



Multiple Sclerosis Society

Professional resources  
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# Translating the NICE and NSF guidance into practice

A guide for occupational therapists

College of  
Occupational  
Therapists





# Foreword

**Multiple sclerosis (MS) is the most common disabling neurological condition affecting young adults. We estimate that in excess of 85,000 people in the UK have MS, a disease for which currently there is no cure.**

When MS is active, areas of the brain and spinal cord become inflamed and damaged by the body's own immune system. It is very hard to predict how MS will affect a person, as the course it takes is different in every individual. What is definite, however, is that it makes life unpredictable for everyone; it affects every aspect of life, and also impacts on the family. At different times in their lives, people with MS will need the help of neurologists, MS specialist nurses, therapists, social workers and many others. Sometimes it can be troublesome getting the help they need at the time it is needed.

The MS Society is delighted that the National Institute for Health and Clinical Excellence (NICE) *Clinical Guideline 8: Multiple Sclerosis* (2003) spells out clearly what services are needed for people with MS at a local level. This excellent guideline offers all of us who are concerned about MS a key opportunity to work together to raise standards of care and services. People with MS have always asserted that occupational therapy plays a vital part in maintaining health and independence. The NICE guideline for MS puts neuro-therapists at the heart of the specialist neurological rehabilitation team that is required for the local MS population.

Since its publication in March 2005, the Department of Health's *National Service Framework for Long-term Conditions* (NSF) has given further guidance to occupational therapists.

This occupational therapy guidance document (based on the successful *Translating the NICE and NSF guidance into practice – a guide for Physiotherapists* (MS Society, 2008, Second edition)) will provide essential further guidance for all occupational therapists in their key role in the care and management of people with MS. It aims to demystify the topic by extracting the most pertinent elements of the multi-dimensional NICE MS guideline and the NSF, providing more salient detail for busy clinicians. It poses clear reflective questions and audit statements for occupational therapists and assistants to consider when faced with the complexities a person with MS may have to deal with. We hope that it will enable every occupational therapy practitioner to engage with the NICE MS guideline and the NSF, and to translate them into practice with enthusiasm.

As well as abiding by and implementing the guidelines, it is essential that an occupational therapy practitioner undertakes routine risk assessments and maintains their training in manual handling, as appropriate for people with a long-term neurological condition.

As a result of the successful implementation of the NICE guideline and the NSF, people with MS should expect a more consistent provision of services - through the wider availability of specialist neuro-rehabilitation teams that are of high quality and are available when they need them.

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A pdf version of this publication is available at [www.mssociety.org.uk/professionals](http://www.mssociety.org.uk/professionals)



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This guide for occupational therapists draws on the 2003 National Institute for Health and Clinical Excellence *Clinical Guideline 8: Multiple Sclerosis. Management of multiple sclerosis in primary and secondary care* ([www.nice.org.uk](http://www.nice.org.uk)) and the Department of Health 2005 *National Service Framework for Long-term Conditions* ([www.dh.gov.uk](http://www.dh.gov.uk)).

# Background

When NICE committed to develop a guideline for the management of MS in primary and secondary care, those working in the field hoped it was the start of a process that would address the postcode lottery of service provision – where centres of excellence existed alongside areas that had no services at all. Given the authoritative nature of NICE, with its commitment to evidence-based recommendations and consensus on clinical management, the guideline was welcomed as a vehicle to raise standards of care. Unfortunately, the results of a survey undertaken three years after its publication showed that there is little evidence of its implementation across England (Royal College of Physicians and the MS Trust 2008).

The MS Society seeks to support the clinical implementation of the NICE guideline and, as part of an ongoing strategy, supports occupational therapists as one of the key professional stakeholders in the process.

Many saw the introduction of the Department of Health's NSF in 2005 as superseding the NICE guideline, when in fact the two are mutually supporting, as the cross-referencing in this guide demonstrates. By applying the NICE guideline, the quality requirements of the NSF are also being met.

## Aims

This guide aims to:

1. Support occupational therapists in the implementation of the NICE and NSF guidance for the management of MS in primary and secondary care.
2. Place the NICE and NSF guidance in the context of everyday occupational therapy practice.
3. Pose key questions for occupational therapists in relation to clinical decision-making in MS.
4. Direct occupational therapists to additional information and resources.

## How to use this guide

It is important to read this publication alongside the 2003 NICE guideline for MS and the 2005 Department of Health NSF for Long-term Conditions, as these documents expand on the information contained within this guide.

For further information on the recommendations and a breakdown of the aims and rationale behind each quality requirement, please refer to the NICE and NSF documents.

The guidance section of this publication (on pages 8 to 50) lists the NICE recommendations most relevant to occupational therapists, and shows how they link to the quality requirements (QRs) of the NSF.

Alongside quotations from these two documents are questions and statements that have been designed to assist occupational therapists in their clinical decision making. These do not cover every eventuality but should encourage clinicians to think critically about their practice.

Useful resources that complement the extensive reference list in the NICE guideline are given at the end of this guide – to direct you to helpful associations, websites and documents.

# Methodology

Based on the MS Society 2008 physiotherapy guidance, this occupational therapy guide is informed by the consultation with key stakeholders used to develop the physiotherapy version (MS Society, MS Trust, people affected by MS).

## MS Society response to the NICE guideline for MS, in relation to occupational therapy

- identification of the need for guidance to link the NICE MS guideline to clinical practice
- facilitation of an inclusive approach: College of Occupational Therapists, MS Society, College of Occupational Therapists Specialist Section – Neurological Practice
- appointment of project leader with support from MS Society, College of Occupational Therapists project manager
- formation of an advisory working group comprised of specialist MS occupational therapists

## Developing the guide for occupational therapists

- using the structure of the NICE MS guideline
- building on the NICE MS guideline to link to occupational therapy practice
- devising a format to structure the information
  - ‘NICE’ highlights the numbered sections of the NICE guideline for MS most relevant to occupational therapists
  - ‘Key reflections’ raises issues of most relevance to occupational therapists
  - ‘Useful resources’ identifies sources of information
- drafting the document for initial consultation

## Capturing expert opinion

- identification of expert clinicians and academics across the UK
- invitation to one-day workshop which looked at
  - consideration of sections of the NICE MS guideline in groups
  - identification of useful information and resources
- submission of comments on initial draft guide for occupational therapists

## Collating expert opinion

- aggregation of comments on initial draft document and feedback from group work
- devising a format to theme the key reflections in relation to occupational therapy
  - person-centred (important for the person affected by MS)
  - problem (challenging issue)
  - assessment
  - intervention
  - management
- preparation of the final guide for occupational therapists

## Finalising the guide for occupational therapists

- development of the guide by a working group of specialist occupational therapists working with people with MS, and peer review by members of the College of Occupational Therapists Specialist Section, Neurological Practice, Long Term Conditions Forum
- final edit by occupational therapy advisory working group

# 1.1 General principles

## 1.1.1 Communication (QR1)

### NICE

1.1.1.1 All communication with all people with MS should comply with the general principles of good communication. (see Table 1, page 9)

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

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

### NSF

QR1 People with long-term neurological conditions are offered integrated assessment and planning of their health and social care needs. They are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.

#### Evidence-based markers of good practice for QR1

Arrangements are in place to ensure that:

- all people have a named point of contact for advice and information.

Local arrangements for providing information ensure that:

- people receive timely, quality-assured, culturally appropriate information in a range of formats on: all relevant aspects of service provision; the condition and how best to manage it; wider social inclusion issues (eg employment and transport).

People with long-term neurological conditions and their carers can access education and self management programmes, tailored to their individual needs, and these are available at different stages of the condition.

## Key reflections

1. Have I fully considered what this person wants in terms of information and advice?
2. Could the following dimensions have a potential negative impact on communication?
  - depression
  - cognitive deficits
  - anxiety
  - visual problems
  - distraction by issues, eg
    - bladder and bowel disturbance
    - fatigue
  - situational/ contextual factors, eg
    - environment
  - my own skills and knowledge
3. Could any of the following assist my communication?
  - plain language
  - written instructions
  - access to translation
  - information available in a variety of languages
  - access to interpreter
  - asking if they would like copies of relevant correspondence
  - person/ therapist agreement of goals in partnership
  - repeating / presenting information in different ways
  - using a communication aid
  - considering the environment, eg a private room
  - using a diary
  - considering the timing of sensitive information eg introduction of walking aids

4. Would it be helpful for a family member or carer to be present, eg to remember details, ask questions or reinforce information?

