

# 5 Rehabilitation and maintenance: functional activities and social participation

## 5.1 General introduction

The guidelines to this point have primarily concentrated upon issues that concern the early phases of MS. At that time most people with MS are leading normal unrestricted lives, but rehabilitation should be considered from the time of diagnosis, especially for anyone who has any symptoms or limitations on activities that concern them. Progression is not inevitable but in those who do worsen, it is likely that roles such as work and active leisure pursuits will be affected first. The smaller number of people who go on to develop more severe limitations on their activities will usually only do so later in their life. Furthermore, even those people who do develop more severe impairments usually still wish to maximise their level of independent activities and social participation.

This rehabilitation section therefore starts by considering those recommendations that specifically concern social participation, activities and contextual factors because a) they are likely to be of greatest concern to most people with MS, b) they will arise before or at the same time as concerns about more basic activities and c) even the recommendations concerning impairments covered in Section 6 will all be set in the context of maximising participation and activities.

One key feature of rehabilitation is that it involves a structured, organised approach to complex problems (ie problems that many factors influence and that require multifocal interventions and/or interventions spread over a long time). Consequently many of the recommendations made in Section 3 concern rehabilitation.

**The reader is strongly advised to read Section 3 in conjunction with this section.**

It is also worth stressing that many of the interventions that may help people with MS require close collaboration with other statutory and non-statutory services. The most obvious is social services who have, for example, shared responsibility for much equipment supplied and for providing personal care in the home. However, other services such as employment and housing will often be involved. Given the closer collaboration being fostered nationally and the blurred and indistinct boundaries that vary around the country, these guidelines have made some recommendations that will apply to the NHS more in some parts of the country than in others, but that certainly are of importance to the person with MS.

It is therefore important at all times to recall recommendation R18.

While many of the recommendations in this section are generally applicable to the process of rehabilitation, it is important to stress some special features particular to the person with MS. As in any patient, rehabilitation for people with MS should first be directed towards the restoration of activities and functions that have become limited.

In people with MS, rehabilitation must also take account of the fact that the disease process may cause progressive impairment and consequent loss of abilities, so that maintenance of activities

in the face of physical deterioration is a common goal of rehabilitation. Another common goal is to minimise the secondary effects of the disease process such as the development of contractures or pressure ulcers, the stress on relatives, and the emotional consequences for the person with MS. This proactive and preventative approach should if possible be adopted at a very early stage in the condition and is likely to be centred in the individual's home and/or workplace rather than in a rehabilitation unit.

The evidence base specifically concerning rehabilitation for people with MS is relatively limited. Interventions in these areas do not easily lend themselves to the traditional randomised control trial approach because rehabilitation interventions are individually tailored, and outcomes expressed in specific rather than general terms. Research is further complicated by the difficulty in describing accurately but succinctly the nature of the tailored intervention. Comparison groups often tend to be those given traditional or no treatments or those treated after a delay. Few studies specifically investigate rehabilitation in specific domains of disablement.

However the general principles of rehabilitation are similar whatever the disease or domain, and so the recommendations are similar for each part and draw on general evidence from other diseases. Therefore this section has the following structure:

- general rehabilitation recommendations
- recommendations relating to vocational and leisure activities
- recommendations concerning mobility
- recommendations specific to other domains including equipment and environmental alterations.

The whole section depends upon initial recognition that the person with MS has a difficulty in some area of their life that might benefit from further assessment and treatment. R7 to R11 in Section 3 covers this.

## 5.2 General rehabilitation

Rehabilitation is a process that focuses on increasing performance of activities and aims to optimise social participation and to minimise stress and distress for both the person with MS and any carers involved. The rehabilitation process is mainly a problem-solving approach that will involve multifocal interventions at differing levels (eg impairment, environment) from a specialist team over time. Consequently the process of rehabilitation will only begin when a problem has been recognised, and it starts with a detailed assessment of the individual's problem(s). This part focuses on two aspects of rehabilitation:

- ensuring that the persons' situation is considered as a whole, and not piecemeal, and
- making recommendations about specific ways of treating activities that are limited.

