

1 **NATIONAL INSTITUTE FOR HEALTH AND CARE**
2 **EXCELLENCE**

3 **Guideline scope**

4 **Multiple sclerosis in adults: management**
5 **(update)**

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

8 The guideline will be developed using the methods and processes outlined in
9 [developing NICE guidelines: the manual](#).

10 This guideline will also be used to update the NICE [quality standard](#) for
11 multiple sclerosis QS108.

12 **1 Why the update is needed**

13 New evidence that could affect recommendations was identified through the
14 surveillance process. Full details are set out in the [surveillance review](#)
15 [decision](#).

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

- 17 • What is the role of the MS specialist nurse?

18 ***Why the guideline is needed***

19 **Key facts and figures**

20 Multiple sclerosis (MS) is the most prevalent chronic inflammatory disease of
21 the central nervous system, affecting at least 100,000 people in the UK.

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

1 MS may lead to physical disability and cognitive impairment, which negatively
2 affect the person's quality of life and ability to work and study. It is associated
3 with high costs for people with MS, their families, and society as a whole.

4 There are three main types of MS:

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

12

13 People with progressive disease (i.e., primary progressive MS and secondary
14 progressive MS) are similar because they do not have periods when their
15 disability gets better (remissions), but their condition gradually gets worse
16 over time.

17 Either relapsing or progressive disease can be further characterised by the
18 presence of activity (which includes relapses and new lesions on MRI scans).
19 MS is a multifactorial disease, which means that multiple genetic and
20 environmental factors have a role in causing MS. The main modifiable risk
21 factors are vitamin D deficiency, tobacco smoking, and obesity.

22 **Current practice**

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

1 Management of MS includes both disease-modifying therapies and
2 symptomatic treatments, including pharmacological and non-pharmacological
3 interventions. Non-pharmacological interventions are the core components of
4 a multidisciplinary rehabilitation programme, which includes physiotherapy,
5 occupational therapy, speech-and-language therapy, and cognitive
6 rehabilitation. There are many disease-modifying therapies licensed to reduce
7 relapses in MS and only 1 treatment to slow down progression in primary
8 progressive MS. Recent evidence suggests that early treatment with disease-
9 modifying therapies is associated with reduced progression over time.
10 Effective management of MS, which puts people with MS at the centre of the
11 interventions, is critical to reduce the effect of disability on daily activities,
12 improve quality of life and help patients to continue employment or education.

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

17 People experience wide variability in access to specialist services, in
18 particular poor access to neurological rehabilitation, and poor integration of
19 services for people with MS.

20 **2 Who the guideline is for**

21 This guideline is for:

- 22 • healthcare professionals
- 23 • commissioners and providers
- 24 • social care practitioners
- 25 • adults with suspected or diagnosed MS and their families and carers.

26 NICE guidelines cover health and care in England. Decisions on how they
27 apply in other UK countries are made by ministers in the [Welsh Government](#),
28 [Scottish Government](#) and [Northern Ireland Executive](#).

1 ***Equality considerations***

2 NICE has carried out [an equality impact assessment](#) during scoping.

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

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

7 **3 What the updated guideline will cover**

8 **3.1 Who is the focus?**

9 **Groups that will be covered**

- 10 • Adults (18 and over) with suspected or diagnosed MS.
- 11 The guideline may also be applicable to young people aged 16 and 17 who
12 are being treated in adult services.
- 13 No specific subgroups of people have been identified as needing specific
14 consideration.

15 **3.2 Settings**

16 **Settings that will be covered**

- 17 • Any setting that provides primary, community, secondary and tertiary NHS
18 care, including social care and voluntary sector settings.

19 **3.3 Activities, services or aspects of care**

20 **Key areas that will be covered in this update**

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

- 24 1 Diagnosing MS and differential diagnosis.
- 25 2 Providing information and support.
- 26 3 MS symptom management and rehabilitation.

1 4 Coordination of care and the role of MS nurse specialists.