5. Has the person been offered a named point of contact or do I know who to refer them to for both specific and general issues?

## Audit statements

1. Information is available and offered in a variety of formats and languages.
2. Professionals have access to all relevant records and information to assist the person in their decision making.
3. The person has an individual care plan to cover current and anticipated needs, with appropriate contact numbers.
4. Access to all appropriate sources of information, both local and national, are available to service user and health/ social care professional.

# Table 1 Principles of good communication in healthcare

<b>Principle</b> <b>In any communication, the healthcare professional should:</b>	<b>Comment</b>
Communicate in a suitable environment, usually a quiet area or room free from distraction or interruption	Privacy and quiet are important
Seek agreement from the person with MS that anyone present can be there and ensure that as far as possible anyone he or she wants present is there	Consider especially students and family
Start by asking what the person knows or believes already	Establishes expectations
Establish the nature and extent of the information that the person wishes to receive	Establishes expectations
Consider carefully the balance between the benefits and the risks associated with giving each item of information	Once given, information cannot be withdrawn
Tailor the communication to the person's: <ul style="list-style-type: none"> <li>– specific situation</li> <li>– communication</li> <li>– culture</li> </ul>	Makes information relevant
Limit information given to that within their own knowledge, referring on to others as necessary for more detailed information	Do not give information if uncertain about it
Clarify any choices and options the person may need to choose, specifying: <ul style="list-style-type: none"> <li>– likely outcomes of each choice</li> <li>– benefits and risks of each choice</li> </ul>	Both in diagnosis and treatment
Offer back-up with information being given: <ul style="list-style-type: none"> <li>– in different ways (e.g. written leaflets, tapes)</li> <li>– by different people (e.g. specialist nurse)</li> <li>– at another time (e.g. follow-up appointment)</li> </ul>	Information is often forgotten
Inform the person with MS about any recommended local or national sources of further information, including employment and voluntary sector sources	Allows person with MS to follow up and take more control
Consider need for emotional support during process, especially if the information might be stressful, and arrange emotional support if needed	Should be considered an intrinsic part of the process
Document in notes and inform other closely-involved healthcare staff, especially the general practitioner, what has been communicated over time and across settings	Ensures consistency over time and across settings

(NICE 2003, p59)

## 1.1.2 Emotional support

(QR9, 11)

### NICE

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

### NSF

QR9 People in the later stages of long-term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms, offer pain relief, and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care.

QR11 People with long-term neurological conditions are to have their specific neurological needs met while receiving care for any other reasons in any health or social care setting.

## Key reflections

1. How can I provide the right environment to build a therapeutic relationship with this person? Am I:
  - allowing sufficient time to explore and express feelings
  - being empathetic
  - using plain language
  - allowing them to talk freely
2. Have I recognised the impact that this person's emotional state may have on their ability to participate in occupational performance areas?
3. Have I considered factors that might impact on this person's emotional state eg fear, anxiety, reduced sleep and fatigue?
4. Does this person have a useful support network, such as family, friends and work colleagues?
5. Might the following be useful in my management strategy?
  - identifying other sources of support eg meeting others affected by MS and educational courses for newly diagnosed people
  - arranging access to 'review' appointments, to ensure the provision of support over time
  - identifying referral routes if more formal emotional support is required eg counsellor or more specialist palliative support

## Audit statements

1. Factors that are likely to affect the person's emotional state are documented.
2. The person's support network is documented.

## 1.1.3 Encouraging autonomy/ self-management

(QR1, 4, 5, 6, 7, 8, 9, 11)

### NICE

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

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

- Information and advice provided in written, audio or other media on:
  - specific activities that promote health maintenance and prevent complications
  - changes in their health that may require them to take further action
  - the condition and its management (including both local and national sources of further information and support in clear and accessible language).

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

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

### NSF

QR4 Timely, good, rehabilitation offers quality people the chance to achieve goals for independent living.

QR5 People with long-term neurological conditions living at home are to have ongoing access to a comprehensive range of rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy, and help them to live as they wish.

QR7 People with long-term neurological conditions are to receive timely, appropriate assistive technology/equipment and adaptations to accommodation to support them to live independently, help them with their care, maintain their health and improve their quality of life.

## Key reflections

1. Have I explained the role of occupational therapy and established what this person expects from me?
2. Am I person-centred in my approach, and is the person optimally engaged in the management of their condition?
3. Have I facilitated the person to identify priorities and goals for intervention?
4. Have I considered what factors may impact on this person's ability to participate actively in self-management? For example:
  - cognition
  - physical ability
  - fatigue
  - mental health
  - pain
  - co-morbidities
5. Have I considered which occupational therapy model, frame of reference and approach would be appropriate when working with the person to encourage autonomy and self-management?
6. Have I considered different approaches to self-management? For example:
  - education
  - compensation
  - rehabilitation
  - adaptation
7. Have I informed the person on how to access services as required?
8. Am I aware of an Expert Patient Programme in my area?

## Audit statements

1. Ongoing informed consent for unchanged routine care is documented in the notes.
2. Local self-management programmes for the different stages of MS are offered or signposted and recorded in the notes.
3. Consent for changes in care or the care plan is documented in the notes.
4. The routes and mechanisms for ongoing access or re-referral to services have been explained, followed up with a written explanation, and documented in the notes.

NB Services might always be accessible, or might have a limited number of sessions. Some cases may be closed. Services users should always have an explanation of the process for re-assessing the service, in writing, with appropriate contact details.

## 1.1.4 Support to family and carers

(QR10)

### NICE

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

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

### NSF

QR10 Carers of people with long-term neurological conditions are to have access to appropriate support and services that recognise their needs both in their role as carer and in their own right.

## Key reflections

1. Have I gained consent to contact and involve family members and carers?
2. Have I identified family and/or carers' issues and concerns?
3. Have I identified the impact of MS on their family, eg signs of carer strain/involvement of children in provision of care?
4. Have I established the family/carers' understanding of the condition?
5. Have I considered any cultural issues regarding the psycho-social environment that might impact on my practice? For example:
  - dependence is a mutually acceptable and beneficial concept in some cultures
  - tasks done in specific ways or with the use of specific equipment (manual handling) such as toileting, feeding and so on
6. Have I identified potential referral routes to other sources of support? Such as:
  - advocacy services
  - voluntary organisations
  - benefits agencies
  - day centres
  - family therapy services
  - the local branch of the MS Society
  - other relevant health and social care services
  - respite centres
  - social work care management services
  - MS specialist practitioners

## Audit statements

1. Consent for the carers to be involved has been obtained from the service user and documented in the notes.
2. Carers' issues and concerns are documented.
3. Routes to access appropriate sources of support (as in 6 above) are up to date and easily available to the health/ social care professional.

# 1.1.5 Assessment and measurement

(QR1, 2, 3, 4, 5, 7, 8, 11)

## NICE

1.1.5.1 The review checklist [shown in Table 2, page 14] should be used each time a person with MS starts a new 'episode of care' (including initial diagnosis), and whether or not the presenting issues relate to the MS. The healthcare professional should:

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

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

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

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

1.1.5.4 When initially assessing an individual, and when undertaking any treatment, healthcare staff should consider the characteristics of a measure [see Table 3, page 15] recognising that:

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

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

## NSF

**QR1 Rationale** An integrated approach to assessment of care and support needs, and to the delivery of services is key to improving the quality of life of people with long-term neurological conditions...The most effective support...is provided when local health and social services teams communicate; have access to up-to-date case notes and patient-held records and work together to provide coordinated services.

**QR2 Rationale** Improved diagnosis can result from...improved training in recognising important symptoms for all staff likely to have contact with people first presenting with neurological problems.

