which is consistent with current clinical practice.

A research recommendation on identifying clinical and cost-effective pharmacological interventions for the management of spasticity was developed to encourage further research in this area.

How the recommendations might affect practice

The recommendations reflect current best practise in the approach to the assessment and management of spasticity in people with MS. The committee recognised that not all clinicians would have direct access to specialist spasticity management services to deliver treatments beyond initial pharmacological approaches. However, services that specialise in the management of spasticity should be available at a regional level, ideally as part of a network.

It is not anticipated that the updated recommendations will result in significantly greater resource use to support the assessment and treatment of spasticity in people with MS. There may be resource savings realised through a reduction in complications caused by inappropriate treatment or untreated spasticity.

Return to recommendations

Pain

Recommendations 1.5.33 to 1.5.36

Why the committee made the recommendations

The causes of pain in people with MS are varied. It may neuropathic, caused by MS nerve damage, or secondary to immobility, spasticity or posture issues, or it may be unrelated to MS and caused by other comorbid conditions. Pain is sometimes assumed to be neuropathic in people with MS when it may have a different cause.

Based on their experience, the committee agreed that the first step in managing pain is to investigate and establish the cause. If the underlying cause is correctly identified, it will prevent unnecessary treatment and possible side effects, and ensure pain is managed correctly.

The committee acknowledged the impact that pain can have on mental health. Pain can severely impair mobility and active lifestyle choices, which may lead to low mood and mental health problems. Low mood may also affect the way the person deals with pain. Therefore, it is important that healthcare professionals are mindful of this complex interaction and that people are offered support and advice if pain is affecting their mental wellbeing.

The evidence on non-pharmacological management of pain was limited. The interventions and outcomes were varied, and the study sizes were small. There was some evidence of benefit from interventions such as yoga, relaxation massage, mindfulness, CBT and transcutaneous direct current stimulation and hypnosis with neurofeedback. However, the committee agreed that the evidence was insufficient to make any recommendations for or against particular non-pharmacological interventions. The committee therefore made a research recommendation on non-pharmacological interventions for pain to support future research in this area.

The committee agreed that immobility and problems with posture can often cause or exacerbate pain. It was also acknowledged that spasticity can play a major part in musculoskeletal pain. Therefore, the committee highlighted that musculoskeletal pain should be assessed and treatment offered that is appropriate to and addresses the cause of the pain.

How the recommendations might affect practice

Assessing and investigating the cause of pain is consistent with current best practice. The committee noted that assessment can be done by many different healthcare professionals, such as a rehabilitation physician, a GP, a neurologist, a physiotherapist or an MS nurse. They discussed that this would usually just involve history taking, but for some people further investigations such as scans may be needed. Although there may be costs associated with further investigations, it was

agreed that these are likely to be offset by identifying the cause of pain and offering appropriate treatment.

Acknowledging the impact of pain on mental health would not result in a change in practice or significant resource impact.

Return to recommendations

Cognitive and memory problems

Recommendations 1.5.37 to 1.5.40

Why the committee made the recommendations

There was variation in the interventions covered by the studies on non-pharmacological management of cognitive and memory problems, which made it difficult to for the committee to come to any conclusions. They agreed that the evidence was too limited to make recommendations about the types of interventions that should be offered. Current practice for treating cognitive impairments in MS varies, so the committee were not able to make consensus-based recommendations on which interventions would be most appropriate based on their experience. They agreed that a new research recommendation on cognitive rehabilitation should involve larger trials in this area. A research recommendation on outcome measures for studies of memory and cognition was also made to encourage the use of particular tests or scales for measuring different cognitive functions and improve the ability to pool and interpret data in the future.

Based on their experience, the committee highlighted the need for cognitive symptoms to be assessed as part of the comprehensive review. This assessment is important for people with cognitive symptoms, because their cognitive profile needs to be established before decisions about any interventions can be made, based on their impairments. It was agreed that the type of cognitive assessment needed would differ depending on the person's needs. This might involve a clinical interview with or without carer input or a brief formal neuropsychological assessment. It was noted that a full neuropsychological assessment may be needed in people with a more complex presentation, for example, if fatigue and other disorders may be contributing to cognitive impairments.