The processes involved in rehabilitation are often described as being a 'black box', although in fact they are better considered as a 'Russian doll'. This is because they can be described at many levels, from the global (assess, plan, intervene, review) to the very specific (for example, 'This person will benefit most from 20mg baclofen at night, botulinum toxin injection into the right gastrocnemius muscle, a resting splint at night and a daily stand in a standing frame ...'). Given the large number of impairments that may arise secondary to multiple sclerosis, the large variety of contexts that will apply to people with MS, and therefore the almost infinite number of particular situations, each being unique, it is not practical for these guidelines to give specific

detailed recommendations to cover each potential limitation of activities. Therefore the recommendations made in this section are necessarily only at a relatively high level, covering only more general principles.

There are only a few studies on the general effectiveness of rehabilitation in MS<sup>49,250,251</sup> but the effectiveness of rehabilitation from a specialist multidisciplinary team has been demonstrated beyond all reasonable doubt in other situations, notably stroke.<sup>15</sup> The effectiveness of multidisciplinary rehabilitation has also been shown in other disabling conditions such as head injury<sup>43,44</sup> and back pain.<sup>252</sup> In these studies the patients have had complex problems with many interrelated factors and the rehabilitation process of multifocal interventions by a team has been the intervention investigated and found to be effective. People with MS also have similar features, and it is reasonable to generalise from this evidence. The evidence suggests that in this circumstance an expert (specialist) multidisciplinary team that involves the patient and family actively will achieve a better patient outcome, often at no extra cost.

### ▷ Evidence statements

Three RCTs, two CCTs and two uncontrolled studies assessed the effectiveness of multidisciplinary rehabilitation programs. The first RCT examined an inpatient rehabilitation program, comprising medical, nursing, occupational therapy and physiotherapy input. The results indicated beneficial effects on the functional independence measure (FIM), London Handicap Scale score, improvements in functional abilities and levels of handicap. The second RCT focused upon physical rehabilitation. Results showed significant positive changes on two of the five outcomes assessed, FIM and self-care abilities.<sup>251</sup> The third RCT examined the effectiveness of an outpatient rehabilitation treatment programme. This study reported significant beneficial effects on various outcome measures including the SF-36 (all subscales, fatigue, social experience and depression). No significant effect was found on the EDSS score<sup>253</sup> (Ib). One CCT assessed the efficacy of an occupational and physiotherapy program for MS patients who suffered from moderate to severe ataxia of the upper limbs and trunk. The results indicated significant improvement on half of the outcome measures assessed, which included ADL indices.<sup>254</sup> The second CCT assessed the effectiveness of an outpatients rehabilitation programme. This reported beneficial effects on two of the three outcomes assessed<sup>49</sup> (IIa). Both uncontrolled studies assessed multidisciplinary inpatient rehabilitation programmes. The results of the first study showed beneficial effects on four out of seven subscales of the Nottingham Health Profile Part 1 (NHP-1) assessed, including pain, physical mobility and emotional reactions.<sup>255</sup> The results of the second study indicated beneficial changes on five out of the six RIC-FAS subscales assessed, including transfers, toileting, grooming and dressing<sup>256</sup> (IIb).

### ▷ Economic evidence

There is very little economic evidence relating to rehabilitation in MS. The establishment of a multidisciplinary rehabilitation programme can result in significant benefits to people with MS and their families and carers. An effective programme may also result in future savings to the NHS and social services by reducing subsequent dependency, and in particular by reducing the need for hospitalisation at certain stages during disease progression.

The establishment of a multidisciplinary community MS team in Newcastle increased contacts with many health professionals following team referral, among the 38 people with MS whose

data was analysed. However, these additional referrals were offset by a decrease in GP contacts, hospital consultant contacts and occupied bed days. Over the six-month period of the evaluation total costs for these people were lower than in the six months prior to the establishment of the team. No firm conclusions could be drawn about the effectiveness of the team but survey evidence showed a high degree of patient satisfaction with the team.<sup>257</sup>

An older study from the US considered the costs and benefits of a multidisciplinary, inpatient rehabilitation program designed along the same lines as similar programs that had been shown to be effective in stroke patients.<sup>258</sup> Only 20 people were assessed in this study, but it did suggest that active, intensive multidisciplinary rehabilitation can improve functional outcomes and may result in cost savings in the long term.

