

THE GUIDELINE

3 General principles of care

An effective, efficient and high quality service depends as much upon its organisation and style as it does upon individual competence. For example, there is little point in having an excellent service for people with continence problems if less than 20% of that group are ever seen in the service or have the problem identified. There is much evidence that patient dissatisfaction with services is primarily focused on organisational matters and communication.¹⁴ Consequently this section covers various topics that apply to the overall management of MS.

This section is divided into five main interlinked areas:

- 1) Interaction between the professional and person with MS
- 2) Interactions between the team and the person with MS
- 3) Service organisation and inter-relationships between services
- 4) Within-team communication – a conceptual framework
- 5) Provision of services over time.

Evidence on the areas covered in this section is generally scant and difficult to synthesise, and with little of it specific to MS. For example, the evidence supporting specialist stroke services could be used to support some of the recommendations.¹⁵ Systematic searching was not undertaken for this section, but supporting evidence is provided.

These guidelines cannot cover all general aspects of good patient care; this section will emphasise those areas that specifically concern people with MS. Specific aspects have been given specific recommendations, and important general aspects that apply to all patients with any condition are found in the accompanying tables.

The recommendations made in this section stress the importance of patient-centred teamwork and the need to consider all aspects of a person with MS's situation.

3.1 Interaction between the professional and person with MS

Most studies of the experience of service users¹⁴ show that many professionals appear to have an inappropriate attitude towards people with MS, who often feel deprived of the information and support they want. There are also discrepancies in perception between people with MS and professionals concerning health care needs.¹⁶ These findings suggest the need for improvements in:

- style and manner of communication, especially of initial diagnosis
- accuracy and detail of information given
- recognition of the emotional consequences of the information given
- acknowledgement that people with MS have expertise and have views that should be taken into account
- encouragement of self-management by people with MS.

3.1.1 Communicating and giving information

Many studies have emphasised the importance of good communication between individuals and health care professionals.

Anyone can now access vast amounts of information on any topic using the Internet, and there are books available in public libraries on almost any topic. However much of this information is of low quality, inaccurate, and/or difficult to understand. Therefore it is vital for health care professionals to take seriously the provision of accurate, relevant and appropriately presented information to people with any disease.

Many people with MS have some impairment of cognitive skills, and some have visual impairment. These are two important factors to consider in all communication. All the basic principles of good practice apply (see Table 2) and information provided in the section on 'Encouraging autonomy/self-management' (3.1.3) is also of relevance.

▷ Health economic statements

It is not possible to say anything certain about the economic implications of improved information provision and communication. It is not clear what NHS resources are currently devoted to this, but they are unlikely to be substantial. Improvements in co-ordination of information could potentially result in savings through increased efficiency, and this is particularly true of the interface between primary and secondary care and between the NHS and social services. Good information provision may directly improve patient well-being by reducing uncertainty, relieving stress and contributing to empowerment if the patient is more involved in decisions about care. This may also have subsequent effects in terms of functional status. In addition, information may change the pattern of service use and this will also have the potential to benefit patients, carers and their families. However, if current provision is very poor, then substantial resource increases may be required in order to improve the situation. A significant part of this will be required to equip health professionals with the necessary skills to assess individual patient needs for information.

RECOMMENDATIONS

- | | | |
|----|--|---|
| R1 | All communication with all people with MS should comply with the general principles of good communication, shown in Table 2. | D |
| R2 | 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 health care professional should: <ul style="list-style-type: none">● be straightforward● check the person has understood● back up what was said with written (and other) material● reinforce as necessary. | D |

LOCAL IMPLEMENTATION POINTS

Local services will need to:

- provide leaflets and other information for the people with MS detailing local NHS, social care and voluntary sector resources

- ensure that information is accurate and up to date and takes into account local ethnic and language needs
- ensure that there are mechanisms for disseminating information to those who need it.