In the absence of new evidence, the committee agreed that the previous recommendations on cognition and memory problems should be retained and updated based on their experience and agreed by informal consensus. They agreed that medication should be added to the list of factors that may affect cognition, and that appropriate management of these factors should be offered.

The committee agreed that the recommendation on referral for assessment and management of cognitive impairment should be updated so that referral can be to an occupational therapist, or a neuropsychologist as needed, rather than both, in line with current practice. Referral and the assessment and management of cognitive impairment should be tailored to the person's individual needs, because the cognitive profile of each person is likely to differ.

How the recommendations might affect practice

The recommendations are in line with current practice.

Cognitive assessment is usually available if the person has been offered a referral, although there may be some regional differences. It was noted that a simple assessment takes 10 to 15 minutes and does not need specific expertise. This type of assessment may be a change in practice for some services, but it is unlikely to have a significant resource impact. A full, longer neuropsychological assessment is a more costly assessment. However, it was noted that only a very small proportion of people are likely to need this longer assessment and future assessments are not as resource intensive as the baseline assessment. Given that only a small number of people would need this more expensive assessment (fewer than 1 % of the MS population) and that it may already be current practice for some services, it was not thought to represent a significant resource impact.

Many people with MS already have access to an occupational therapist who is skilled in cognitive assessment and interventions. A proportion will also have access to a neuropsychologist.

Return to recommendations

Pharmacological management of ataxia and tremor

Why the committee did not make recommendations

There was a lack of evidence for pharmacological management of ataxia and tremor in people with MS. Only one new study was identified, which compared botulinum toxin with a placebo. This study was analysed alongside a similar study included in the previous guideline, but the committee agreed that this evidence was insufficient to make recommendations for or against its use. Botulinum toxin is not generally used in current practice for ataxia and tremor, and this use is off label. A research recommendation on the pharmacological management of ataxia and tremor was developed to support future research in this area.

Context

Multiple sclerosis (MS) is an acquired chronic immune-mediated inflammatory condition of the central nervous system , affecting both the brain and spinal cord. It affects approximately 100,000 people in the UK. It is the most common cause of serious physical disability in adults of working age.

People with MS typically develop symptoms in their late 20s, experiencing visual and sensory disturbances, limb weakness, gait problems, and bladder and bowel symptoms. They may initially have partial recovery, but over time develop progressive disability.

The cause of MS is unknown. It is believed that an abnormal immune response to environmental triggers in people who are genetically predisposed results in immune-mediated acute, and then chronic, inflammation. The initial phase of inflammation is followed by a phase of progressive degeneration of the affected cells in the nervous system. MS is a potentially highly disabling disorder with considerable personal, social and economic consequences. People with MS live for many years after diagnosis with significant impact on their ability to work, as well as an adverse and often highly debilitating effect on their quality of life and that of their families.

This guideline updates and replaces NICE clinical guideline 186 (2014) and covers diagnosis, information and support, coordination of care and management of MS-

related symptoms. The guideline does not address all symptoms and problems associated with MS. Some areas are addressed in other NICE guidance, for example, urinary symptoms and swallowing, and these are referenced where appropriate. Many of the interventions used in rehabilitation to alleviate symptoms such as weakness, cardiorespiratory fitness, sensory loss, visual problems (apart from oscillopsia), and secondary complications of immobility such as deconditioning and contractures, have not been covered because these are beyond the scope of the guideline. Many of these problems are complex and need personalised assessment and management strategies carried out by healthcare professionals with appropriate expertise in rehabilitation and MS.

The guideline does not cover the use of disease-modifying treatments. However, NICE has published technology appraisals on these treatments (see the NICE Pathway on multiple sclerosis for more information).

The guideline is aimed primarily at services provided in primary and secondary care. It does not map out a model of service delivery. Many people with MS may also attend specialised tertiary services, often established to provide and monitor disease-modifying therapies.

Finding more information and committee details

To find NICE guidance on related topics, including guidance in development, see the NICE webpage on neurological conditions.

For details of the guideline committee see the committee member list.

Update information

June 2022

This guideline is an update of NICE guideline CG186 (published October 2014) and will replace it.

We have reviewed the evidence on diagnosis, information and support, symptom management and rehabilitation, coordination of care and the role of MS nurse specialists.

Recommendations are marked **[2022]** if the evidence has been reviewed.

