Multiple sclerosis (MS) is the commonest neurological cause of disability in young adults. The clinical course is extremely variable, but typically a relapsing-remitting phase of variable duration is followed by a gradual progression in disability. However, the diagnosis of MS may have an impact that reaches beyond the physical disabilities into many other aspects of life, including career and family. The time of diagnosis is one of the most important in the course of the illness and the way in which investigations are conducted, the timing and manner of imparting the diagnosis, and subsequent support and education may have far-reaching consequences. The diagnostic phase thus presents a difficult management challenge for the neurologist and other health workers attempting to address these issues. This review considers the steps involved in reaching the diagnosis, together with ways in which the overall quality of
life of the patient may be maximized during this period.

Introduction

MS is a chronic, demyelinating inflammatory disorder which affects the central nervous system in an unpredictable fashion. There is a tendency to develop progressive disability over time and currently there is no cure (1). Because it most commonly occurs in young adults, the diagnosis may have a profound impact on active working, social and family lives. It is, therefore, important to place the diagnostic process within a wider context than the purely medical. This chapter will address some of the issues involved, including the optimum setting for investigations, the timing and manner of communicating the diagnosis and the importance of ongoing support and counseling after the diagnosis is made. Such factors may be just as important to the patient as the investigation process itself, and have perhaps not received the attention they deserve. Therefore, this review will not only outline the steps involved in making the diagnosis but also will attempt to redress the balance in favor of these more general considerations.

The Nature of the Disease

Although MS may affect any part of the central nervous system and thus has myriad clinical manifestations, some anatomical sites are preferentially affected, and these include the optic nerves, the spinal cord, the cerebellum and brainstem. In the majority (approx. 85%) of patients, onset is monosymptomatic and classically will resolve fully. The subsequent clinical course is initially relapsing and remitting for most patients (90%), but in time remissions usually become less complete and the disease enters a secondary progressive phase of accrued irreversible neurological deficit. However, about one-third of those who are at first relapsing-remitting will remain relatively free of disability for many years (benign MS). In contrast, 10% of patients will have progressive disease from the onset, without relapses and remissions (primary progressive MS) (2).

How the Diagnosis is Made

The diagnosis of MS is still a clinical one and rests upon three essential criteria: (i) evidence of lesions in 2 or more separate sites in the central nervous system which must (ii) occur on 2 or more separate occasions, i.e., dissemination in space and time, and (iii) the exclusion of other conditions that can produce a clinical similar picture (1). Even with recent advances in diagnostic tests, the most valuable tools in providing evidence for dissemination in space and time are a careful history and thorough neurological examination. The exclusion of other conditions may require further investigations.

Although many diagnostic classifications have been used in the past, there is now a generally agreed set of criteria (4) that contains 2 groups of patients (definite and probable), each with 2 subgroups (clinical and laboratory supported). A number of investigations are included which may either help to establish dissemination in space or time (giving so-called paraclinical evidence) or suggest an underlying immunological abnormality (giving laboratory support) (Table I).

Exclusion of other treatable conditions

The exclusion of other conditions was in the past difficult, requiring invasive techniques such as myelography or pneumoencephalography. Computerized axial tomography, although less invasive, has now been replaced by magnetic resonance imaging (MRI) as the investigation of choice. MRI can provide high resolution images that are particularly useful in detecting structural lesions affecting the posterior fossa, foramen magnum and spinal cord. The most important of these conditions are intrinsic and extrinsic tumors, but arteriovenous abnormalities and the Arnold-Chiari malformation must also be considered (Fig. 1).

Demonstration of immunological abnormality

There is considerable evidence that immunological mechanisms play an important role in the pathogenesis of MS. Abnormalities of both the
humoral and cell-mediated immune responses are found. The most widely used diagnostic test of immune function provides evidence for a humoral (B-cell-mediated) abnormality in the form of raised IgG levels in the cerebrospinal fluid (CSF). This is produced by limited clones of B-lymphocytes, and is detected by immunoelectrophoresis as an oligoclonal band pattern that is not found in serum. The test, therefore, requires the collection of CSF and a simultaneous blood sample. The presence of such bands of IgG in CSF but not in serum indicates intrathecal synthesis, which is highly suggestive – in an appropriate clinical context – of MS. Oligoclonal bands are present in over 90% of patients with clinically definite disease, but are less likely to be detected in those with a less secure clinical diagnosis. They are not, however, specific to MS and may be found in a large number of inflammatory or immune-mediated diseases of the CNS, some of which must be considered in the differential diagnosis. The preferred method of detection of IgG is isoelectric focusing. There are