Table 2 Principles of good communication in health care

Principle (what the health care professional should do in any communication)	Comment
Communicate in a suitable environment, usually a quiet area or room free from distraction or interruption.	Privacy and quiet are important.
Seek agreement from the person with MS that anyone present can be there and ensure that as far as possible anyone she or he wants present is there.	Consider especially students and family.
Start by asking what the person knows or believes already.	Establishes expectations.
Establish the nature and extent of the information that the person wishes to receive.	Establishes expectations.
Consider carefully the balance between the benefits and the risks associated with giving each item of information.	Once given information cannot be withdrawn.
Tailor the communication to the person's: <ul style="list-style-type: none"> • specific situation • communicative and cognitive abilities • culture. 	Makes information relevant.
Limit information given to that within your own knowledge, referring on to others as necessary for more detailed information.	Do not give information if uncertain about it.
Clarify specifically any options and choices the person may need to choose, specifying: <ul style="list-style-type: none"> • likely outcomes of each choice • benefits and risks of each choice. 	Both in diagnosis and treatment.
Offer back-up with information being given: <ul style="list-style-type: none"> • in different ways (eg written leaflets, tapes) • by different people (eg specialist nurse) • at another time (eg follow-up appointment). 	Information is often forgotten.
Inform the person with MS about any recommended local or national sources of further information including employment and voluntary sector sources.	Allows person with MS to follow-up and take more control.
Consider need for emotional support during process, especially if the information might be stressful, and arrange emotional support if needed.	Should be considered an intrinsic part of the process (see R3).
Document in notes and inform other healthcare staff closely involved what has been communicated, especially to the general practitioner.	Ensures consistency over time and across settings.
<p>Failure in communication between health care professionals and people with MS was a common theme in the focus groups. The development group there felt it was essential to have recommendations on communication, and indeed took this as the first topic to consider. The development group reviewed the evidence summarised in 4.2 and took into account all the evidence of factors (such as poor memory and visual disturbance) that might affect communication. During several long discussions and debates, a series of specific recommendations were derived, primarily through consensus. In the interest of brevity and clarity, these were then converted to this table of recommendations.</p>	

3.1.2 Giving emotional support to people with MS

MS is a disease that causes emotional distress in many ways:

- it often starts at a young age when individuals are anticipating marked life development
- it is unpredictable and causes much uncertainty
- it has a bad 'reputation' and expectations are often worse than reality
- it can lead to many cumulative losses over many years
- feelings of control can be lost
- the effects on family members and changing interactions between family members can also increase emotional distress.

The management of anxiety and depression is covered in Section 6. Here we consider the emotional support that may be required by any person, at any time, and which is frequently requested by people with MS, especially in the early stages.¹⁷ When reading the evidence and considering the recommendations, we have taken the following into account. *Counselling* is a word used both in relation to giving information, and in relation to giving emotional support. *Emotional support* may take two forms: a formal therapeutic process (eg psychotherapy) that usually requires training and expertise, and an informal process that, although it may be improved by training, is part of many personal interactions which occur between the person with MS and both professionals and non-professionals.

This section is primarily concerned with informal emotional support. Within the process of informal emotional support given by knowledgeable professionals there is also inevitably a component of giving information (another aspect of 'counselling'), which may itself reduce emotional distress.

▷ Evidence statements

Three RCTs that assessed the utility of neuropsychological compensatory training, psychotherapy and coping skills training for persons with MS were identified (Ib). The first RCT assessed the effectiveness of traditional psychotherapy compared to participation in a 'current affairs' topic group or no intervention. The results showed psychotherapy to be superior on two of the four outcome measures assessed, namely depression and locus of control. However, it had no significant effect on either anxiety levels or levels of self-esteem.¹⁸ The second RCT examined a coping skills group compared to non-directive peer telephone support. The coping skills group entailed formal therapist support and considerable contact time, whilst the telephone support group was informal and only entailed one hour a month. No overall differences between the groups were observed on any of the five outcome measures.¹⁹ The last RCT compared neuropsychological compensatory training to supportive psychotherapy. The results indicated beneficial effects on measures of social aggression, but no difference between the groups on measures of depression or personality change.²⁰

One controlled clinical trial (CCT) compared client-centred psychotherapy to a no-treatment control in patients with MS. The results indicated beneficial effects on four of the seven outcome measures assessed, with all of these being within inter- or intra-personal domains²¹ (IIa). Two further CCTs were identified that examined therapeutic groups for persons with either MS or spinal cord injury. However, both of these studies reported only within subject results and therefore no comparison could be made as to the efficacy of the interventions between the groups.^{22,23}

Two uncontrolled pre-post studies examining coping skills training and stress management instruction were also included. The first study assessed coping skills training in patients with MS. The results showed an overall beneficial effect on measurements of depression, physical mobility and emotional reaction.²⁴ The second study examined the efficacy of stress management instruction in patients with disease of mixed aetiology. The results showed a positive effect on two of the four outcome measures assessed^{24,25} (III).

▷ Economic statements

The current resources devoted to emotional support are not known. Any recommendation to increase assessments for psychological symptoms and offer various types of counselling will result in increased resource use. However, savings may result from increased efficiency if counselling is being used inappropriately at present, and also if counselling reduces the need for other health interventions. The benefits for patients, carers and their families are potentially very large, including reduced stress and anxiety and improved functional status. Good quality cost effectiveness analyses of psychological support for people with MS, including the different ways in which this support could be provided, are required.

▷ From evidence to recommendations

Formal psychotherapy may require many resources, and we felt that the evidence reviewed was insufficient to allow any firm recommendations to give formal therapeutic intervention. However the evidence suggests some possible benefits for giving emotional support in some way which leads to our consensus recommendations.