Recommendations that have been deleted, or changed without an evidence review

We propose to delete some recommendations from the 2014 guideline. Table 1 sets out these recommendations and includes details of replacement recommendations. If there is no replacement recommendation, an explanation for the proposed deletion is given.

For recommendations shaded in grey and ending **[2014, amended 2022]**, we have made changes that could affect the intent without reviewing the evidence. Yellow shading is used to highlight these changes, and reasons for the changes are given in table 2.

For recommendations shaded in grey and ending **[2014]**, we have not reviewed the evidence. In some cases, minor changes have been made – for example, to update links, or bring the language and style up to date – without changing the intent of the recommendation. Minor changes are listed in table 3.

See also the previous NICE guideline and supporting documents.

Table 1 Recommendations that have been deleted

Recommendation in 2014 guideline	Comment
1.1.4 Before referring a person suspected of having MS to a neurologist, exclude alternative diagnoses by performing blood tests including: • full blood count • inflammatory markers for example erythrocyte sedimentation rate, C-reactive protein • liver function tests • renal function tests • calcium • glucose • thyroid function tests • vitamin B_{12} • HIV serology.	The blood tests should be tailored to the individual according to presenting symptoms
1.1.9 Offer people suspected of having MS, information about support groups and national charities.	Providing information and support on MS without a confirmed diagnosis increases anxiety. There are so many possible diagnosis due to the diversity of symptoms information and support should be provided once a diagnosis of MS in confirmed
1.2.1 NICE has produced guidance on the components of good patient experience in adult NHS services. This includes recommendations on communication, information and coordination of care. Follow the recommendations in the NICE guideline on patient experience in adult NHS services.	Replaced by a cross reference to the relevant NICE guidance
1.4.4 Offer flu vaccinations to people with MS in accordance with national guidelines, which recommend an individualised approach according to the person's needs.	Recommendations on vaccination were replaced by a cross reference to national guidance: Offer vaccinations in line with advice from the Joint Committee on Vaccinations and Immunisation and the Green Book Immunisation against infectious disease for people with MS and their carers. (1.4.3)
1.5.21 Consider tizanidine or dantrolene as a second-line option to treat spasticity in people with MS. 1.5.22 Consider benzodiazepines as a third-line option to treat spasticity in MS and be aware of their potential benefit in treating nocturnal spasms.	There is no clinical and health economic evidence to support these recommendations.

Table 2 Amended recommendation wording (change to intent) without an evidence review

Recommendation in 2014 guideline	Recommendation in current guideline	Reason for change
1.2.2 The consultant neurologist should ensure that people with MS and, with their agreement their family members or carers, are offered oral and written information at the time of diagnosis. This should include, but not be limited to, information about: • what MS is • treatments, including disease-modifying therapies • symptom management • how support groups, local services, social services and national charities are organised and how to get in touch with them • legal requirements such as notifying the Driver and Vehicle Licensing Agency (DVLA) and legal rights including social care, employment rights and benefits.	1.2.1 The consultant neurologist should ensure that people with MS, and with their agreement their family members or carers, are offered oral and written information at the time of diagnosis. This should include, but not be limited to, information about: • what MS is • treatments, including disease modifying therapies • symptom management • how support groups, local services, social services and national charities are organised and how to get in touch with them • online resources • legal requirements such as notifying the Driver and Vehicle Licensing Agency (DVLA) and legal rights including social care, employment rights and benefits. [2014, amended 2021]	Added online resources to reflect how people currently access information

1.3.1 Care for people with MS using a coordinated multidisciplinary approach. Involve professionals who can best meet the needs of the person with MS and who have expertise in managing MS including: • consultant neurologists • MS nurses • physiotherapists and occupational therapists • speech and language therapists, psychologists, dietitians, social care and continence specialists • GPs.	1.3.2 Care for people with MS using a coordinated multidisciplinary approach. Involve professionals who can best meet the needs of the person with MS and who have expertise in managing MS including: • MS nurses • consultant neurologists • neurological physiotherapists and occupational therapists • speech and language therapists, psychologists, dietitians, social care, continence specialists and specialist neuropharmacists or specialist MS pharmacists • consultants in rehabilitation medicine • primary healthcare team. [2014, amended 2022]	Changes were made to reflect current practice of who may be part of a multidisciplinary team
1.5.14 Help the person with MS continue to exercise, for example by referring them to exercise referral schemes.	1.5.17 Help the person with MS continue to exercise, for example, by referring them to a physiotherapist or exercise referral schemes. [2014, amended 2021]	Added physiotherapist to reflect current clinical practice