▷ From evidence to recommendations

The GDG considered the evidence available here in the light of other evidence concerning MS reviewed elsewhere in this document and also in the light of strong evidence supporting specialist rehabilitation in other fields. It also noted that people with MS might present with new onset activity limitations needing medical diagnosis of the cause. Next, it noted that some readers might need explicit guidance on the components of the rehabilitation process. Finally, it was aware of emerging evidence in stroke that task-centered therapy may be more effective. The GDG agreed the recommendations made by unanimous consensus where direct evidence was lacking.

## RECOMMENDATIONS

- |     |  |        |
|-----|--|--------|
| R61 | <p>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:</p> <ul style="list-style-type: none"> <li>● is it due to an unrelated disease?</li> <li>● is it due to an incidental infection?</li> <li>● is it due to a relapse of the MS?</li> <li>● is it part of a gradual progression?</li> </ul>  | D      |
| R62 | <p>If the limitation persists, despite treatment of any identified cause, the person with MS should be seen and assessed by a multidisciplinary service, specialised in neurologically based disability.</p> <p>This service should implement a rehabilitation programme.</p>  | D<br>A |
| R63 | <p>The components of the rehabilitation programme should include the following:</p> <ul style="list-style-type: none"> <li>● establishing the wishes and expectations of the person with MS</li> <li>● 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: <ul style="list-style-type: none"> <li>– identifying and treating any treatable underlying impairments</li> <li>– giving task-related practice of a specific activity or activities</li> <li>– providing suitable equipment (with training in its use)</li> <li>– altering the environment as needed</li> <li>– teaching others how to assist with (or take over) tasks</li> </ul> </li> <li>● monitoring progress against set goals; the goals should be reviewed and reset, until no further goals exist and no further interventions are needed.</li> </ul> | D      |

- R64 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). D

## LOCAL IMPLEMENTATION POINTS

Local services will need to:

- identify how people with MS access neurological rehabilitation services at any stage in the course of their disease
- ensure that people working within neurological rehabilitation services work with appropriate statutory and voluntary organisations, both health and non-health.

### 5.3 Vocational activities: employment and education

Many people who develop or have MS will be finishing education or training, or will be in employment. In some people the MS will have little impact, but for most people MS will have some impact. It is important to minimise the impact if possible because being in employment has many health benefits and among other things enables an individual to retain self-esteem, social contacts, financial independence and a valued place in society. The importance of vocational rehabilitation services for people with MS at all stages but especially in the early stages was emphasised many years ago,<sup>17</sup> and has been reiterated recently.<sup>259</sup>

The Department of Employment has some schemes available for people with disability, but generally specialised vocational rehabilitation services are not available. MS is relatively rare and usually poses very specific problems. For example cognitive losses and fatigue are probably the major impairments affecting employment, yet both are outside the normal scope of employment services. Therefore health service personnel have a vital role to play in providing people with MS and their employers with accurate, impartial information and advice, recognising both the abilities and limitations of the person with MS. Sometimes they may need to offer advice about alternative appropriate work.

#### ▷ Evidence statement

Two studies were identified that examined interventions for limitations in undertaking employment in persons with MS. One RCT examined the effectiveness of a job retention programme combined with standard medical care compared to standard medical care alone.<sup>260</sup> The results indicated no beneficial effect of the programme (Ib). One CCT<sup>261</sup> assessed the utility of an accommodation team planning approach compared to traditional job seeking skills for people who were unemployed.<sup>261</sup> Again the results indicated no benefit for the programme (IIb).

#### ▷ From evidence to recommendations

The very little evidence on vocational rehabilitation available does not allow any conclusion to be drawn. However the Department for Work and Pensions, the British Society of Rehabilitation Medicine, and the Department of Health all recognise the potentially important role of the NHS in vocational rehabilitation. The GDG therefore thought it important to make recommendations to support this approach, and a consensus was easily reached.