RECOMMENDATION

- R3 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. D

LOCAL IMPLEMENTATION POINT

Local services will need to agree which individual people or services locally, both within the NHS and elsewhere, are sufficiently expert and knowledgeable about MS to provide emotional support to people with MS who have particularly great need.

3.1.3 Encouraging autonomy/self-management

People with MS have their disease for life, and may only see any individual professional for a short time. Moreover, the person with MS has to live with the consequences of any decisions made and in the absence of firm evidence for most decisions, it is especially appropriate to involve the individual in all decisions as far as they wish. Encouraging self-management is consistent with recent moves towards the 'expert patient',²⁶ which aims to use patients to give other patients the skills, knowledge and confidence to participate actively in all aspects of their own health care.

▷ Evidence statements

One RCT assessed the effect of a self-care program for patients with MS living in the community. Overall, the results showed no positive benefit with significant changes only on two out of six of the items assessed.²⁷

▷ Health economic statements

The economic implications of encouraging patient autonomy are uncertain. An intensive patient education programme for self-management in people with asthma resulted in improved outcomes in the intervention group with no significant difference in costs.²⁸ However, the patient group and the geographical location (Finland) undermine the relevance of these to the population of people with MS in the UK. The balance of resource burden between the NHS and the patient and their family is an important factor in any move towards self-management.

▷ From evidence to recommendations

The evidence specific to MS is sparse. However, the GDG also took into account emerging evidence in other areas of health care, and the move from NHS towards encouraging greater patient autonomy. It therefore reached strong consensus behind the recommendations made.

RECOMMENDATIONS

R4 People with MS should be enabled to play an active part in making informed decisions in all aspects of their MS health care by being given relevant and accurate information about each choice and decision. D

R5 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: D

- 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 should 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 health care professionals (for example, through participation in the Expert Patient Programme (<http://www.doh.gov.uk/cmo/progress/expertpatient/index.htm>)).

LOCAL IMPLEMENTATION POINTS

Local services will need to discuss and specify:

- who is responsible for providing information on self-management for people with MS
- who is responsible for providing access to self-management programmes (such as the Expert Patient Programme) for people with MS
- making all screening and disease-prevention programmes accessible to people with long-term illness.

3.1.4 Support to family and informal carers

Family members, and sometimes close friends, of a person with MS may play three roles, related to the MS, and often need help with these.

- 1) They may provide physical assistance or supervision. While many families will do this willingly, there is a risk that a normal family relationship may change to a patient-carer relationship.
- 2) They may become the main social contact for the person with MS, making the relationship increasingly intense. This may then lead to significant interpersonal strains, and distress both the person with MS and the family member(s).
- 3) They may take over responsibility for family roles once held by the person with MS, such as earning money, running the household or being a parent. This may cause stress on the family member if other roles are not relinquished, may upset the person with MS and may stress family relationships.

Such informal supporters and carers often live under the same roof, but some may perform these roles at a distance. Children (sometimes of a young age) are often involved in one or more of these roles and the effects of having a parent with a disabling condition can be severe.

The recognition of these factors and the provision of assistance where possible may benefit both the person with MS and the family itself. Sometimes the needs and wishes of family members may conflict with those of the person with MS, and this must be acknowledged. One must bear in mind that a) the person with MS and the family member(s) may have different general practitioners and social workers and b) the primary responsibility of the health care team is usually to the person with MS.

▷ Evidence statements

Three studies assessed the effectiveness of support for caregivers of people after stroke. One RCT and one CCT assessed the benefits of an educational group for patients who had suffered a stroke and their main caregiver. The RCT that compared a stroke educational program to the use of standard stroke unit information leaflets showed beneficial effects only in terms of the patient and carer's knowledge about stroke. No differences were observed between the groups on any measure of either patients' or carers' health status, activities of daily living (ADL) or levels of anxiety and depression²⁹ (Ib). The CCT compared a group educational program to home visits or no intervention for patients caregivers. The results showed beneficial effects for both programs compared to no intervention on two of the four outcome measures, but no significant difference between the different program groups³⁰ (IIa). The last RCT examined the utility of Stroke Association family support compared to normal care. The results showed beneficial effects on two out of the four measures assessed for carers, but no difference between groups on any outcome measures for the patients³¹ (Ib).

▷ From evidence to recommendations

Consensus was used to agree recommendations as the evidence available neither supported nor refuted the benefits of providing carer support.

RECOMMENDATION

- R6 Family members (including any school children) living in the same house as a person with MS, and family members delivering substantial support (even if living elsewhere), should be supported by: D
- asking about their physical and emotional health and well-being, especially in the case of children aged 16 years or less, and offering advice and referring on for additional support if necessary
 - providing them with general factual information about MS; this should only be extended to include more specific information related to the person with MS with the permission of that person
 - ensuring that they are willing to undertake support of personal activities of daily living (such as dressing and toileting), are safe and competent at such tasks, and that the person with MS is happy for them to provide such assistance
 - informing them about social services and their entitlement to carer assessment and support procedures.