1.6.3 Tailor the comprehensive review to the needs of the person with MS assessing: • MS symptoms: ○ mobility and balance including falls ○ need for mobility aids including wheelchair assessment ○ use of arms and hands ○ muscle spasms and stiffness ○ tremor ○ bladder (see the NICE guideline on urinary incontinence in neurological disease), bowel (see the NICE guideline on faecal incontinence in adults) and sexual function ○ sensory symptoms and pain ○ speech and swallowing (see the NICE guideline on nutrition support for adults) ○ vision ○ cognitive symptoms ○ fatigue ○ depression (see the NICE guideline on depression in adults with a chronic physical health problem) and anxiety (see the NICE guideline on generalised anxiety disorder and panic disorder in adults) ○ sleep ○ respiratory function. • MS disease course: ○ relapses in last year. • General health: ○ weight ○ smoking, alcohol and recreational drugs	1.6.3 Tailor the comprehensive review to the needs of the person with MS assessing: • MS symptoms: ○ mobility and balance including falls ○ need for mobility aids including wheelchair assessment ○ use of arms and hands ○ muscle spasms and stiffness ○ tremor ○ bladder, bowel and sexual function (see NICE's guidelines on urinary incontinence in neurological disease and faecal incontinence in adults) ○ sensory symptoms and pain ○ speech and swallowing (see NICE's guideline on nutrition support for adults) ○ vision ○ cognitive symptoms ○ fatigue ○ depression and anxiety (see NICE's guidelines on depression in adults with a chronic physical health problem and generalised anxiety disorder and panic disorder in adults) ○ sleep ○ respiratory function. • MS disease course: ○ evidence of progression ○ evidence of active disease	Changes were made to include important elements of assessing MS disease course. Evidence of progression and active disease were added to ensure comprehensive review is complete. Discussion of whether disease modifying treatments are appropriate was added.

○ exercise ○ access to routine health screening and contraception ○ care of other chronic conditions. • Social activity and participation: ○ family and social circumstances ○ driving and access to transport ○ employment ○ access to daily activities and leisure. • Care and carers: ○ personal care needs ○ social care needs ○ access to adaptations and equipment at home	○ relapses in past year ○ eligibility for disease modifying treatments (see the section on other treatments). • General health: ○ weight ○ smoking, alcohol and recreational drugs ○ exercise ○ access to routine health screening and contraception ○ care of other chronic conditions. • Social activity and participation: ○ family and social circumstances ○ driving and access to transport ○ employment ○ access to daily activities and leisure. • Care and carers: ○ personal care needs ○ social care needs ○ access to adaptations and equipment at home. [2014, amended 2022]	
1.6.9 Discuss the care provided by carers and care workers as part of the person's care plan. Ensure carers know about their right to a carer's assessment (see the NICE guideline on supporting adult carers for recommendations on identifying, assessing and meeting the caring, physical and mental health needs of families and carers).	1.6.9 Discuss the care provided by carers and care workers as part of the person's care plan. Ensure that carers (including young carers) know about their right to a carer's assessment (see NICE's guideline on supporting adult carers for recommendations on identifying, assessing and meeting the caring, physical and mental health needs of families and carers and the Young Carers [Needs Assessment] Regulations 2015). [2014 amended 2022]	Changes were made to include young carers.

1.7.18 Identify whether the person with MS having a relapse or exacerbation needs additional symptom management or rehabilitation	1.7.18 Identify whether the person with MS having a relapse or exacerbation needs additional symptom management, rehabilitation or consideration for disease-modifying treatments. [2014 amended 2022]	Changes were made to reflect current practice of considering disease-modifying treatments after a relapse.

Table 3 Minor changes to recommendation wording (no change to intent)

Recommendation numbers in current guideline	Comment
1.1.11 Diagnosis of neuromyelitis optica should be made by an appropriate specialist based on established up-to-date criteria	Neuromyelitis optica has been changed to neuromyelitis optica spectrum disorder to reflect current terminology.