NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline scope

Multiple sclerosis in adults: management (update)

This guideline will update the NICE guideline on multiple sclerosis in adults: management (CG186).

The guideline will be developed using the methods and processes outlined in developing NICE guidelines: the manual.

This guideline will also be used to update the NICE quality standard for multiple sclerosis QS108.

1 Why the update is needed

New evidence that could affect recommendations was identified through the surveillance process. Full details are set out in the surveillance review decision.

One new area for review was identified from the surveillance review:

- What is the role of the MS specialist nurse?

Why the guideline is needed

Key facts and figures

Multiple sclerosis (MS) is the most prevalent chronic inflammatory disease of the central nervous system, affecting at least 130,000 people in the UK.

MS is typically diagnosed between the age of 20 and 40. A first episode of neurological symptoms, called a clinically isolated syndrome, often represents the onset of MS. This may be followed by further episodes and, over time, the development of progressive disability.

MS may lead to physical disability and cognitive impairment, which negatively affect the person's quality of life and ability to work and study. Neurodegeneration is the major cause of neurological disability. Multiple sclerosis is associated with high costs for people with MS, their families, and society as a whole.

There are three main types of MS:

- Relapsing–remitting MS is when episodes of acute or subacute neurological disability occur, followed by a full or partial recovery.
- Secondary progressive MS is when, many years from onset, people with relapsing–remitting MS develop a progressive deterioration of neurological function.
- Primary progressive MS affects a minority of patients who have a progressive course of MS from onset.

Primary progressive MS and secondary progressive MS are similar and may be related. People with these types of MS do not have periods when their disability gets better (remissions), and their condition gradually gets worse over time. Relapsing and progressive disease can be further characterised by the presence of activity (which includes relapses and new lesions on MRI scans).

MS is a multifactorial disease, which means that multiple genetic and environmental factors have a role in causing MS. The main modifiable risk factors are vitamin D deficiency and tobacco smoking.

Current practice

The diagnosis of MS is based on a combination of clinical, MRI, and laboratory findings, the exclusion of other neurological conditions and on MRI evidence of dissemination of lesions. The McDonald diagnostic criteria for MS were developed to diagnose MS in people who present with at least clinically isolated syndrome, and not to differentiate MS from other neurological disorders. MS is sometimes misdiagnosed because the diagnostic criteria are applied to people with symptoms atypical for demyelination.

Management of MS includes both disease-modifying therapies and symptomatic treatments, including pharmacological and non-pharmacological interventions. Non-pharmacological interventions are the core components of a multidisciplinary rehabilitation programme, which includes physiotherapy, occupational therapy, speech-and-language therapy and cognitive rehabilitation. There are many disease-modifying therapies licensed to reduce relapses in MS and only 1 treatment to slow down progression in primary progressive MS. There is uncertainty about when treatment with disease-modifying therapies should be started, with emerging evidence suggesting that early treatment may be associated with reduced progression. Effective management of MS, which puts people with MS at the centre of their care, is critical to reduce the effect of disability on daily activities, improve quality of life and help patients to continue employment or education. Access to social care is essential to maintain an active life and to support independence.

Since the publication of the NICE guideline on multiple sclerosis in 2014, more information has become available: on diagnosing MS, including the revised McDonald criteria; information and support; the role of the MS nurse specialist; and management of symptoms such as fatigue and spasticity.

People experience wide variability in access to specialist services, in particular poor access to neurological rehabilitation, and poor integration of services for people with MS. There is also variability in treatment initiation and escalation across different regions.

2 Who the guideline is for

This guideline is for:

- healthcare professionals
- social care practitioners
- commissioners and providers of health and social care services
- adults with suspected or diagnosed MS, and their families and carers.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the Welsh Government, Scottish Government and Northern Ireland Executive.

Equality considerations

NICE has carried out an equality impact assessment during scoping.

- lists equality issues identified, and how they have been addressed
- explains why any groups are excluded from the scope.

The guideline will look at inequalities relating to people who may become pregnant and people living in rural areas.

3 What the updated guideline will cover

3.1 Who is the focus?

Groups that will be covered

- Adults (18 and over) with suspected or diagnosed MS.

The guideline may also be applicable to young people aged 16 and 17 who are being treated in adult services.

3.2 Settings

Settings that will be covered

- Any setting that provides primary, community, secondary or tertiary NHS care, or social care, including voluntary sector settings.

3.3 Activities, services or aspects of care

Key areas that will be covered in this update

We will look at evidence in the areas below when developing this update. We will consider making new recommendations or updating existing recommendations in these areas only.