LOCAL IMPLEMENTATION POINTS

Local services should:

- identify services able to assess and support children of people with MS
- collate and publicise information about statutory and non-statutory support services available for families and carers locally and how to access them.

3.2 Team approaches to rehabilitation

3.2.1 Interactions between the team and the person with MS: approaches to rehabilitation

Specific aspects of rehabilitation are covered in later sections; here we consider the general approach to rehabilitation. Because few of these issues are specific to MS, no systematic review has been undertaken.

▷ Assessment and measurement

The process of assessment refers both to the collection and to the interpretation of data needed to identify problems (screening) and to inform the solutions. The process of assessment may or may not include measurement, which is the quantification of data against some metric. In other words, an assessment procedure may be considered to have two purposes which may be distinct or combined:

- the **detection** of a phenomenon (ie diagnosis); and,
- the **measurement** of a phenomenon.

Evaluation of a diagnostic tool in one setting is not necessarily transferable: a measure for use in one context, such as research with a small, homogenous group, may be unsuitable for day-to-day clinical practice. Few studies have evaluated measures in different settings or in comparison with each other. Consequently we have not systematically reviewed the evidence and cannot make any specific recommendations about which measures to use (see Table 4 and Appendix H).

A common approach across all services will make assessment more efficient, less repetitious for the person with MS, and provide an impetus towards an integrated delivery of services.

The specific issues relating to the detection (diagnosis) of specific problems arising in people with MS are that the person:

- may have or develop one or more of a large range of specific problems
- may have problems that are not always obvious, and which may come on insidiously so that even the person with MS is unaware
- may be unaware that something can be done to alleviate problems and so may not mention them
- may be in touch with someone who focuses on only one problem, and who may fail to detect or know about others, consequently not referring the patient on to appropriate services for further treatment.

Consequently it is important to have systems in place that:

- check at appropriate intervals whether the person with MS has common problems
- do not waste the time of the person with MS or the health care professional.

The specific issues relating to the measurement of problems arising in people with MS are that:

- the person with MS may have many problems that could be measured, and each measure may take considerable time and effort that may waste resources unless each measurement has a clear and relevant purpose
- many measures are available for almost every single phenomenon but there is minimal data available to guide the choice of measure, and none may be appropriate
- the presence of multiple impairments in one person may make the measurement of some phenomena either difficult or impossible, and also may complicate interpretation of the data.

One solution in many clinical situations is for the team members to identify and specify their goals as a method for evaluating an intervention. This is often referred to as 'goal attainment scaling' which has become well recognised as a useful method for evaluating complex and varied interventions.^{32–34}

The recommendations made here are intended to ensure that the person with MS has any difficulties detected as soon as possible so that the difficulty is managed, often by referring on to the appropriate service for expert further assessment and management. The recommendations are also intended to give general guidance on measurement. Because the clinical situation and time course of people with MS can vary so greatly, this section uses an 'episode of care' to mean any series or programme of interactions with health care staff or teams concerned with the same underlying problem. It is trying to ensure that problems are not overlooked without overloading the health care system or the person with MS.

The guidelines have not recommended any specific, named measures for use in any specific situation. A quick review of the evidence tables will show that over 60 different measures have been used in research and apart from the Expanded Disability Status Score (EDSS) few have been used on more than 10 occasions (see Appendix H). There is very little research comparing the utility of different measures in different situations. Indeed, relatively few measures have any evaluative data published at all. Systematically reviewing the available evidence would be a major undertaking, and because the number of measures supported by different people and

organisations is large, consensus will not be achieved. Therefore we agreed not to recommend any specific measures.

RECOMMENDATIONS

- R7 The review checklist shown in Table 3 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 health care professional should: **D**
- record the information for future comparison
 - refer to the specific recommendations made in this document if any problem is identified.
- R8 Health care staff who frequently undertake MS-specific assessments or treatments should: **D**
- be familiar with simple methods for detecting impairment and limitations on activities
 - be trained in their use and interpretation (if used).
- R9 All health care staff within a local health community should use the same simple methods for common assessments. **D**
- R10 When initially assessing a person, and when undertaking any treatment, health care staff should consider the characteristics of a measure (see resource pack on the NICE website: www.nice.org.uk/pdf/cg008_msresourcepack.pdf) recognising that: **D**
- formally evaluated measures may not exist or be practical
 - personalised measures should be considered, including comparing the outcome against goals agreed (goal attainment scaling).
- R11 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. **D**

Further guidance may be found at the Department of Health consent website at www.doh.gov.uk/consent/index.htm

LOCAL IMPLEMENTATION POINTS

Local services will need to set guidelines on:

- the specific measures and assessment procedures to be used locally for common problems
- training of all staff in the use of simple screening methods for impairment, and in the use of simple measures of activities.