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

7 **Proposed outline for the guideline**

8 The table below outlines all the areas that will be included in the guideline. It
9 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

10

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

1 **Areas that will not be covered by the guideline**

- 2 1 Treatment of contractures at joints.
- 3 2 Disease-modifying therapies covered by existing technology appraisals
- 4 and autologous haematopoietic stem cell transplantation (AHSCT).

5 **Related NICE guidance**

6 ***Published***

- 7 • [Suspected neurological conditions](#) (2019) NICE guideline NG127
- 8 • [Cannabis-based medicinal products](#) (2019) NICE guideline NG144
- 9 • End of life care for adults: service delivery (2019) NICE guideline NG142
- 10 • [Cladribine tablets for treating relapsing–remitting multiple sclerosis](#) (2019)
- 11 NICE technology appraisal TA616
- 12 • [Percutaneous venoplasty for chronic cerebrospinal venous insufficiency in](#)
- 13 [multiple sclerosis](#) (2019) NICE interventional procedure guidance IPG640
- 14 • [Ocrelizumab for treating primary progressive multiple sclerosis](#) (2019)
- 15 NICE technology appraisal TA585
- 16 • [Ocrelizumab for treating relapsing–remitting multiple sclerosis](#) (2018) NICE
- 17 technology appraisal TA533
- 18 • [Beta interferons and glatiramer acetate for treating multiple sclerosis](#) (2018)
- 19 NICE technology appraisal TA527
- 20 • [Infection control](#) (last updated 2017) NICE guideline CG139
- 21 • [The management of pressure ulcers in primary and secondary care](#) (2014)
- 22 NICE guideline CG179
- 23 • [Dimethyl fumarate for treating relapsing-remitting multiple sclerosis](#) (2014)
- 24 NICE technology appraisal TA320
- 25 • [Alemtuzumab for treating relapsing-remitting multiple sclerosis](#) (2014)
- 26 NICE technology appraisal TA312
- 27 • [Teriflunomide for treating relapsing–remitting multiple sclerosis](#) (2014)
- 28 NICE technology appraisal TA303
- 29 • [Fingolimod for the treatment of highly active relapsing–remitting multiple](#)
- 30 [sclerosis](#) (2012) NICE technology appraisal TA254

- 1 • [Urinary incontinence in neurological disease: assessment and](#)
2 [management](#) (2012) NICE guideline CG148
- 3 • [Generalised anxiety disorder and panic disorder \(with or without](#)
4 [agoraphobia\) in adults](#) (2011) NICE guideline CG113
- 5 • [Neuropathic pain](#) (2010) NICE clinical guideline CG96
- 6 • [Depression in adults](#) (2009) NICE guideline CG90
- 7 • [The treatment and management of depression in adults with chronic](#)
8 [physical health problems](#) (2009) NICE guideline CG91
- 9 • [Functional electrical stimulation for drop foot of central neurological origin](#)
10 (2009) NICE interventional procedure guidance IPG278
- 11 • [Natalizumab for the treatment of adults with highly active relapsing-](#)
12 [remitting multiple sclerosis](#) (2007) NICE technology appraisal TA127
- 13 • [Faecal incontinence](#) (2007) NICE guideline CG49
- 14 • [Dementia](#) (2007) NICE guideline CG42
- 15 • [Nutrition support in adults](#) (2006) NICE guideline CG32
- 16 • [Deep brain stimulation for tremor and dystonia \(excluding Parkinson's](#)
17 [disease\)](#) (2006) NICE interventional procedure IPG188
- 18 • [Pressure relieving devices](#) (2003) NICE guideline CG7
- 19 • [Guidance on beta interferon and glatiramer acetate for the treatment of](#)
20 [multiple sclerosis](#) (2002) NICE technology appraisal TA32
- 21 • [Guidance on the use of computerised cognitive behavioural therapy for](#)
22 [anxiety and depression](#) (2002) NICE technology appraisal TA51