## RECOMMENDATIONS

- R65 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. D
- R66 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 neurorehabilitation service. D
- R67 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 D
  - to advise the employer or others, with permission from the person with MS, on strategies, equipment and adaptations to assist; and/or D
  - to give information to the disability employment advisor, if involved (see R68).
- R68 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. D
- R69 Any individual who cannot stay in or find alternative employment should be advised about other options such as voluntary work and where to find information about these options. D

## LOCAL IMPLEMENTATION POINTS

Local health, social and employment services will need to:

- agree an integrated approach to vocational rehabilitation, including defined referral criteria for relevant services, and methods for exchanging relevant information
- disseminate information on the location of and means of referral to the Disability Employment Officer at the local job centre and other employment services (including those in the voluntary sector)
- collect, collate and disseminate information about educational and retraining opportunities, and work within the voluntary sector.

### 5.4 Leisure and social interaction

All people, those in and out of employment, will have a range of key leisure activities. Leisure gives balance to life, as well as giving opportunities for social interaction. The impairments and disabilities that may affect work will usually also affect leisure, but the person with MS can have more control over their leisure pursuits. Loss of independent social activity is very common in people with MS; one survey in the USA found that 62% of people with MS were either socially inactive or depended upon the initiative of others.<sup>262</sup> The importance of leisure as a valid focus for specialist rehabilitation services is being increasingly recognised, but specific services are rare and are often run by social services or voluntary agencies. While the NHS does not have a responsibility to provide specific ongoing opportunities to undertake leisure (eg day centres), the NHS does have a clear responsibility to all patients, including people with MS, to assess their needs in relation to leisure activities and then to give, where possible, the skills and techniques

needed to pursue chosen leisure pursuits and then to identify local resources and put the person with MS in touch with them.

### ▷ Evidence statements

No studies were identified that met the inclusion criteria.

### ▷ From evidence to recommendations

Although no research on leisure rehabilitation specific to MS has been undertaken, there is evidence that quality of life (in patients with stroke) is related to leisure activities and the GDG agreed that recommendations were needed and agreed those made by consensus.

## RECOMMENDATION

- R70** 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: **D**
- 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.

## LOCAL IMPLEMENTATION POINTS

The local services should:

- maintain an up-to-date list of local organisations that can provide information on social activities for people with disabilities
- maintain an up-to-date list of local community transport providers
- have procedures to enable easy cross-agency working to optimise leisure activities for people with MS.

## 5.5 Mobility

The ability to negotiate the environment independently is fundamental to all aspects of daily life and almost all aspects of social participation are dependent upon adequate mobility. Limitation in mobility is one of the prime determinants of the amount (time and number of people) of 'care needs', whether given by family or paid carers. Limitation in mobility is common in people with MS. For example in one study 58% of people could not climb stairs unaided and 42% needed mobility aids including wheelchairs.<sup>262</sup>

The construct of mobility is or can be much broader than simply walking. It includes moving in bed, getting out of bed, moving into and out of chairs, going up and down stairs and slopes, getting to and from shops, using special mobility equipment such as walking aids and wheelchairs, and using public transport. It may also include endurance.

Reduced mobility is a common disability in many neurological and non-neurological conditions, and many studies have investigated treatments focused on improving mobility, usually walking. Furthermore, improvements in (or reduction in loss of) mobility are a common outcome measure in many other studies, including almost all interferon beta trials (the EDSS is primarily a measure of mobility).

▷ Evidence statements

Two RCTs and one randomised crossover trial assessed different interventions for mobility problems (Ib). The first RCT examined the use of fully trained service dogs for wheelchair mobile people with MS.<sup>263</sup> The results showed significant beneficial effects on all of the eight outcome measures assessed including psychological, social, employment and care needs indices. The second RCT assessed the intervention of awareness through movement classes compared to just educational sessions. The results showed no difference in the number of falls or functional balance performance or self-efficacy between the groups.<sup>264</sup> The randomised crossover trial compared hospital outpatient physiotherapy to home-based physiotherapy and no treatment. The results showed beneficial effects for the majority of outcomes assessed for physiotherapy interventions. There were no overall differences observed between the different physiotherapy interventions.<sup>265</sup>

▷ Economic evidence

There are no formal economic evaluations of any interventions for mobility problems in MS. However the randomised crossover trial of physiotherapy described above<sup>265</sup> did consider the costs of providing home- and hospital-based therapy alongside the outcomes. No significant difference was found between the outcomes of home-based against hospital-based physiotherapy. Home therapy was more expensive than hospital outpatient sessions, even when patient travel costs to hospital (including time) were taken into account. Patient travel costs were approximately 40% of total hospital session costs.