1 Diagnosing MS and differential diagnosis.

2 Providing information and support.
3 MS symptom management and rehabilitation.
4 Coordination of care and the role of MS nurse specialists.

Note that guideline recommendations for medicines will normally fall within licensed indications; exceptionally, and only if clearly supported by evidence, use outside a licensed indication may be recommended. The guideline will assume that prescribers will use a medicine’s summary of product characteristics to inform decisions made with individual patients.

Proposed outline for the guideline

The table below outlines all the areas that will be included in the guideline. It sets out what NICE plans to do for each area in this update.

Area in the guideline	What NICE plans to do
1.1 Diagnosing MS	Review evidence on key diagnostic features: update existing recommendations as needed
1.2 Providing information and support	Review evidence: update existing recommendations as needed
1.3 Coordination of care	Review evidence: update existing recommendations as needed
1.4 Modifiable risk factors for relapse or progression	No evidence review: stand down recommendations on vaccinations (1.4.2 to 1.4.4) and add cross reference to Joint Committee on Vaccinations and Immunisation advice on influenza vaccinations, and the Green Book on immunisation against infectious disease. Retain all other recommendations from existing guideline
1.5 MS symptom management and rehabilitation	Review evidence: update existing recommendations as needed
1.6 Comprehensive review	No evidence review: retain recommendations from existing guideline
1.7 Relapse and exacerbation	No evidence review: retain recommendations from existing guideline
1.8 Other treatments	No evidence review: retain recommendations from existing guideline

Recommendations in areas that are being retained from the existing guideline may be edited to ensure that they meet current editorial standards, and reflect the current policy and practice context.

Areas that will not be covered by the guideline

1 Treatment of contractures at joints.

2 Disease-modifying therapies covered by existing technology appraisals and autologous haematopoietic stem cell transplantation (AHSCT).

Related NICE guidance

Published

- Suspected neurological conditions (2019) NICE guideline NG127
- Cannabis-based medicinal products (2019) NICE guideline NG144
- End of life care for adults: service delivery (2019) NICE guideline NG142
- Generalised anxiety disorder and panic disorder (with or without agoraphobia) in adults (2019) NICE guideline CG113
- Neuropathic pain (2019) NICE clinical guideline CG173
- Cladribine tablets for treating relapsing–remitting multiple sclerosis (2019) NICE technology appraisal TA616
- Percutaneous venoplasty for chronic cerebrospinal venous insufficiency in multiple sclerosis (2019) NICE interventional procedure guidance IPG640
- Ocrelizumab for treating primary progressive multiple sclerosis (2019) NICE technology appraisal TA585
- Ocrelizumab for treating relapsing–remitting multiple sclerosis (2018) NICE technology appraisal TA533
- Beta interferons and glatiramer acetate for treating multiple sclerosis (2018) NICE technology appraisal TA527
- Dementia: assessment, management and support for people living with dementia and their carers (2018) NICE guideline NG97
- Infection control (last updated 2017) NICE guideline CG139
- Nutrition support in adults (2017) NICE guideline CG32
- The management of pressure ulcers in primary and secondary care (2014) NICE guideline CG179

- Dimethyl fumarate for treating relapsing‑remitting multiple sclerosis (2014) NICE technology appraisal TA320
- Alemtuzumab for treating relapsing‑remitting multiple sclerosis (2014) NICE technology appraisal TA312
- Teriflunomide for treating relapsing–remitting multiple sclerosis (2014) NICE technology appraisal TA303
- Fingolimod for the treatment of highly active relapsing–remitting multiple sclerosis (2012) NICE technology appraisal TA254
- Urinary incontinence in neurological disease: assessment and management (2012) NICE guideline CG148
- Depression in adults (2009) NICE guideline CG90
- The treatment and management of depression in adults with chronic physical health problems (2009) NICE guideline CG91
- Functional electrical stimulation for drop foot of central neurological origin (2009) NICE interventional procedure guidance IPG278
- Natalizumab for the treatment of adults with highly active relapsing-remitting multiple sclerosis (2007) NICE technology appraisal TA127
- Faecal incontinence (2007) NICE guideline CG49
- Guidance on the use of computerised cognitive behavioural therapy for anxiety and depression (2006) NICE technology appraisal TA97
- Deep brain stimulation for tremor and dystonia (excluding Parkinson's disease) (2006) NICE interventional procedure IPG188
- Pressure relieving devices (2003) NICE guideline CG7
- Guidance on beta interferon and glatiramer acetate for the treatment of multiple sclerosis (2002) NICE technology appraisal TA32