23 **NICE guidance about the experience of people using NHS services**

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

- 27 • [Medicines optimisation](#) (2015) NICE guideline NG5
- 28 • [Patient experience in adult NHS services](#) (2012) NICE guideline CG138
- 29 • [Service user experience in adult mental health](#) (2011) NICE guideline
30 CG136
- 31 • [Medicines adherence](#) (2009) NICE guideline CG76

1 **3.4 Economic aspects**

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

9 **3.5 Key issues and draft questions**

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

- 12 1 Diagnosing MS and differential diagnosis
 - 13 1.1 What are the key diagnostic criteria for the following: multiple
14 sclerosis; probable multiple sclerosis; neuromyelitis optica and clinically
15 isolated syndrome?
- 16 2 Providing information and support
 - 17 2.1 What information, education and support do adults with MS,
18 including people receiving palliative care, their families and carers find
19 most useful?
 - 20 2.2 What information and support do people with MS who may become
21 pregnant find most useful?
- 22 3 MS symptom management and rehabilitation
 - 23 3.1 For adults with MS, including people receiving palliative care, what is
24 the clinical and cost effectiveness of interventions for spasticity?
 - 25 3.2 For adults with MS, including people receiving palliative care, what is
26 the clinical and cost effectiveness of interventions for pain?
 - 27 3.2 For adults with MS, what is the clinical and cost effectiveness of
28 interventions for mobility?
 - 29 3.3 For adults with MS, what is the clinical and cost effectiveness of
30 interventions for fatigue?
 - 31 3.4 For adults with MS, what is the clinical and cost effectiveness of
32 interventions for memory and cognitive problems?

1 3.5 For adults with MS, what is the clinical and cost effectiveness of
2 interventions for ataxia and tremor?

3 4 Coordination of care and the role of MS nurse specialists

4 4.1 What is the clinical and cost effectiveness of processes of care,
5 including the role of MS specialist nurses, to improve care coordination
6 and health outcomes?

7

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

10 **3.6 Main outcomes**

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

- 13 • health-related quality of life, for example assessed using EQ-5D, SF-36,
14 Leeds MS quality of life scale, MS impact scale
- 15 • patient-reported outcomes, for example symptoms, activities
- 16 • impact on carers
- 17 • level of disability, for example, assessed using functional scales such as
18 the Expanded Disability Status Scale (EDSS), the Multiple Sclerosis
19 Functional Composite (MSFC), the Cambridge Multiple Sclerosis Basic
20 Score (CAMBS), the Functional Assessment of Multiple Sclerosis (FAMS)
21 or the National Fatigue Index (NFI)
- 22 • mobility, for example assessed using the MS walking scale
- 23 • cognitive functions, such as memory and concentration, and physical
24 symptoms including fatigue, spasticity, spasms, assessed by validated and
25 disease-specific scales, questionnaires or similar instruments, for instance
26 the Scripps Neurologic Rating Scale (SNRS) or the Krupp Fatigue Severity
27 Scale (FSS).
- 28 • psychological symptoms assessed by validated and disease-specific
29 scales, questionnaire or similar instruments
- 30 • pain assessed using scales such as the Visual Analogue Scale (VAS)
- 31 • health service use for example hospitalisations and outpatient
32 appointments

- 1 • adverse effects of treatment.

2 **4 NICE quality standards and NICE Pathways**

3 **4.1 NICE quality standards**

4 **NICE quality standards that may need to be revised or updated when** 5 **this guideline is published**

- 6 • Multiple sclerosis (2016) NICE quality standard 108.

7 **4.2 NICE Pathways**

8 When this guideline is published, we will update the existing NICE Pathway on
9 [multiple sclerosis](#). NICE Pathways bring together everything NICE has said on
10 a topic in an interactive flowchart.

11 **5 Further information**

This is the draft scope for consultation with registered stakeholders. The consultation dates are 20 January 2020 to 17 February 2020.

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.

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