## Key reflections

1. Have I completed a thorough assessment of occupational performance and performance components, taking into account the person's needs and wants and any potential risks?
2. When assessing, have I considered the following?
  - the type of MS (benign, relapsing remitting, secondary progressive, primary progressive)
  - the phase of MS
    - newly diagnosed
    - relapsing remitting – mild, moderate or severe symptoms
    - secondary progressive – mild, moderate or severe symptoms
    - primary progressive – mild, moderate or severe symptoms
    - benign MS
3. Do the assessment tools I am using help me to identify the person's difficulties?
4. Do the outcome measures I am using measure what occupational therapy intervention is aiming to change with an individual (objective and subjective, standardised, non-standardised)?
5. Do I need to assess the person in a variety of different environments and contexts?
6. Have I shared the results of the assessment with the person and, where appropriate, other professionals?

## Audit statements

1. There is evidence that results of the assessments have informed the intervention and are documented in the notes.
2. There is evidence of completed outcome measures in client documentation.
3. Information sharing and any consent issues are documented in the notes.

# Table 2 Review checklist

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

## Initial question

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

## Activity domains

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

- "Are you still able to undertake the following, as you wish:
- vocational activities (work, education, other occupations)?
  - leisure activities?
  - family roles?
  - shopping and other community activities?
  - household and domestic activities?
  - washing, dressing, using the toilet?
  - getting about (either by walking or in other ways) and getting in and out of your house?
  - controlling your environment (opening doors, switching things on and off, using the phone)?"

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

## Common impairments

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

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

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

## Final question

It is always worth finishing off with a further open-ended question: "Are there any other new problems that you think might be due to MS that concern you?"

# Table 3 Characteristics of a useful measure

When considering measuring the effect of a treatment or the extent of some aspect of a person's situation, any potential measures should be considered against the following characteristics:

Domain	Question
Feasibility	Can the measure be used in this situation? Will the process be acceptable to the person with MS?
Utility	Is the measure going to be useful? Will the time and effort required be worthwhile?
Validity	Is the measure going to measure whatever it is I am interested in? Does the measure also include unrelated phenomena that reduce its validity?
Reliability	How much variation occurs from time to time when there is no 'real' change? How much variation occurs between observers?
Sensitivity	Will this measure detect the change or difference that I am looking for? Does the measure cover the whole range of possible change?
Communicability	Can I communicate this result? Will other people involved understand the result?

(National Collaborating Centre for Chronic Conditions 2004, p28)

# 1.2 Teamwork

## 1.2.1 Teams and goal setting

(QR1, 2, 4, 5, 6, 7, 8, 9, 10, 11)

### NICE

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

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

1.2.1.2 The goals set should:

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

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

### NSF

QR4 People benefit most from specialist neuro-rehabilitation if they are:

- assessed by a multi-disciplinary specialist team as early as possible in the acute setting, to provide specialist support and advice to prevent secondary complications developing.

## Key reflections

1. How can I actively involve this person throughout the goal setting process?
2. How does my service enable effective teamwork? Methods could include:
  - patient-held records
  - ensuring therapists ask the person affected by MS to tell them who else is involved in their management
  - joint visits eg workplace, gym
  - inter-professional care pathways
  - joint clinics/care management discussions with health and social care professionals
3. Have I ensured effective goal setting?
  - joint goal setting with other health and social care professionals
  - identification of SMART goals (Specific, Measurable, Achievable, Realistic and Time-limited)
  - regular review and prioritisation of goals
4. Have I considered longer-term requirements given the progressive nature of the condition?

## Audit statements

1. There is evidence of communication between interdisciplinary agencies to ensure care is coordinated along a dedicated, agreed pathway, and this is documented in the notes.
2. All interventions are well documented to national standards, are timely, person-centred and goal orientated.

## 1.2.2 Specialist services

(QR1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11)

### NICE

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

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

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

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

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

- dietetics
- liaison psychiatry
- continence advisory and management services
- pain management services
- chiropody and podiatry
- ophthalmology services.

### NSF

QR4 People with long-term neurological conditions who would benefit from rehabilitation are to receive timely, ongoing, high quality rehabilitation services in hospital or other specialist setting to meet their continuing and changing needs. When ready, they are to receive the help they need to return home for ongoing community rehabilitation and support.

People with complex needs may require ongoing access to specialist neuro-rehabilitation as their needs change.

## Key reflections

1. Am I aware of the full range of specialist services in my area that could benefit this person?
2. What are the referral criteria and pathways for specialist services in my area?
3. If I work in a specialist service, do I provide feedback on my assessment and management plans to relevant people involved in this person's management?
4. If I work in a specialist service, do I support other health and social care professionals? For example with:
  - education and training
  - joint working
  - the development of care pathways
5. Can I advise or make referrals to other primary and secondary care teams to ensure problems are identified early and rehabilitation provided at appropriate points and settings?
6. Is there a system in place to notify the specialists if a person with MS is admitted to a generalist setting with problems associated with their MS?
7. Am I aware of how to signpost people with MS to other services as required?

## Audit statements

1. Services available to people with MS are documented and kept up to date.
2. Team members are documented in the notes with relevant contact details.
3. Re-referral mechanisms to and back into the services available are clear, unambiguous and available to the health professional and service user.
4. There is evidence of communication between interdisciplinary agencies to ensure care is coordinated and this is documented in the notes.

## 1.2.6 Support over time

(QR1, 3, 4, 5, 6, 7, 8, 9, 11)

### NICE

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

- responding in a timely and flexible way to the intermittent acute needs of people with MS, especially in the early phases
- identifying and reducing the risks of complications that might develop in the individual.

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

- ensure that any necessary long-term support needs are met
- ensure that the person with MS knows who to contact and how to contact them, in the event that the person with MS experiences a change in his/her situation
- discuss with the person with MS whether they want a regular review of their situation and, if so, agree on a suitable and reasonable interval and method of review (for example, by phone or post or as an outpatient).

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

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

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

### NSF

QR1 Rationale Successful care planning is person-centred and recognises that needs will change over time.

## Key reflections

1. Does the person know how to re-refer himself or herself to appropriate services?
2. Does my service provide flexibility to the person's changing needs?
3. Is it occupational therapy that is required or is it more appropriate for another healthcare professional to be involved?
4. Have I identified a means of communication between health and social care services (and other agencies)? For example:
  - integrated care meetings
  - clinical review meetings
  - assessment/discharge reports
  - telephone calls

## Audit statements

1. Re-referral mechanisms back into the services available are clear, unambiguous and available to the service user.
2. The end of episode of care (discharge) summary includes information on how the person refers themselves back into the service.
3. There is evidence of communication between interdisciplinary agencies to ensure care is coordinated and this is documented in the notes.

## 1.2.4 Timing of actions

(QR 1,3,4,6,7)

### NICE

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

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

## Key reflections

1. Does my service have clear clinical priorities and/or agreed protocols to promote timely interventions?
2. If so, do I use these routinely to assist in managing my work load and resources?
3. Do I regularly attain the views of the person and their family regarding how timely they feel services have been initiated?
4. Am I aware of appropriate waiting times for services I refer to in order to communicate this to the person?
5. Have I considered the impact of delay on the provision of intervention?

## Audit statements

1. Policies and procedures have review dates.
2. Policy and procedure review dates are monitored and audited regularly to assess compliance and quality of service.
3. Appropriate recommendations and changes are made as a result of this monitoring and changes in best practice.
4. There is documented evidence of service user involvement to assess the management and quality of service.
5. Up-to-date service waiting times are available to occupational therapy practitioners and/ or members of the public.

## 1.2.5 Within team communication

(QR1)

### NICE

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

## Key reflections

1. Am I knowledgeable in the application of this classification system?
2. Do I routinely use the appropriate vocabulary within my professional communications?

## Audit statements

1. Copies of the WHO ICF are easily available to occupational therapy practitioners for reference.
2. All documentation demonstrates the use of the WHO ICF model of illness and its vocabulary.

# 1.3 Diagnosis

## 1.3.1 Involving the individual in the diagnostic process

(QR1, 2)

### NICE

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

- put in touch with, or introduced to, a skilled nurse or other support worker, ideally with specialist knowledge of MS and/or other neurological conditions and counselling experience
- offered written information about local and national disease-specific support organisations including details of local rehabilitation services
- offered information about the disease, preferably in the form of an information pack, specific to the newly diagnosed.