▷ From evidence to recommendation

The evidence reviewed only considered one intervention (physiotherapy) and only in one group of patients (those able to walk, or likely to). The section refers to all aspects of mobility. Furthermore, many of the topics considered elsewhere in this guideline might improve mobility. The recommendations therefore approach all aspects of mobility, taking into account not only the specific evidence reviewed above but a) other evidence within this document, b) general principles of rehabilitation, and c) evidence in other conditions such as stroke.

## RECOMMENDATIONS

- R71 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 neurorehabilitation service. The assessment should determine which of the following interventions are needed: D
- 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 of others how to safely assist with (or take over) tasks such as walking, climbing stairs, moving in bed or transferring.

- R72      Physiotherapy treatments aimed at improving walking should be: A
- offered to a person with MS who is, or could be, walking
  - given at home or on an outpatient basis, depending on the preference of the person with MS and local resources.

### LOCAL IMPLEMENTATION POINTS

Local services will need to:

- identify how people with MS whose activities are affected or threatened by reduced mobility can easily access neurological rehabilitation services
- agree common measures of mobility to be used locally.

## 5.6 Activities of daily living

A significant proportion of people with MS may eventually experience limitations on their ability to undertake a variety of activities needed to live independently such as shopping, housework and undertaking personal care. Collectively these activities are referred to as activities of daily living (ADL), in contrast to vocational and leisure activities. Occupational therapists are usually the professional group with most expertise in, and who lead on the rehabilitation of, activities of daily living. The limitation may arise from many of the common impairments including cognitive losses. The amount of direct support from other people needed by a person is determined primarily by their need for support with personal activities and/or with their mobility. Various terms are used in this part.

‘Community activities’ are those that involve the person leaving their home and undertaking activities in public areas and buildings, such as shopping, using public transport, negotiating the environment safely (primarily avoiding traffic), and accessing other public amenities (eg leisure facilities). Parents may also need to accompany children to school. Community activities depend greatly upon adequate independent mobility and upon adequate cognitive skills.

‘Domestic activities of daily living’ are those activities needed around the house to maintain life and safety, and a reasonable standard of cleanliness. They include cooking, washing up, all aspects of managing clothing (eg washing, ironing) and keeping the house clean. They may also include in some people other activities such as caring for children, and responding to financial and other demands such as paying bills. In contrast to personal activities, domestic activities often make more demands on cognitive skills, and consequently may be influenced more by cognitive deficits.

‘Personal activities of daily living’ refers to basic daily activities such as dressing, washing and bathing, grooming, using the toilet, controlling continence and getting around the house.

▷ Evidence statements

No studies were identified that met the inclusion criteria.

▷ From evidence to recommendations

No studies explicitly studied rehabilitation of these activities, but measures of these activities, especially personal activities of daily living, were the primary outcome measure in the RCTs of specialist neurological rehabilitation already reviewed (see 5.2.1). The GDG agreed unanimously that the recommendations below were reasonably derived from evidence reviewed elsewhere in this document, and from the evidence in other neurological conditions such as stroke.