<table>
<thead>
<tr>
<th>Category</th>
<th>Attacks</th>
<th>Clinical evidence</th>
<th>Paraclinical evidence</th>
<th>CSF OB/IgG</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinically definite (CD)</td>
<td>2</td>
<td>2</td>
<td>and 1</td>
<td></td>
</tr>
<tr>
<td>CDMS A1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CDMS A2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laboratory supported definite (LSD)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LSDMS B1</td>
<td>2</td>
<td>1</td>
<td>or 1</td>
<td>+</td>
</tr>
<tr>
<td>LSDMS B2</td>
<td>1</td>
<td>2</td>
<td></td>
<td>+</td>
</tr>
<tr>
<td>LSDMS B3</td>
<td>1</td>
<td>1</td>
<td>and 1</td>
<td>+</td>
</tr>
<tr>
<td>Clinically probable (CP)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CPMS C1</td>
<td>2</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CPMS C2</td>
<td>1</td>
<td>2</td>
<td>and 1</td>
<td></td>
</tr>
<tr>
<td>CPMS C3</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laboratory supported probable (LSP)</td>
<td></td>
<td></td>
<td></td>
<td>0</td>
</tr>
<tr>
<td>LSPMS D1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

OB/IgG = oligoclonal bands or increased IgG; + = present. From Poset et al. 1983 (4).

Fig. 1. Sagittal magnetic resonance imaging (MRI) scan demonstrating a Type II Arnold-Chiari malformation with herniation of the cerebellum caudally.
Currently no other serum immunological tests available that are of routine use in the diagnosis of MS.

Providing evidence for dissemination in space and time

1) Magnetic resonance imaging

Since the first demonstration by Young and colleagues in 1991 (5) that pathologically proven demyelinating lesions were clearly revealed by magnetic resonance imaging (MRI), this technique has revolutionized the diagnosis of MS. Areas of increased signal are seen on conventional T2-weighted images in over 95% of patients with clinically definite disease (6). Furthermore, the distribution of lesions in the brain is often (but not always) characteristic of MS, with a predilection for the periventricular, callosal and cerebellar white matter (Fig. 2). Although these appearances may be quite characteristic, they are by no means specific, and many other conditions can produce a similar picture. These include inflammatory conditions such as systemic lupus erythematosus (SLE), Behcet’s disease and sarcoidosis (Fig. 3). Furthermore, in normal individuals over the age of about 50, the white matter changes of cerebrovascular disease may cause diagnostic difficulty. The differentiation of MS lesions from these nonspecific vascular changes may be improved by applying stringent interpretation criteria (7). These problems probably, at least in part, reflect the lack of pathological specificity of MRI, which cannot distinguish between edema, demyelination, axonal loss and gliosis.

Despite these difficulties, MRI remains the single most useful test in the diagnosis of MS (8). The benefit of MRI in diagnosis is illustrated by the patient who presents with symptoms and signs of a single anatomical lesion but is then found to have multiple typical abnormalities on MRI images.

Fig. 2. Axial MRI scan through the lateral ventricles in a patient with clinically definite relapsing-remitting multiple sclerosis showing typical hyperintense periventricular white matter abnormalities.

Fig. 3. Axial MRI scan through the lateral ventricles showing extensive irregular periventricular signal abnormality, especially in the frontal lobes, with mild hydrocephalus. Biopsy of the left frontal region revealed non-caseating granulomata typical of sarcoidosis.
(that may represent clinically silent lesions). This provides evidence of dissemination of disease in space. In conjunction with the contrast agent gadolinium-DTPA, which enhances in regions of inflammation associated with new disease activity, evidence of temporal dissemination may also be obtained; more recent or acute lesions enhance, whereas older lesions do not. An intriguing observation is that new episodes of disease activity as judged by such enhancement occur up to 10 times as often as clinically apparent relapses (9).

The role of spinal cord MRI in the diagnosis of MS is not yet as well established as that of brain imaging, but it is likely to become more important with the development of increasingly sensitive and rapid imaging techniques. Studies using multi-array coils and fast imaging (10, 11) showed that 75% of patients with MS had spinal cord lesions compared with only 2% of normal controls. This suggests that spinal cord imaging may be especially valuable in the diagnosis of MS in patients over the age of 50 years, since cord lesions are likely to be more specific for MS than brain white matter lesions in this group. Another potential role is in the patient suspected to have MS, but who has a normal MRI brain, when detection of cord lesions may help to confirm the diagnosis. It should be noted that, as with brain imaging, signal changes in the spinal cord are not specific for multiple sclerosis. Anterior spinal artery thrombosis, sarcoidosis, SLE, Behcet’s disease and acute disseminated encephalomyelitis (ADEM) may all cause abnormalities on spinal cord imaging that may resemble those of MS.