3.2.2 Teamwork and goal setting

People with MS often have several problems that need resolution and consequently will usually need actions from more than one person. Co-ordination of interventions, often delivered by several people over time, requires teamwork from a group of individuals working together towards a single goal or set of goals. A group of individuals who happen to work with one person with MS is not a team but a workgroup;³⁵ a team must communicate and work jointly. The difficulties and weaknesses of community teams in the UK have been discussed^{36–38} and clinical standards have been produced for rehabilitation teams both in hospitals and in the community.^{39,40}

Table 3 Review checklist*

Initial question

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

Activity domains

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

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

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

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

Common impairments

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

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

- fatigue, endurance, being 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 the movement?
- vision and your eyes?
- thinking, remembering?
- your mood?
- your sexual function or partnership relations?
- how you get on in social situations?

Final question

Finally, it is always worth finishing with a further open-ended question. *Are there any other new problems that you think might be due to MS that concern you?*

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

Table 4 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 measure should be considered against the following characteristics.

Domain	Questions
Feasibility	<ul style="list-style-type: none"> • Can the measure be used in this situation? • Will the process be acceptable to the person with MS?
Utility	<ul style="list-style-type: none"> • Is this measure going to be useful? • Will the time and effort required be worthwhile?
Validity	<ul style="list-style-type: none"> • Is this measure going to measure whatever it is I am interested in? • Does this measure also include unrelated phenomena that reduce its validity?
Reliability	<ul style="list-style-type: none"> • How much variation occurs from time to time when there is no 'real' change? • How much variation occurs between observers?
Sensitivity	<ul style="list-style-type: none"> • Will this measure detect the change or difference that I am looking for? • Does the measure cover the whole range of possible change?
Communicability	<ul style="list-style-type: none"> • Can I communicate this result? • Will other people involved understand the result?

The agreeing of goals is one way of facilitating effective teamwork. Goal setting refers to the identification of, and agreement on, an outcome or group of outcomes that the person with MS and family, therapist or team will work towards over a specified period of time. The important characteristics of goal setting in a rehabilitation service have been the subject of a non-systematic review.⁴¹

Recommendations are needed to ensure that efficient and effective teamwork occurs.

RECOMMENDATIONS

- R12** When several health care 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: **D**
- towards common agreed goals
 - using an agreed common therapeutic approach.
- R13** The goals set should: **D**
- 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.
- R14** Goal attainment scaling should be considered as one way of setting goals and evaluating progress. **D**

LOCAL IMPLEMENTATION POINTS

Local services need to discuss and agree common:

- approaches to therapies to be used within and between teams
- terminology to be used within and between teams
- documentation to be used within and between teams.

3.3 Service organisation

Specific recommendations made in later sections can only be successful if a) services are organised so that they can be used efficiently by the person with MS, and b) service staff have appropriate knowledge and skills to advise on the specific problem. An audit in Oxfordshire documented the long and tortuous routes people traversed to resolve specific problems,⁶ suggesting that people with MS are often seen by people without appropriate skills to solve specific problems.

In terms of service organisation, effectiveness and efficiency depend upon two separate matters:

- the *grouping* of people with different skills into named services, and
- the *timing* of actions undertaken by the organisation.

This section makes recommendations concerning specialisation and timing.

Expertise is a key issue here. For this document the following definitions will apply:

- a *specialist* is a health care professional with the necessary knowledge and skills in managing people with the problem concerned, usually evidenced by having a relevant further qualification, and keeping up to date through continuing professional development
- a *specialist team or service* is a group of specialists *who work* together regularly managing people with a particular group of problems, and who between them have all the necessary knowledge and skills to assess and resolve over 90% of all problems faced.

In practice, the person with MS will rarely present with a new problem to a specialist, and so it is important that clear and unhindered routes of referral exist, but at the same time it must be recognised that many problems can be resolved by clinicians and services with less MS-specific expertise. In other words, all health staff should work within their level of competence:

- *competence* is defined as the sufficient knowledge and skills to assess and resolve the problem and to recognise when further, more specialist help is needed.

A single service will be unlikely to cover all problems presented to it. Many problems will be simple, only peripherally related to MS, or well within the competence of the service first approached. Specialist services, on the other hand, can only retain expertise if they are not overwhelmed by simpler problems. Consequently it is inevitable that some people will need to be referred on from one service to another (or even to two or more others). Recommendations need to take this into account.

Lastly, services will be developed over time, and it is important that people with MS are involved in discussions about the development of services used by them.