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

### NSF

QR1 People with long-term neurological conditions...are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.

## Key reflections

1. Am I competent to be offering diagnostic support to the person newly diagnosed with MS?<sup>1</sup>
2. How can I ensure my services are offered in the early management of this newly diagnosed person?
3. When providing information about MS and support organisations, have I considered the following?
  - what this person is asking for
  - how much information they are ready to receive
  - whether the format is appropriate for their understanding of MS
  - the timescale: what period of time is necessary to deliver the information
  - how additional information can be obtained if required
4. Does the service I provide offer educational programmes to newly diagnosed people such as Getting to Grips with MS?<sup>2</sup>
5. How can I be involved in contributing to such a programme (eg vocational advice and fatigue)?

## Audit statements

1. There is evidence of CPD relating to all aspects of MS.
2. There is evidence of ability to comply with the competency framework as applicable to occupational therapy practitioners.

<sup>1</sup> Competencies for MS specialist nurses: Downloadable as pdf file from <http://www.mstrust.org.uk/>

<sup>2</sup> This course has been developed by the MS Society and is run locally by MS Society branches and MS specialist nurses. Log onto <http://www.mssociety.org.uk/>

## 1.3.3 Diagnosis of an acute episode

(QR1, 2, 3)

### NICE

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

### NSF

QR2 Some people with long-term neurological conditions may need planned clinical reviews to monitor their condition and unplanned reviews if they deteriorate suddenly or develop complications.

## Key reflections

1. Am I aware of the impact of symptoms on occupational performance that may be associated with an acute relapse, and is occupational therapy appropriate at this stage?
2. Could this person's deterioration in symptoms/occupational performance be caused by factors other than a relapse eg urinary tract infection, constipation, stress, anxiety, pressure areas?
3. Do I need to involve other professionals at this time eg medical review, care manager, physiotherapy?
4. Have I considered that the person may require immediate support and equipment at the point of relapse that may not be needed once recovered, or which may require review on recovery eg wheelchair?

## Audit statements

1. Records of response times for people with MS to the services offered are monitored and kept within the defined limits of the service specifications.
2. Other factors that may influence the course of the disease process in each episode are documented.
3. The service offers access to management of acute episodes (relapses).

# 1.4 Treatment

## 1.4.2 Rehabilitation for an acute episode

(QR1, 2, 3, 4)

### NICE

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

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

### NSF

QR4 Early rehabilitation... reduces the risk of developing preventable secondary complications and reduces length of stay in hospital and re-admission rates.

## Key reflections

1. Am I aware of the range of symptoms that may be associated with an acute relapse and have I considered if occupational therapy intervention is appropriate at this stage?
2. Have I considered the importance of occupational therapy as part of a multi disciplinary/ inter-disciplinary rehabilitation programme in the rehabilitation of an acute relapse?
3. Have I considered that the person may require immediate support and equipment at the point of relapse that may not be needed once recovered, or which may require review on recovery e.g. wheelchair?
4. How quickly can my service respond to a need for occupational therapy? Should we offer nurse/therapy-led clinics?
5. Am I aware that this person's deterioration in occupational performance may be caused by factors other than a relapse e.g. urinary tract infection, constipation, stress, anxiety, pressure sores?
6. Do I need to involve other health and social care professionals at this time e.g. medical review, home care manager?
7. Do I have a clear pathway of referral?

## Audit statements

1. Referral pathways into services are clear, unambiguous and regularly monitored and updated as appropriate.
2. Records of response times for people with MS to the services offered are monitored and kept within the defined limits of the service specifications.
3. Other factors that may influence the course of the disease process in each episode are documented.

# 1.5 Altering the risk of relapse

## 1.5.2 Pregnancy

(QR1, 3, 4, 5, 7, 8, 9, 11)

### NICE

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

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

### NSF

QR2 People may also need advice and support in managing side-effects or if they are considering stopping treatment, for example during pregnancy, and should have the opportunity to discuss this with their health professional.

## Key reflections

1. Am I aware of the physical and emotional impact of pregnancy upon this person?
2. Can I offer flexible, holistic care to address specific needs during pregnancy?
3. Have I considered the special needs of this person e.g. fatigue, changing mobility?
4. Am I confident in my knowledge of the disease trajectory over the pregnancy/ post-partum period?
5. Have I considered how to discuss planning for the higher potential of a relapse post-partum?
6. Have I considered if and when it would be appropriate to offer advice on any of the following?
  - back care
  - fatigue management
  - postural control
  - activities of daily living
  - childcare specific tasks eg feeding, changing, playing, bathing
  - moving and handling the baby
  - equipment that may assist with the above activities
7. Have I identified other health and social care professionals who could benefit this person?  
For example:
  - MS specialist nurse for general advice
  - neurologist for advice on changes to medication
  - physiotherapist regarding back care, mobility, exercise, and fitness
  - social worker for adjustment to care package
  - women's health physiotherapist.

## Audit statements

1. The service has systems in place to monitor women in the post-partum period and offer timely, responsive interventions.
2. The service has documented links and referral systems to other professionals involved in care provision.

# 1.6 Rehabilitation and maintenance of functional activities and social participation

## 1.6.1 General points

(QR1, 4, 5, 6, 7, 8, 10)

### NICE

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

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

1.6.1.2 If the limitation persists, despite treatment of any identified cause, the person with MS should be assessed by a multi-disciplinary service, specialised in neurologically-based disability. This service should implement a rehabilitation programme.

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

- establishing the wishes and expectations of the person with MS
- assessing and, if necessary, measuring relevant factors, in order to identify and agree goals with the person; these might include one or more of the following:
  - identifying and treating any treatable underlying impairments
  - giving task-related practice of a specific activity or activities
  - providing suitable equipment (with training in its use)
  - altering the environment as needed
  - teaching others how to assist with (or take over) tasks.
- monitoring progress against set goals; the goals should be reviewed and reset, until no further goals exist and no further interventions are needed.

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

### NSF

QR5 People with long-term neurological conditions face many complex challenges in attempting to live as they would wish. At different times, they can experience physical, emotional, psychological and social difficulties. These can limit their ability to participate in society and can lead to social isolation, anxiety and depression. These problems can cause increased dependency on care services and can affect partner and sexual roles, as well as placing an additional burden on family and friends. These effects are long-term and people and their families may need ongoing intervention and support appropriate to their needs.

QR7 People with long-term neurological conditions can find it difficult to maintain their independence in the face of increasing disability. Providing up-to-date and appropriate assistive technology/ equipment and home adaptations can help people to live with their condition and promote social inclusion and independence.

## Key reflections

1. Have I asked this person what they want to achieve through rehabilitation, and discussed to what extent their goals are achievable?
2. Have I offered the person a holistic occupational therapy assessment considering physical, emotional, psychological, social and environmental contexts, and access to participatory activities?
3. Do I have a clear and empathetic understanding of what the new limitations mean to the person in terms of their functional level and quality of life?
4. Have I considered any secondary factors that may affect functional activity and discussed problem-solving strategies?
5. Have I considered timescales?
6. Can I offer rehabilitation within the person's most appropriate environment eg at home, work, leisure?
7. Have I developed protocols to help coordination and collaboration with other specialist health services that might be needed eg health and social care/ voluntary agencies?
8. Does my service have the appropriate specialist knowledge and skills to assist the person or their carers?
9. Is the devised care plan client-centred with clear achievable/ measurable goals, taking into account family and carers' needs?
10. Have I considered prescription of assistive techniques/ equipment and devices, and provided suitable training?
11. Have I considered alterations to the environment, with referral to other agencies as appropriate?

## Audit statements

1. The documented occupational therapy functional assessments are holistic and person-centred, with clear, achievable, measurable intervention goals, and with agreed re-assessment dates.
2. The family and carer needs are taken into account and documented.
3. Family and carers are offered appropriate guidance and training in the most suitable environment where applicable.
4. There is documented evidence of communication and liaison with other MDT members across organisations, and evidence of ongoing communications with the person and their family.
5. Consent issues for information sharing have been addressed and documented.