In the case of a clinically isolated syndrome suggestive of MS (for example a first episode of optic neuritis or a transverse myelitis), the potential role of MRI in prognosis should be mentioned. There is now evidence that the presence of brain MRI abnormalities at presentation with such a syndrome is a predictor of the risk of developing clinically definite MS, as well as the extent of disability over the next 10 years. One study (12) has shown that 83% of such patients with an abnormal brain scan at presentation went on to develop clinically definite MS, in contrast to only 11% of those with a normal baseline scan. This clearly has important implications for the way in which the diagnosis should be communicated and for any subsequent advice given.

2) Evoked potential studies

These include visual, brainstem and somatosensory evoked potential (VEP, BSEP and SSEP). Of these, the VEP is the most useful in diagnosis, firstly because it is sensitive even to subclinical lesions of the optic nerve, secondly because abnormalities are stable and persist over a considerable time, and thirdly it is a very commonly affected site in multiple sclerosis (13). In optic neuritis there is typically a reduction in amplitude and a prolongation in latency of the VEP pattern (14) (Fig. 4). If these changes are found in a patient with symptoms and signs of a single CNS lesion elsewhere, for example in the spinal cord, then it can be stated that there is dissemination in space, supporting a diagnosis of MS. VEP may be particularly important in helping to establish the diagnosis of primary progressive MS, in which a progressive spinal cord disturbance is commonly seen without clinical evidence of involvement of other anatomical sites (15). BSEP and SSEP have a more limited role in demonstrating abnormal conduction in other CNS pathways. Taken together, evoked potential studies are abnormal in over 75% of patients with clinically definite MS.

**Differential Diagnosis**

There are many conditions that cause a multifocal CNS disorder resembling MS in young adults. These may be divided into those with a monophasic, multiphasic or progressive course (Table II), and have recently been reviewed (3).

---

![Visual evoked potential of a patient with a left optic neuritis showing increased latency and reduction in amplitude of the affected compared to the unaffected eye.](image)

---

D.J. Werring and A.J. Thompson
Table II: Differential diagnosis of MS

**Monophasic Course**
- Acute disseminated encephalomyelitis

**Multiphasic Course**
- Inflammatory disorders, including systemic lupus erythematosus, primary Sjögren’s syndrome, Behcet’s disease, polyarteritis nodosa, isolated angiitis of the CNS
- Infectious diseases including Lyme disease, brucellosis
- Granulomatous disorders including sarcoidosis, Wegener’s granulomatosis
- Arteriovenous malformations
- Prothrombotic states, bacterial endocarditis (rarely)
- Arnold-Chiari malformations

**Progressive Course**
- Compressive lesion
- Tropical spastic paraparesis (particularly in patients of Japanese or Caribbean origin)
- Hereditary spastic paraparesis
- Adrenoleucodystrophy
- Leber’s optic atrophy

**Monophasic conditions**

The monophasic group includes acute disseminated encephalomyelitis (ADEM), a condition which often affects children following a viral illness. It typically causes symptoms and signs of CNS disturbance at multiple sites in association with reduced conscious level. The latter feature may help in distinguishing ADEM from MS but is not invariably. The MRI appearance of ADEM can closely mimic that of MS (16), and oligoclonal bands may be present in CSF (but may then subsequently fade). Therefore, it is not always possible to make a firm diagnosis until follow-up.

**Multiphasic conditions**

A number of inflammatory conditions may affect the CNS to produce a multiphasic clinical course which can closely resemble that of MS. These include SLE, isolated angiitis, primary Sjögren’s syndrome, Behcet’s disease, Whipple’s disease and polyarteritis nodosa. The physician must therefore be aware of the other systemic manifestations of these conditions and have a high index of suspicion. Blood tests including inflammatory indices (erythrocyte sedimentation rate and C-reactive protein) and appropriate serological tests have a useful place in screening for these diseases, but more detailed investigation may be indicated. The second group of conditions that may give a relapsing-remitting picture are the granulomatous diseases including sarcoidosis and Wegener’s granulomatosis. Sarcoidosis in particular can cause considerable diagnostic difficulty and, although relatively rare, is important to recognize since it may respond dramatically to immunomodulatory therapies including corticosteroids. Although the screening tests of serum and CSF angiotensin converting enzyme (ACE), together with a chest radiograph, have a useful role, if sarcoidosis is clinically suspected then more specific tests including skin biopsy, Kveim testing and gallium nuclear scanning may be necessary, and are ideally carried out in a specialist unit. Infectious diseases can occasionally resemble MS, for example Lyme disease and brucellosis. A careful history will often provide additional clues (e.g., the characteristic migrating erythematous rash in Lyme disease) to direct the physician toward these conditions. Rarely an arteriovenous or Arnold-Chiari malformation may cause relapsing-remitting symptoms, but these conditions are usually readily seen on MRI scans (Fig. 1).