NICE guidance about the experience of people using services

NICE has produced the following guidance on the experience of people using the NHS and social care services. This guideline will not include additional recommendations on these topics unless there are specific issues related to multiple sclerosis:

- People's experience of adult social care services (2018) NICE guideline NG86
- Supporting adult carers (2020) NICE guideline NG150
- Decision-making and mental capacity (2018) NICE guideline NG108
- Transition between inpatient hospital settings and community or care home settings for adults with social care needs (2015) NICE guideline NG27
- Medicines optimisation (2015) NICE guideline NG5
- Patient experience in adult NHS services (2012) NICE guideline CG138
- Service user experience in adult mental health (2011) NICE guideline CG136
- Medicines adherence (2009) NICE guideline CG76

3.4 Economic aspects

We will take economic aspects into account when making recommendations. We will develop an economic plan that states for each review question (or key area in the scope) whether economic considerations are relevant, and if so whether this is an area that should be prioritised for economic modelling and analysis. We will review the economic evidence and carry out economic analyses, using NHS and personal social services perspective, as appropriate.

3.5 Key issues and draft questions

While writing the scope for this updated guideline, we have identified the following key issues and draft questions related to them:

1 Diagnosing MS and differential diagnosis

1.1 What are the key diagnostic criteria for the following: multiple sclerosis; probable multiple sclerosis; neuromyelitis optica and clinically isolated syndrome?

2 Providing information and support

2.1 What information, education and support do a) adults with clinically isolated syndrome b) adults with MS c) adults with MS receiving palliative care d) adults with MS who may become pregnant, and their families and carers find most useful?

3 MS symptom management and rehabilitation

3.1 For adults with MS, including people receiving palliative care, what is the clinical and cost effectiveness of interventions for spasticity?

3.2 For adults with MS, including people receiving palliative care, what is the clinical and cost effectiveness of interventions for pain?

3.3 For adults with MS, including people receiving palliative care, what is the clinical and cost effectiveness of pharmacological interventions for mobility?

3.4 For adults with MS, including people receiving palliative care, what is the clinical and cost effectiveness of interventions for fatigue?

3.5 For adults with MS, including people receiving palliative care, what is the clinical and cost effectiveness of interventions for memory and cognitive problems?

3.6 For adults with MS, what is the clinical and cost effectiveness of interventions for ataxia and tremor?

4 Coordination of care and the role of MS nurse specialists

4.1 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?

The key issues and draft questions will be used to develop more detailed review questions, which guide the systematic review of the literature.

3.6 Main outcomes

The main outcomes that may be considered when searching for and assessing the evidence are:

- health-related quality of life, for example assessed using EQ-5D, SF-36, Leeds MS quality of life scale, MS impact scale
- people-reported outcomes, for example symptoms, activities, wellbeing, ability to carry out daily living activities
- impact on carers
- level of disability, for example, assessed using functional scales such as the Expanded Disability Status Scale (EDSS), the Multiple Sclerosis

Functional Composite (MSFC), the Cambridge Multiple Sclerosis Basic Score (CAMBS), the Functional Assessment of Multiple Sclerosis (FAMS) or the National Fatigue Index (NFI) or measures of independence

- mobility, for example assessed using the MS walking scale
- cognitive functions, such as memory and concentration, and physical symptoms including fatigue, spasticity, spasms, assessed by validated and disease-specific scales, questionnaires or similar instruments, for instance the Scripps Neurologic Rating Scale (SNRS) or the Krupp Fatigue Severity Scale (FSS).
- psychological symptoms assessed by validated and disease-specific scales, questionnaire or similar instruments
- pain assessed using scales such as the Visual Analogue Scale (VAS)
- health service use for example hospitalisations and outpatient appointments
- adverse effects of treatment.

4 NICE quality standards and NICE Pathways

4.1 *NICE quality standards*

NICE quality standards that may need to be revised or updated when this guideline is published

- Multiple sclerosis (2016) NICE quality standard 108.

4.2 *NICE Pathways*

When this guideline is published, we will update the existing NICE Pathway on multiple sclerosis. NICE Pathways bring together everything NICE has said on a topic in an interactive flowchart.

5 Further information

This is the final scope, which takes into account comments from registered stakeholders during consultation.

The guideline is expected to be published in May 2022.

You can follow progress of the guideline.

Our website has information about how NICE guidelines are developed.