## 1.6.2 Vocational activities – employment and education

QR6

### NICE

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

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

1.6.2.3 The results of the assessment should be used:

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

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

### NSF

QR6 People with long-term neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support to enable them to find, regain or remain in work and access other occupational and educational opportunities.

## Key reflections

1. If the person is in work or education, have I asked if they have any problems? For example:
  - has the person identified work as a priority area?
  - have I discussed with this person the importance of work (including values, roles, habits and beliefs)?
2. Am I aware of any physical, cognitive, sensory or psychological issues that are interfering with their ability to work? For example:
  - mobility
  - dexterity and coordination
  - fatigue
  - memory
  - vision
  - anxiety or low mood
3. Have I considered referral onwards for assessment to a specialist vocational rehabilitation service or a specialist neuro-rehabilitation service?
4. Do I know if the person has disclosed their diagnosis in the workplace? Have I considered how this will impact intervention?
5. Do I have adequate knowledge of the Disability Discrimination Act (DDA) 1995 and 2005?
6. In my assessment, have I considered the following?
  - what the job involves
  - alternative strategies, equipment and adaptations that may help them to optimise/manage their performance at work
  - whether the person needs help to manage employers' expectations, to educate the employers about the DDA, the condition and/or reasonable adjustments that may be made
  - transport to and from work
  - access to the workplace and facilities within it
  - whether there is a supportive attitude at the workplace and at home
7. Have I considered activity analysis and the reasonable adjustments that may be required to maximise performance at work? For example:
  - environmental adaptation
  - provision of equipment
  - adaptation of tasks
  - changes to working hours
  - support workers for specific duties
8. Have I considered if a workplace visit is appropriate and/or essential?
9. Have I identified other professionals who might benefit this person? For example:
  - disability employment advisors
  - other health and social care workers
  - work-based healthcare professionals
  - human resource managers
  - union representation
  - access to work schemes
  - other services such as Working Life Service and other employment opportunities
  - Disability Law Service and law centres
  - ACAS (Advisory, Conciliation and Arbitration Service)
  - computer adaptations
10. When work cannot be maintained, have I looked at rebalancing occupational roles with leisure, social and volunteering activities?

## Audit statements

1. Work / education issues have been addressed and documented.
2. If the person has disclosed their diagnosis at work it has been clearly documented.
3. The DDA is readily available for reference purposes.

## 1.6.3 Leisure and social interaction

(QR1, 5, 7, 8, 10, 11)

### NICE

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

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

### NSF

QR5 Existing good practice and evidence suggest that good quality, fully integrated rehabilitation and social care includes... interventions that focus on wider social participation, such as leisure and recreational activities, including those provided by the voluntary sector.

## Key reflections

1. Have I identified the person's previous and current leisure activities?
2. Have I explored the person's needs and wants in relation to leisure pursuits and social activities of their choice?
3. Am I aware of all the obstacles that may prevent their participation in the chosen leisure pursuit?
4. Am I aware of local services, including the voluntary sector that could assist?

## Audit statements

1. All occupational therapists in your service ask about leisure and social participation during an initial assessment, and document this in the notes.
2. Up-to-date and comprehensive resources on leisure activities in the area covered by the service are available to occupational therapy practitioners and service users.

## 1.6.4 Mobility

(QR1, 2, 3, 4, 5, 6, 7, 10, 11)

### NICE

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

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

### NSF

QR5 People with long-term neurological conditions living at home are to have ongoing access to a comprehensive range of rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them to live as they wish.

## Key reflections

1. In my assessment have I considered functional mobility in its broadest sense? Including:
  - standing to carry out daily tasks, transfers, reduced bed mobility
  - community transport.
2. What factors, other than physical impairments, might interfere with this person's mobility? For example:
  - unsuitable equipment or lack of equipment
  - fatigue eg achieving a balance between walking and participation in other activities of daily living while considering fatigue and energy costs
  - cognitive deficits
  - sensory deficits
  - psycho-social problems
  - de-conditioning.
3. Have I discussed potentially sensitive issues such as the use of wheelchairs, rails, and/or stair-lifts, in order to support this person in making the best choices at this point in time?
4. Have I considered if other health and social care professionals could improve this person's mobility? For example:
  - physiotherapists
  - mobility centres eg driving assessment
  - local wheelchair services
  - other rehabilitation services

## Audit statements

1. Full functional mobility assessments of previous and current levels have been undertaken and documented.
2. Provision of, or referral for, equipment and adaptations to maximise the person's functional mobility has been made and documented in the notes.

## 1.6.5 Activities of daily living

(QR 1,2,4,5,6,7,8,9,10,11)

If a person has a problem with activities of daily living (ADL), they should receive an assessment from a multi-disciplinary team, which should always include an occupational therapist. Ensuring choice and control is fundamental to the person's sense of dignity and independence.

Key considerations around personal care should include:

- reliable and flexible choice of accommodation options
- appropriate respite and longer term care settings
- information about Direct Payment schemes.

### NICE

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

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

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

1.6.5.2 A comprehensive assessment of this type should:

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

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

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

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

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

### NSF

QR 8 Health and social care services work together to provide care and support to enable people with long-term neurological conditions to achieve maximum choice about living independently at home.

## Key reflections

1. Have I assisted the person to identify priorities for activities of daily living involving family/carers as appropriate?
2. Am I able to assess a person in different environments such as home, work and community?
3. Am I able to assess a person on more than one occasion if required?
4. Has my assessment taken into account both current and future needs of the person?
5. Am I able to work in partnership with social care services and the voluntary sector?

## Audit statements

1. There is evidence that when an occupational performance problem has been identified by any member of the multi-disciplinary team, an assessment has been undertaken by an occupational therapist.
2. There is evidence of person-agreed goals.
3. There is evidence of intervention goals being reviewed.

## 1.6.6 Equipment, adaptations and personal support (QR1, 6, 7, 8, 10, 11)

### NICE

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

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

The environmental changes considered should include the following:

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

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

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

### NSF

QR 7 People with long-term neurological conditions are to receive timely, appropriate assistive technology/ equipment and adaptations to accommodation to support them to live independently; help them with their care; maintain their health and improve their quality of life.

## Key reflections

1. Have I considered the following in my assessment?

- the person's abilities and support systems available
- what equipment this person already has and whether it is still appropriate
- whether new equipment could overcome the current problem and/or prevent deterioration
- the changing needs of this person – do I need to plan ahead (eg wheelchair and seating provision/home alterations/environmental control systems)
- whether this person, their family and carers, are confident and safe in using specific handling techniques and their equipment
- whether a joint assessment with other health and social care professionals would be useful
- whether there are funding implications in providing this equipment

2. Have I given this person and their family and carers sufficient information and time to consider the equipment options discussed? For instance:

- information about direct payments, individual budgets and voucher schemes

3. When providing new equipment have I ensured the following?

- there are appropriate mechanisms in place to monitor and review equipment
- a checklist of maintenance is in place
- contact details of repairers are available
- appropriate systems are in place to record the teaching of this person, their family and carers, in the use of equipment and specific handling techniques

## Audit statements

1. There is evidence that all aspects of best practice have been addressed in the assessments undertaken.

## Personal support (1.6.6 cont.) (NSF QR8,9,10,11)

### NICE

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

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

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

### NSF

**QR8** Health and social care services work together to provide care and support to enable people with long-term neurological conditions to achieve maximum choice about living independently at home.

## Key reflections

1. Have I facilitated awareness of how to access the full range of personal care and supported living options/benefits available locally eg do they know about DSS benefits, direct payments, individual budgets and voucher schemes?
2. Have I ensured that I have assessed and provided appropriate strategies to enable the person to optimise his/her functional abilities?
3. Have I facilitated awareness of the person to be able to retain their personal preferences /aspirations, and fulfill their commitments?
4. Have I offered carers educational support/taught skills to ensure the dignity and respect of the person is maintained?
5. Have I taught and documented appropriate safe moving and handling techniques?

## Audit statements

1. There are systems in place to review support systems on at least an annual basis, or after a significant change in condition.
2. There is documented evidence of appropriate education in manual handling.