3.3.1 Specialist services

The evidence in support of specialisation in general, and relating to specialisation in the management of people with MS in particular, has not been searched systematically. It is widely accepted that specialisation can deliver many benefits in terms of effectiveness and efficiency, for example to patients with conditions such as cancer or vascular disease.

The benefits of specialist services have been well demonstrated in stroke where specialised stroke units are effective in research settings¹⁵ and also have better processes in practice.⁴² Similarly, specialist neurological rehabilitation teams can improve outcome after head injury.^{43,44} The Health Select Committee, in its report on Rehabilitation after Traumatic Brain Injury,⁴⁵ drew attention to the inefficiencies resulting from the fragmented management structure for rehabilitation in most NHS trusts, and recommended that the best single way to avoid such fragmentation of NHS rehabilitation services would be for every NHS trust providing rehabilitation to appoint a named general manager to be responsible for all elements of the rehabilitation services operated by the trust.

At least five studies have investigated the effect of a specialist neurological rehabilitation team specifically in the management of MS, and found benefits.^{46–51}

The evidence is given in more detail later (4.5, 5.2). In summary, one study has shown that the input of a specialist rehabilitation team was associated with improved outcome three months after an acute relapse; one study showed that a two week inpatient specialist rehabilitation was associated with sustained benefits at six months; one study showed that outpatient specialist rehabilitation was associated with sustained benefits; one study showed that specialist rehabilitation lead to positive change at 15 weeks; and two controlled clinical trials have demonstrated sustained benefits after input from a specialist neurological rehabilitation team. This must be set in the context of a much greater volume of evidence for specialist neurological rehabilitation services in other neurological conditions such as stroke and head injury.

This section makes general recommendations concerning specialist services, without detailing the model of service delivery or resource implications. There are particular difficulties in specifying a 'core team' because people with MS may need help from almost any profession or service at some point. The recommendations are based on consensus informed by the existing studies, studies in other areas, and the logical consequences of the many recommendations made elsewhere in this guideline.

▷ Health economics statements

Many of the recommendations made in this section and elsewhere in this guideline imply an increase in the number of specialists and specialist centres that can diagnose and treat people with MS. At present, the provision of services is inadequate and geographically variable. It is well established that there is a shortage in the required number of consultant neurologists in the UK. There are currently around 350 consultant neurologists, giving a population ratio of 1:177,000 – much lower than other European countries. In some areas, like the South East, the ratio is 1:100,000, whereas in less well-served areas it is 1:250,000. An Association of British Neurologists (ABN) survey in 2001 revealed that the average waiting time to see a consultant neurologist from GP referral varied from 13 weeks in North West Thames to 51 weeks in Wales.⁵²

Anecdotal evidence suggests that for specialist MS services the situation is worse, but there is no formal evidence to back this up. The vast majority of people with MS are treated as outpatients so they will suffer from the long waiting times reported here. In addition they are adversely affected by the lack of specialist centres where multidisciplinary team-based care can be provided. Preparatory work for the UK health departments risk-sharing scheme (see Section 4.6) shows that 66 centres in the UK have self-nominated as ‘specialist’ centres, but the number of centres that can actually provide multidisciplinary team-based care is probably around half of this number. The result is that only the minority of people with MS have access to a specialist centre and many do not even have access to a neurologist.

We have not attempted to estimate the resource increase that will be needed to provide these improved services, and neither do we have appropriate evidence to make judgements on the cost-effectiveness of using NHS resources in this way; this is an important area for future research. It is not simply a matter of making finance available, as the implications for the training of health professionals are also important. As a minimum, the ABN, for example, suggests that the number of consultant neurologists must be doubled to provide an acceptable service. They have estimated that this could be achieved by 2008 if the number of trainees was increased by two per year (from the current figure of around 158). Future research should investigate the need for improved services, the potential benefits to the NHS, people with MS and their families, and the resources involved, including any potential resource savings that might accrue elsewhere in the health care system.

RECOMMENDATIONS

- R15** Every health care commissioning authority should ensure that all people with MS have ready access to a specialist neurological service for: **D**
- 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.
- R16** The health care commissioning authority should also ensure that its population has ready access to a specialist neurological rehabilitation service. This should be available to all people with MS when the presenting problem is outside the competence of the first point of contact, for: **D**
- undertaking assessment (that is, diagnosis) when the person has complex problems
 - undertaking specific pharmacological or other therapies
 - providing an integrated programme of rehabilitation when the person has complex problems
 - monitoring change, especially when the person with MS has more severe impairments or limitations on activities
 - giving advice to other services.
- R17** As a minimum, the specialist neurological rehabilitation service should have as integral members of its team, specialist: **D**
- 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: D

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

LOCAL IMPLEMENTATION POINTS

Local services will need to discuss and agree on:

- which specialist services are available to each primary care trust (PCT), or GP
- the most appropriate point of referral into each service in different circumstances
- specific referral pathways and mechanisms
- which health workers are in the local core team and which are additional to the team
- how health care workers who are additional to the team should be contacted.