## RECOMMENDATIONS

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

- R73 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: **D**
- 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.
- R74 A comprehensive assessment of this type should: **D**
- 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.
- R75 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. **D**
- R76 If the individual agrees, the programme of interventions should be shared with social services, and this must occur if social services are to be responsible for maintenance interventions. **D**
- R77 There should be regular monitoring to check how effective the interventions are, with a view to changing them if necessary. **D**

R78 At the end of the planned programme, the person should know how to obtain a re-assessment if their situation changes. D

## 5.7 Equipment, adaptations and personal support

The consequences of any disease are influenced greatly by the person's environment. This includes both peri-personal (within immediate reach, eg clothes, wheelchairs) and local (outside immediate reach, eg ramps, rails) environmental factors and extends to the general community. The importance of providing equipment has been stressed by the Audit Commission,<sup>122</sup> who also illustrated the enormous variability in current provision. The effectiveness of providing equipment has also been demonstrated in an RCT in the USA.<sup>267</sup> These guidelines do not consider the need to ensure that the public environment is made more appropriate for individuals with a variety of impairments, but this is important to people with MS.

The physical environment, as the term is used here, also includes the availability of other people in a supporting role (ie as assistants, not specifically as social contact). In most instances family members will undertake this role but it must be recognised that friends and neighbours also provide additional support, and that for a substantial number of people paid carers provide support. It should also be recognised that the support offered by the carer may extend (legitimately) well beyond hands-on support to include monitoring safety, providing prompts, and even providing the reassurance needed to allow the person to perform the activity independently.

Increasingly, services are being encouraged to have a joint approach to funding and providing equipment. However at present some equipment and adaptations may be provided by social services and they may seek advice from health professionals about the current health of the individual with MS and about the likely course of the illness. It may be important to stress that the course of MS is unpredictable in any individual and that appropriate equipment should be made available both for the current needs of the individual and for their needs at any predictable or likely worse state, such as when suffering an incidental infection.

Equipment and adaptations can be costly but they can also make an enormous difference to the quality of life of people with MS and their families and carers. The Audit Commission report argued that resources could be saved by better targeting of equipment to people's needs and better coordination of services to improve the efficiency of provision.<sup>122</sup> In addition if equipment and adaptive technology enable people to remain independent in the community, this is preferable to admitting them for treatment in other parts of the health care system. There is a clear need for research on the costs and benefits of equipment and adaptive technology for people with MS.

### ▷ Evidence statement

One two-phase study encompassing both an RCT and an uncontrolled pre-post phase examined the effects of tilting the wheelchair seating position for patients with MS.<sup>268</sup> The results of the uncontrolled phase showed beneficial effects on four of the five outcome measures assessed, namely measures of respiration and voice volume, with a tilt of the seating angle of 25 degrees. The results of the RCT phase indicated that there were no differences between the groups when the seating angle was tilted by either 25 or 45 degrees. This phase did not include a 'no tilt' control group (Ib).

▷ From evidence to recommendations

There are few randomised studies of the value of equipment, and the best (Mann *et al*, 1999) was the basis of the Audit Commission report.<sup>122</sup> Much equipment is so self-evidently effective (eg a wheelchair for someone whose legs are paralysed) that trials are probably unethical. The GDG drew on the Mann *et al* study and Audit Commission report, and easily reached consensus on the recommendations made.

## RECOMMENDATIONS

- R79 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: D
- 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: D

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

*Equipment and adaptations*

- R80 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. D

- R81 The service providing or recommending the equipment should ensure the equipment's continuing appropriateness and safety, at appropriate intervals. D

*Personal support*

- R82 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. D

- R83 If personal support is provided by family, friends or paid carers, an expert should offer knowledge and skills to help the carer(s) 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. D

- R84 If support is given on a daily basis for more than one 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 event (for example, infection, relapse, complication, departure of family member). Any person involved in hands-on D

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.

### LOCAL IMPLEMENTATION POINTS

Local health and social services must have systems in place to provide an integrated approach to assessment and provision of a) non-specialist equipment, b) specialist equipment and c) personal support services. To this end they need to:

- identify who assesses people with MS for specialist and non-specialist equipment and home adaptations they may need
- identify funding mechanisms in collaboration with social care providers
- set up local audit mechanisms showing average delays and the proportion of equipment which is actually used
- specify how pieces of equipment are monitored and maintained, and changed as necessary in line with changing needs
- agree how carers, including family members, are taught necessary skills and are assessed for competence in all aspects of caring undertaken
- specify how family members and other carers can contact appropriate experts for further advice and tuition.