# 1.7 Managing specific impairments

## 1.7.1 Fatigue

(QR1, 2, 4, 5, 6, 7, 8, 10, 11)

### NICE

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

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

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

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

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

## Key reflections

1. Have I asked this person to describe their fatigue?
2. Have I considered how fatigue affects this person's life? For example:
  - if fatigue limits their expectations of what they can do
  - if certain activities precipitate fatigue eg driving, a hot environment
  - whether they use any coping strategies to manage their fatigue
  - how long it has been a problem
  - to what extent the effort of mobilising is contributing to fatigue
3. Does fatigue present as a major barrier that limits function or causes distress to the person?
4. Have I established if this is an acute (less than six weeks) or chronic (more than six weeks) problem?
5. Have I considered secondary factors, which may be contributing to the experience of fatigue? For example:
  - medication changes/side effects
  - co-morbid infection (eg urinary tract infection)
  - pain/muscle spasms
  - interrupted sleep (as a consequence of urinary frequency, pain, spasms or mood)
  - depression
  - de-conditioning
6. Is the MDT aware of contributory factors (consider source of occupational therapy referral)? If not, refer to MDT to address secondary factors.
7. Have I established if the person requires or is receiving physiotherapy for aerobic and strength training to address de-conditioning?
8. Have I considered if the person requires individual or group intervention to address fatigue?
9. Have I considered the following in the fatigue management programme?
  - education
  - goal setting and measurement
  - coping strategies eg use of fatigue diary, time organisation
  - energy conservation techniques
  - relaxation strategies
  - improving fitness
  - lifestyle and behavioural adjustments
  - access to equipment, support and other resources

## Audit statements

1. Fatigue issues are well documented in the notes and regularly reviewed.
2. General advice and training on how to manage fatigue (including aerobic exercise and energy conservation) has been given and documented in the notes.

## 1.7.2 Bladder problems

(QR7,8,9,10,11)

### NICE

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

1.7.2.3 [People with urgency or urge incontinence sufficient to be bothersome or cause incontinence should be offered advice on changes to clothing, and/or toilet arrangements (for example, provision of a commode downstairs).]

1.7.2.6 Any person with MS who, despite treatment, has incontinence more than once a week should be referred to a specialist continence service for further assessment and advice.

## Key reflections

1. Have I discussed bladder control and continence issues with the person, as part of a holistic assessment?
2. If urinary continence issues are present, have I discussed practical/functional solutions, eg clothing alterations, environmental assessment of toileting facilities?
3. Have I asked if sleep disturbances from nocturia impact on other areas/symptoms eg fatigue?
4. Have I asked if bladder problems may be impacting on functional tasks or social participation – from a physical, psychological, or emotional perspective?

## Audit statements

1. Continence issues are documented in the holistic occupational therapy assessment, taking into account physical, emotional, and social factors.
2. Practical, functional management strategies are discussed and documented.
3. There is evidence of onward referral for specialist advice if recurrent continence issues are present.

## 1.7.5 Weakness and cardio-respiratory fitness (QR1, 2, 4, 5, 6, 7, 8, 10, 11)

### NICE

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

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

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

## Key reflections

1. Have I considered how muscular weakness is impacting on the person's ability to manage daily life tasks?
2. Have I considered the person's overall posture management in a 24-hour period?
3. Have I considered what interventions are required to manage their muscular weakness?  
For example:
  - physiotherapy
  - equipment

## Audit statement

1. Completed physical assessment and its impact on function has been undertaken and documented.

## 1.7.6 Spasticity and spasms

(QR1, 2, 4, 5, 7, 8, 9, 10, 11)

### NICE

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

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

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

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

- standing and weight-bearing through legs
- splints
- serial casting
- special or customised seating, such as tilt-in-space chairs
- intrathecal baclofen
- phenol injections to motor points or intrathecally.

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

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

## Key reflections

1. Have I considered how spasticity will impact on the person's occupational performance?
2. What factors might aggravate this person's spasticity? For example:
  - muscle imbalance
  - contractures
  - pain
  - pressure ulcers
  - constipation
  - ill-fitting splints
  - inappropriate seating
  - infections
  - temperature
2. Have I considered referral to appropriate team members? For example:
  - physiotherapist
  - neurologist
  - neuro-rehabilitation consultant
3. Is this person at risk of developing contractures or abnormal posture as a result of spasticity or secondary complications associated with it (eg muscle shortening, joint stiffness, reduced ligament length)?
4. Have I considered if the person uses spasticity to function (eg to stand or transfer)?
5. If it has been determined that modifying this person's spasticity will improve function and quality of life, have I considered management options? For example:
  - splinting
  - seating
  - positioning

6. What can I do to ensure that I am involved in the early and on-going management of spasticity in collaboration with other health and social care professionals (eg Pathways of Care)?

7. Am I aware of specialist spasticity management services?

## Audit statements

1. All aspects of the spasticity assessment have been documented.
2. There is evidence of onward referral for specialist interventions as appropriate.

## 1.7.7 Contractures at joints

(QR1, 2, 4, 5, 7, 8, 9, 10, 11)

### NICE

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

1.7.7.2 Any person with MS at risk of developing contractures should have the underlying impairments assessed and ameliorated if possible.

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

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

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

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

These are usually combined with:

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

## Key reflections

1. Do contractures impact on occupational performance?
2. Have I identified appropriate management? For example:
  - splinting
  - positioning
  - seating
3. Have I explained to this person and their family and carers the risk of developing contractures and what they can do to minimise this?

## Audit statements

1. Contractures that are a problem to occupational performance have been identified and documented.
2. Evidence of appropriate management and relevant onward referrals is documented.
3. Evidence of explanations of impact/ risk and avoidance strategies being discussed is documented.

## 1.7.8 Ataxia and tremor

(QR1, 2, 4, 5, 7, 8, 9, 10, 11)

### NICE

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

- by a specialist rehabilitation team for medicines, treatment techniques and equipment (using the general principles of goal setting and evaluation recommended).

And, if problems remain severe and intractable, the person should be assessed:

- by a neurosurgical team from a specialist centre, for suitability for an operation to reduce ataxia (after being given a full explanation of its major risks and possible benefits).

## Key reflections

1. Have I considered if this tremor and ataxia impacts upon this person's occupational performance and quality of life? For instance through:
  - social stigma eg walking as if drunk, social isolation
  - lack of autonomy eg dependence for feeding
  - occupational deprivation eg through avoidance of leisure and social activities
2. Have I identified factors that could be contributing to this person's ataxia? For example:
  - stress/anxiety
  - fatigue
  - sensory impairment
  - reduced core stability
3. Have I identified any of the following management strategies as being helpful?
  - advice on positioning and seating
  - interventions to improve postural control eg stabilisation techniques in tasks, provision of equipment
  - education on appropriate compensation strategies
  - environmental controls system
  - adaptation of the physical environment (work, home, social/ leisure)
  - energy conservation/ fatigue management strategies
  - relaxation techniques
4. Have I considered referral to and liaison with other members of the health and social care team?
5. After considering the above, and if ataxia remains a primary problem, have I considered a referral back to the GP (neurologist) with a request for the GP (neurologist) to consider the appropriateness of a neuro-surgical team at a specialist centre for a surgical approach?

## Audit statements

1. The impact of ataxia and tremor on the person's occupational performance have been documented.
2. Contributing factors have been identified and documented.
3. There is evidence of onward referral for other advice/ interventions as appropriate from the assessment.

## 1.7.9 Sensory losses

(QR1, 2, 4, 5, 7, 8, 9, 10, 11)

### NICE

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

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

## Key reflections

1. Have I assessed and discussed the person's perceived impact of sensory loss on occupational performance and quality of life?
2. Have I considered the impact of sensory loss in relation to limitations with occupational performance? For example:
  - difficulty handling money
  - difficulty with buttons
  - unsteady gait
  - employment issues
  - driving
3. Have I assessed this person's sensory loss and discussed with them the prevention of problems such as pressure ulcers?
4. Are there any management strategies that would be helpful to this person (eg visual compensation)?
5. Have I considered safety issues associated with a loss of sensation? For example:
  - extremes of temperature
  - strategies to maintain functional safety in the event of visual/auditory disturbances
  - equipment which may help maintain a safe environment
  - telecare solutions
6. Have I discussed the impact of sensory loss with family/carers to facilitate their appreciation of potential safety risks?