3.3.2 Interfaces

People with MS present to any one of a large number of people within any one of a large number of organisations, and may in turn be referred on to many different people.⁶ One of the main complaints made by people with MS is that they are constantly referred on to other services and have to start from the beginning each time. Referral between services and organisations is inevitable, given the nature of the condition and the organisation of statutory services. Therefore it is vital that the interfaces are made as seamless as possible for the person with MS.

People with MS have stressed the importance of having access to a single contact point to provide on-going information and support, and to provide advice and sign-posting to other services. This coordinating and advising role is important both to the person with MS and to the various health and social service professionals involved.

The roles that are needed include:

- service coordinator with wide local authority and voluntary sector links, eg housing
- information signposter
- resources coordinator
- facilitator for an individual person with MS.

RECOMMENDATIONS

- R18** All parts of the health care system, social services and other statutory services should have agreed protocols that specify: **D**
- how responsibility for people with MS is shared with other groups or organisations
 - what agreed descriptive information (that is, a common dataset) about the person with MS should always be shared
 - the point of contact within any service or organisation, and how contact should be made.
- R19** People with MS should be able to identify and contact: **D**
- a named person in their health area who is responsible for all NHS services for local people with MS (including coordination and collaboration with other statutory services)
 - a named person in their health area with clinical expertise who is able to respond to any inquiry on clinical problems (and to guide the person to the most appropriate local service)
 - a named person within any health care team with which they are involved.

LOCAL IMPLEMENTATION POINTS

Services should discuss and agree:

- referral and funding mechanisms between the following agencies; GPs, PCTs/LHGs, specialist neurological services, the specific neuro-rehabilitation services, social services departments, local authority housing department
- standardised data to be shared across each interface
- who will fulfil the specific roles identified in R19 within the area.

3.3.3 Timing of actions

To be useful (that is, to be effective and efficient) it is important that any intervention is timely. Setting a target time for every recommendation would be both wordy and difficult to base on evidence. There is no evidence on appropriate timing, but the government has set targets for some services. Therefore, we have made some general recommendations about timeliness that reflect government targets, the concerns of people with MS and consensus.

RECOMMENDATIONS

- R20** Any action recommended within these guidelines should be undertaken within a time that takes into account: **D**
- 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.

LOCAL IMPLEMENTATION POINT

The local commissioners and service providers should agree a set of timed targets which should include, at a minimum, those time targets contained within this guideline.

3.3.4 Involvement with service development

The involvement of service users in service development and research is government policy within the clinical governance framework, so no specific evidence has been sought concerning these issues. Good guidelines have been produced by the Department of Health in relation to the involvement of patients in research.

People with MS will have several important contributions to make to health service planning and development. First, there will be some services where the issues concern specific MS-related matters. The service responsible for making the original diagnosis and for managing acute relapses and the prescription and monitoring of disease-modifying drugs is the most obvious. However, in practice people with MS probably make more use of, and will be more concerned about an increase in, generic services such as neurological rehabilitation services, continence services, and wheelchair services. Lastly, people with MS should be able to use any other services, with particular attention to health promotion and disease prevention services.

In the first case it is obviously important that people with MS are specifically involved. In the second and third cases it would certainly be appropriate for people with MS to be involved and they are likely to have much to contribute but people with other neurological disabilities could also be involved in addition to, or in place of, people with MS.

It should be emphasised that particular efforts are needed to involve any group of people with disabling conditions, and that their involvement is important because they are active users of most services over most of their lives. However, no specific recommendations will be made because this applies to all patient involvement and is not specific to people with MS.

3.4 Within-team communication

A common vocabulary is fundamental to the success of any complex organisation or service. This will usually depend upon an agreed, comprehensive framework that will facilitate the development of common understanding, and encourage the use of a shared vocabulary that helps communication. This will also increase the likelihood of effective teamwork through the setting of common goals. Although there is no evidence comparing models of illness, the increasing prominence of the World Health Organisation's International Classification of Functioning (see Appendix A) suggests that it should be used, especially as much work has already been devoted to its development. The recommendations made are intended to facilitate cohesive teamwork.

RECOMMENDATION

- R21** All individual clinicians, professional groups and organisations involved in the care of those with MS should use WHO's International Classification of Functioning (WHO ICF) model of illness, and its vocabulary. **D**

LOCAL IMPLEMENTATION POINT

The local services will need to agree a vocabulary that is shared across all organisations including social services.