## Audit statements

1. The impact of sensory losses on occupational performance is recorded.
2. Discussions of functional solutions, with particular reference to safety issues are recorded.

## 1.7.10 Visual problems

(QR1, 7, 10)

### NICE

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

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

## Key reflections

1. Have I provided information in an appropriate format for this person? These formats could include large font, bold typeface or audiotapes.
2. Are visual problems contributing to this person's difficulties? For example:
  - difficulties with balance
  - lack of confidence with activities
3. Have I considered the profound impact that additional sensory loss can have on this visually impaired person?
4. Have I sought advice from and considered referral to a sensory impairment team or orthoptist to optimise vision and facilitate participation, safety and quality of life (eg registration for partially sighted status)?
5. Have I considered equipment which may help, particularly with safety, including telecare solutions?

## Audit statements

1. The impact that any visual disturbance may have on occupational performance is recorded in my occupational therapy assessment.
2. Evidence of onward referral if appropriate from the assessment findings is documented.
3. Evidence of advice being sought where appropriate following the assessment is recorded.

## 1.7.11 Pain

(QR1, 2, 4, 5, 7, 8, 9, 10, 11)

### NICE

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

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

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

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

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

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

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

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

## Key reflections

1. Have I established the severity and pattern of pain and understood how it may impact upon this person's life?
2. Can I identify the different types of pain that the person describes?
3. Do I have information on how to refer the person for appropriate management eg physiotherapy, pain management team, neurologist, GP, palliative care?

## Audit statements

1. Any impact that the person's pain may have on occupational performance is identified and documented in the assessment.
2. There is evidence of onward referral to a relevant team member for appropriate management.

## 1.7.12 Cognitive losses

(QR1, 2, 3, 4, 5, 6, 7, 8, 10, 11)

### NICE

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

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

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

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

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

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

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

## Key reflections

1. Have I identified if the person has any cognitive difficulties?
2. Have I established if fatigue, anxiety, pain, mood, and so on, are impacting on their overall cognitive functioning?
3. Have I considered how to address this person's awareness of their cognitive problems?
4. Have I identified if the person has had a formal cognitive assessment and, if not, is a referral to a neuro-psychologist indicated?
5. Have I considered the safety issues that may result from this person's cognitive loss, such as decreased understanding of the use of equipment?
6. Have I considered how this person's cognitive problems may impact upon their family and carers?
7. Have I provided appropriate strategies to enable them to maximise occupational performance? For example:
  - memory strategies, eg the use of a diary
  - tailoring tasks and commands
  - involvement of family and carers, eg the use of repetition and prompting
  - telecare

## Audit statements

1. Cognitive difficulties are identified and recorded.
2. Appropriate management strategies for the person and/or carers are provided and documented.
3. Appropriate referral to a neuro-psychologist has been made and documented.

## 1.7.13

# Emotionalism

### NICE

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

## Key reflections

1. Have I identified if this person's emotional responses are impacting on occupational performance areas?
2. Have I considered referral back to GP/psychiatrist for psychiatric review?

## Audit statements

1. Emotional responses impacting on occupational performance are documented.
2. There is evidence of appropriate onwards referral.

## 1.7.14 Depression

(QR1, 2, 3, 4, 5, 6, 7, 8, 10, 11)

### NICE

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

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

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

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

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

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

### NSF

QR5 Targeted rehabilitation programmes can increase participation in social and leisure activities and reduce inappropriate behaviour. Counselling and psychological support to help people adjust to altered personal, family and social circumstances are highly valued by people with long-term neurological conditions and their families.

See also QR5 on page 24 of this guide.

## Key reflections

1. Have I considered if depression and low mood is affecting this person's ability to engage in activity?
2. Have I considered if this person has a pre-morbid history of mental health problems, anxiety and/or depression?
3. Have I considered factors that might be contributing to or affected by their depression? For example:
  - adjustment to diagnosis
  - loss of roles
  - reduced activity and participation
  - social isolation
  - fatigue
  - lack of sleep
  - pain
  - fear and anxiety
  - limited support network
4. Have I considered how depression may impact on family relationships, social networks, and roles at home and work?
5. If the person is unable to identify goals, with my help, that address activity and participation and/or aim to reduce social isolation, should I refer them to a GP for psychiatric review?
6. Have I considered that there may be times when this person needs to talk?

## Audit statements

1. Factors in depression affecting the person and their occupational performance are recorded appropriately.
2. The impact of the state of depression on others is recorded appropriately.
3. There is evidence of onward referral appropriate to the assessment findings.

## 1.7.15 Anxiety

(QR 1,2,3,4,5,6,7,8,10,11)

### NICE

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

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

## Key reflections

1. Have I considered whether this person experiences anxiety that affects occupational performance?
2. Have I considered if this person has a pre-morbid history of mental health problems/ anxiety disorder?
3. Have I considered factors contributing to anxiety?  
For example:
  - unpredictability of relapse and remission
  - uncertainty over future
  - confidence in task performance/ability to maintain roles (employment/ domestic and so on)
  - relationship with significant others
  - loss of independence/ autonomy and control.
4. Have I considered the severity of anxiety and its impact on occupational performance? For example:
  - panic attacks
  - avoidance patterns
  - confidence in task performance
5. Is the management of this person's anxiety within the remit of my occupational therapy skills? Can I provide the following:
  - graded functional goals to develop confidence in task performance or maintain roles
  - education (eg fatigue management)
  - facilitating acceptance of assistive equipment (eg pavement scooter and so on)
6. Is this person's anxiety beyond the remit of my occupational therapy skills? Does this person need more specialist intervention eg psychiatric referral, cognitive behavioural therapy?
7. If indicated, have I identified a clinical service to address severe anxiety disorder and made a referral via the GP?

## Audit statements

1. Factors in anxiety affecting the person and their occupational performance are recorded appropriately.
2. The impact of the state of anxiety on others is recorded appropriately.
3. There is evidence of onward referral appropriate to the assessment findings.

## 1.7.16 Swallowing difficulties

QR(1, 2, 3, 4, 5, 7, 8, 9, 10, 11)

### NICE

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

1.7.16.4 Any person with MS who has difficulty swallowing for more than a few days should be assessed by a neurological rehabilitation team to review the need for adjustments to or provision of seating that will increase ease and safety of swallowing and feeding.

## Key reflections

1. Have I identified that the person has difficulty with eating and drinking as part of assessment of occupational performance?
2. Have I identified if this person is known to the speech and language service?
3. Have I identified that this may be because of choking, coughing, delayed swallowing or chewing difficulties?
4. Have I considered what might be contributing to these difficulties eg fatigue, cognitive changes, poor posture?

## Audit statements

1. Swallowing difficulties as part of the assessment in eating and drinking have been documented.
2. Appropriate referral to a specialist speech and language therapist for further investigation, where appropriate, has been made.

## 1.7.17 Speech difficulties

QR(1, 2, 3, 4, 5, 7, 8, 9, 10, 11)

### NICE

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

## Key reflections

1. Have I identified whether someone has difficulty with dysarthria or dysphonia as part of my occupational performance assessment?
2. Have I identified if this person is known to the speech and language therapy service?
3. Do I know how to access speech and language therapy services?
4. Have I considered assessment for assistive technologies?

## Audit statements

1. Difficulties with dysarthria or dysphonia as part of the overall assessment have been identified and documented.
2. Appropriate referral to a specialist speech and language therapist for further investigation, where appropriate, has been made.

## 1.7.18 Sexual dysfunction

(QR1,2,3,4,5,6,7,8,9,10,11)

### NICE

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

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

## Key reflections

1. Have I considered sexual functions and partnership relations in my holistic assessment with the person with MS and/or their partner?
2. Does my communication style facilitate the person with MS and/or their partner to discuss issues regarding sexual relationships and intimacy?
3. Am I aware of the impact MS symptoms have on sexuality and the ability to establish and maintain an intimate relationship eg fatigue?
4. Do I have adequate knowledge about services available locally for people with difficulties with sexual participation? Have I made the information available to the person and/or their partner?

## Audit statements

1. There is evidence documented in the assessment of issues concerning sexual dysfunction and partnership relations being addressed with:
  - the person with MS
  - the partner of the person with MS
2. There is evidence of onward referral to, or signposting of, available services as appropriate.

## 1.7.19 Pressure ulcers

(QR1, 2, 3, 4, 5, 6, 7, 8, 10, 11)

### NICE

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

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

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

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

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

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

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

**1.7.19.6** Any person with MS who develops a pressure ulcer should be nursed on a low-loss mattress (while in bed).

## Key reflections

1. Do I know how to educate a person on how to relieve pressure independently or advise others about how to help them?
2. Am I aware of factors that would increase the risk of this person developing a pressure ulcer? For example:
  - sensory loss
  - difficulty maintaining postures or moving
  - altered tone
  - dehydration
  - decreased nutritional status
  - ill-fitting equipment (eg ankle/ foot orthosis)
  - urinary tract infection
  - incontinence
3. Have I considered any of the following preventive strategies?
  - advice on moving and handling issues (eg multi-glide sheets and hoists)
  - advice on positioning and posture (eg special seating systems)
  - pressure relieving devices (eg cushions and mattresses)
  - spasticity management (eg assessment for botulinum toxin)
4. Have I identified other professionals who might benefit this person? For example:
  - MS specialist nurse
  - physiotherapist
  - tissue viability coordinator
  - wheelchair service
  - district nurse
5. Have I collaborated with health and social care professionals to minimise the risk of pressure ulcers developing if this person is admitted to hospital or for respite care?

## Audit statement

1. Advice and/ or equipment and information to minimise the risk of pressure ulcers developing has been provided and documented in the notes.

## 1.7.20 Complementary therapies

(QR 1,9,10)

### NICE

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

- reflexology and massage
- fish oils
- magnetic field therapy
- neural therapy
- massage plus body work
- t'ai chi
- multi-model therapy.

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

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

## Key reflections

1. Am I aware of the evidence base for the efficacy of complementary therapies in MS?
2. Do I have the knowledge and skills to facilitate the person with MS to make informed choices based on potential benefits, risks and cost to them?
3. Do I encourage the person with MS to discuss the use of complementary therapies with their consultant and/or GP?
4. Am I aware of opportunities for people with MS to participate in complementary therapies in a safe and appropriate environment eg MS Society Yoga groups?
5. Do I have access to evidence-based information regarding the efficacy of complementary therapies?
6. During my holistic occupational therapy assessment, do I facilitate the person to discuss their desire and/or plans to participate in complementary therapies?

## Audit statements

1. Access to information concerning the evidence base and efficacy of complementary therapies for people with MS is readily available to occupational therapy practitioners and service users.
2. Information regarding local availability of qualified and registered complementary therapists is available.
3. Issues concerning complementary therapies — where raised — are recorded in the assessment notes.

# Resources

## Carers UK

32–36 Loman Street, London SE1 0EE.  
Telephone 020 7922 8000 [www.carersuk.org](http://www.carersuk.org)

## Chartered Society of Physiotherapy

14 Bedford Row, London, WC1 4ED.  
Telephone 020 7306 6666 [www.csp.org.uk](http://www.csp.org.uk)

## College of Occupational Therapists

106–114 Borough High Street,  
London SE1 1LB.  
Telephone 020 7357 6480 [www.cot.org.uk](http://www.cot.org.uk)  
A range of titles for professionals including:

- *Guidance on fatigue management for people with multiple sclerosis (2007)*
- *Professional standards for occupational therapy practice (2007)*
- *Guidance on manual handling (2006)*
- *Guidance on risk management (2006)*.

## Functional Electrical Stimulation (FES)

Telephone 0172 242 9065  
Email [enquiries@salisburyfes.com](mailto:enquiries@salisburyfes.com)  
[www.salisburyfes.com](http://www.salisburyfes.com)

## Government

- Disability Discrimination Act 1995 /2005 Chapter 50  
[www.opsi.gov.uk/acts](http://www.opsi.gov.uk/acts)
- Evaluation and further information on the Expert Patient Programme [www.dh.gov.uk](http://www.dh.gov.uk)  
[www.dh.gov.uk/Home/fs/en](http://www.dh.gov.uk/Home/fs/en)

## Multiple Sclerosis International Federation

[www.msif.org](http://www.msif.org)  
● *MS in focus. Special focus on dealing with fatigue.*

## MS Professional Network

The MS Professional Network is a group of health and social care professionals with a common interest in improving services for people affected by MS. Membership is free and includes regular newsletters, conferences and learning events. Join online at [www.mssociety.org.uk/profs](http://www.mssociety.org.uk/profs)

## MS Society

MS National Centre, 372 Edgware Road,  
London NW2 6ND.  
Telephone 020 8438 0700  
[www.mssociety.org.uk](http://www.mssociety.org.uk)

Free, evidence-based publications to order or download:

- *Fatigue*
- *Exercise and physiotherapy*
- *Pain and sensory symptoms*
- *Managing relapses*
- *Tremor with MS*
- *Women's health – pregnancy, menstruation, contraception and menopause*
- *Working with MS – a guide for employees and employers*
- *Caring for someone with MS: a handbook for family and friends*

## Multiple Sclerosis Trust

Spirella Building, Letchworth, Herts SG6 4ET.  
Telephone 01462 476700  
[www.mstrust.org.uk](http://www.mstrust.org.uk)

A range of titles for professionals, including:

- *Multiple Sclerosis: information for health and social care professionals*
- *Therapists in MS: delivering the long-term solutions*

## National Library for Health

[www.library.nhs.uk](http://www.library.nhs.uk)

## National Institute for Health and Clinical Excellence

MidCity Place, 71 High Holborn, London, WC1V 6NA. Telephone 0845 003 7780  
[www.nice.org.uk](http://www.nice.org.uk)

## The Princess Royal Trust for Carers

Unit 14, Bourne Court, Southend Road,  
Woodford Green, Essex, IG8 8HD.  
Telephone 0844 800 4361  
Email [info@carer.org](mailto:info@carer.org)  
[www.carers.org](http://www.carers.org)

## Royal College of Speech and Language Therapists

2 White Hart Yard, London SE1 1NX.  
Telephone 020 7378 3012  
[www.rcslt.org](http://www.rcslt.org)

# Notes

Sections from NICE guideline for MS not covered in this guide.

## 1.2 Teamwork

- 1.2.3 Working across organisations
- 1.2.4 Timing of actions
- 1.2.5 Within team communication – a conceptual framework

## 1.4 Treatment

- 1.4.1 Treatment of acute episodes
- 1.4.3 Interventions affecting disease progression

## 1.5 Altering the risk of relapses

- 1.5.1 Infections and immunisations
- 1.5.3 Stress (various types)

## 1.7 Managing specific impairments

- 1.7.3 Urinary tract infections
- 1.7.4 Bowel problems

## 2. Notes on the scope of the guidance

## 3. Implementation in the NHS

## 4. Research recommendations

## 5. Full guideline

## 6. Related NICE guidance

## 7. Review date

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Members of the College of Occupational Therapists Practice Publications Group

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MS Trust Therapists in MS Audit Tool  
<http://www.therapistsinms.org.uk/audit.jsp>

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## **MS Society Northern Ireland**

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Temple Court  
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## **National MS Helpline**

Freephone 0808 800 8000  
(Monday to Friday, 9am-9pm)

Website

[www.mssociety.org.uk](http://www.mssociety.org.uk)

The Multiple Sclerosis Society of Great Britain and Northern Ireland is a charity registered in England and Wales (207495) and Scotland (SC016433)

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Multiple sclerosis (MS) is the most common disabling neurological disorder affecting young adults and we estimate that around 85,000 people in the UK have MS.

The MS Society is the UK's largest charity dedicated to supporting everyone whose life is affected by MS – personally or professionally. The MS Society works with health and social care professionals to improve services by:

- promoting good practice in MS treatment and care
- publishing newsletters, reports and educational materials
- organising networking opportunities and events
- funding health and social care posts in community, rehabilitation, primary and acute care settings, and in palliative care

- funding research into the cause, cure, and management of MS, as well as development of services, with an overall research commitment of £15 million

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