3.5 Provision of services over time (rehabilitation, maintenance, prevention and palliative care)

It is important to consider the management of MS over time, accepting that the disease is inherently unpredictable. Four time phases have been suggested,⁵³ but only a minority of people with MS will pass through all four and many only experience the first two:

- 1) *Diagnostic phase*: initial symptoms, and diagnosis (with disease modifying drugs now used).
- 2) *Minimal disability*: relapsing-remitting phase with episodes of sudden worsening with partial or complete resolution; some disability; probably stops work and becomes dependent upon others for some aspects of community or household activities.
- 3) *Moderate disability*: progressive increase in limitation on activities at a slower or faster rate; becomes dependent on others for personal activities of daily living.
- 4) *Severe disability*: more-or-less totally dependent upon others at all times; sometimes in residential care; higher rate of complicating medical illnesses such as chest infection.

In the first phase a service that focuses on diagnostic and disease treatment is appropriate. However, it is never too early to apply general rehabilitation principles: for example, the diagnosis of MS may sometimes call for measures relevant to the person's future family, occupational or financial situation. These considerations apply more urgently in the second phase, when therapeutic interventions may also be indicated, often with a preventive as well as a remedial rationale. In the third phase, services maximising activity and participation are more likely to be involved in adapting the social and physical environment, in addition to continuing therapy interventions. In the fourth phase, service delivery will be centred on the provision of support and of a suitable environment, while still aiming to maintain social participation. Health services have an important role to play in all four phases, but social services will become increasingly involved as the person moves into the third and fourth phases.

Neurological rehabilitation services will be used by many people, and factors which apply specifically to people with MS include:

- people with MS are probably the largest single group of people needing specialist neurological rehabilitation aged under 65 years (with people with stroke and head injury being the next two groups)
- the unpredictable, fluctuating, but generally progressing nature of the disease is different from most diseases
- people with MS also fluctuate on a day-to-day basis
- the disease starts in young adult life.

Services, especially but not only neurological rehabilitation services, therefore need to be able to respond flexibly to the specific situations of individual people with MS and their family and carers. When care needs are extensive, the needs of the carers become especially important.

People with MS are at increased risk of many specific additional pathologies such as pressure ulcers, contractures, osteoporosis and deep vein thrombosis. Services should always try to reduce the risk of these. There is evidence that pressure ulcers and contractures are common, and some evidence is available on how to reduce the risk and treat these complications, discussed in sections 6.5 and 6.17. The significance of other complications such as deep vein thrombosis and osteoporosis is difficult to establish in the absence of evidence, and so most other complications have not been mentioned specifically in this guideline. However, individual clinicians should always consider whether the risk of any person with MS suffering a particular complication can be reduced.

▷ Health economic statements

Little is known about the health economics of long-term health support. The provision of this type of care is complex because it must respond to a broad range of needs and is likely to be provided in a variety of different settings. There is no good evidence on the effects of palliative care on quality of life of people with MS. On the cost side it is important to bear in mind that a significant proportion of the burden of long-term care will fall on the patient and their family and carers. One RCT of the cost-effectiveness of a district coordinating service for people who were terminally ill with cancer in South London revealed no difference in outcomes between the two groups but showed that the service could be delivered with lower resource use than standard care. In particular, savings accrued from reduced inpatient days in acute hospital wards.⁵⁴ The authors argue that since people with cancer appear to want to remain at home as long as possible, reductions in hospital stays may generate benefits to patients. It is difficult to know the extent to which these findings are relevant to the population of people with MS. If palliative care is to be provided in residential or nursing homes, this is a particularly expensive type of provision but can produce enormous benefits for patients and their families and carers. More information on the cost-effectiveness of residential care is required.

RECOMMENDATIONS

- R22 Services should cater for the varying needs of people with MS over time, by: D
- responding in a timely and flexible way to the intermittent acute needs of people with MS, especially in the early phases
 - identifying and reducing the risks of complications that might develop in the individual
 - making fully available, to people with MS, population-based programmes of health promotion and/or disease prevention (such as screening for cervical carcinoma), specifically taking into account an individual's possible impairments and activity limitations.
- R23 When any 'episode of care' (medical or rehabilitation treatment programme) ends (that is, when no further benefit is anticipated), the health care team should: D
- ensure that any necessary long-term support needs are met
 - ensure that the person with MS knows whom 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, by post or as an outpatient).

- R24 Health services should ensure that there are mechanisms to allow good communication between health and social services at all times. D
- R25 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: D
- additional support in the home
 - respite care in the home
 - respite care in another age-appropriate setting
 - moving into a residential or nursing home.

LOCAL IMPLEMENTATION POINTS

Local service commissioners and providers need to agree:

- which specialist rehabilitation service will be responsible for maintaining function and for long-term support
- what local social opportunities exist for people with a range of impairments and limited activities and how they are accessed
- which residential and nursing homes are suitable for younger people
- clear mechanisms for agreeing funding for complex, expensive care home support packages and/or respite support and/or residential care.