**Progressive conditions**

Conditions with a progressive course can be difficult to distinguish from MS (particularly the primary progressive subgroup that constitutes about 10% of all cases of MS). The most important of these to exclude is a compressive lesion causing a progressive paraparesis or quadraparesis, but rarer diseases including hereditary spastic paraparesis (HSP) and tropical spastic paraparesis must also be borne in mind in the appropriate clinical context. A family history would increase the suspicion of HSP, whereas a tropical spastic paraparesis is more likely in a patient of Japanese or Caribbean origin. In tropical spastic paraparesis high serum and CSF antibody titers to human T-cell lymphotrophic virus (HTLV-1) are usually found. One phenotype of X-linked adrenoleukodystrophy presents as a progressive spastic paraparesis with sensory loss in the second decade or later. Plasma very long-chain fatty acids measurement is the most useful diagnostic test. Finally, in a young patient with unexplained rapid or progressive visual loss (usually affecting both eyes within a year), Leber’s hereditary optic neuropathy should be excluded by seeking the appropriate mitochondrial DNA mutation.
Important Issues in the Diagnostic Phase

Current practice

Before considering ways in which the diagnostic process could be optimized, the most widely adopted general pathway used in the United Kingdom will be discussed.

1) Noninvasive investigations

a) History and examination

The importance of a good history and clinical examination has already been emphasized, and is the most important initial step in determining which patients should be investigated further (and to what extent). In some cases, the diagnosis of clinically definite MS may be made at this stage (4), but in the majority of cases further investigations will be indicated for the purposes of excluding other conditions and to give prognostic information.

b) Evoked potentials and MRI

If the diagnosis is suspected but dissemination in time and space has not been demonstrated, then MRI and/or VEP will usually be performed in an effort to obtain such evidence. VEP has now been largely standardized, and generally a pattern-evoked cortical potential (the P100) is obtained and any abnormality in delay or amplitude noted. In optic neuritis there will typically be increased latency and reduced amplitude of the P100 (Fig. 4).

The type of MRI investigation most commonly used as standard at present is a combination of a T2-weighted and a proton-density study. A gadolinium-enhanced T1-weighted scan may also be performed in difficult cases. Many different scan sequences have now been developed in order to maximize the detection of MS lesions. Among the most promising is fast fluid-attenuated inversion recovery (FLAIR) which suppresses the bright CSF signal which may reduce the conspicuity of lesions, particularly in the periventricular regions that are commonly affected in MS. The optimization of imaging sequences is an active area of research, and many new techniques are under investigation, for example, diffusion imaging, magnetization transfer imaging and spectroscopy. These do not form part of routine practice at present, however. It should be emphasized that the diagnosis can often be established without the need for MRI, and that local resource limitations may not permit its routine use.

c) Central motor conduction time (CMCT)

This investigation detects slowing of conduction in the CNS and may be of value when a patient has a motor deficit (e.g., a spastic paraparesis) with either no imaging abnormalities or imaging findings of unclear significance. The demonstration of CMCT delay provides evidence of a central pathway disruption. The test may also have a role if a patient has motor disability but without the typical physical signs. CMCT abnormality will then at least suggest an organic illness causing CNS conduction disturbance.

2) Invasive investigations

a) Lumbar puncture

There is no doubt that lumbar puncture (LP) has a valuable role in the diagnosis of MS, but it should not be seen as a routine part of the investigation pathway in every patient. Although in experienced hands the discomfort and risk are minimal, and the likelihood of a postlumbar puncture headache is low, the investigation should only be performed when judged to be clinically necessary. Indications for LP include cases where there is a high index of suspicion of the disease but atypical features are present, for example, late age of onset, a normal brain MRI or associated systemic symptoms. Because over 90% of those with clinically definite disease will have oligoclonal bands in CSF, their absence may make the neurologist question the diagnosis (3). Similarly, an abnormal cell count or very raised protein level in the CSF will point away from MS as the most likely diagnosis.

Although the diagnostic pathway outlined above is vital, it does not address many concerns that are often voiced by patients. It has already been stated that the diagnosis can have a profound effect on many aspects of life, including career and family, and the experiences of the patient at this time can have far-reaching consequences. Patients frequently express dissatisfaction with the manner and timing of diagnosis and of the quality and extent of information given (17). We will now examine some of the key issues, many of which were identified during a recent workshop (18).

Setting and timing of investigations

It is important that once patients seek medical advice with neurological symptoms suggestive of
MS they are referred promptly to a consultant neurologist, ideally with an interest in MS, to minimize the delay in arranging appropriate investigations (18). At present there are few diagnostic clinics solely concerned with MS, but there are certainly arguments in favor of such an arrangement. Such a clinic might include a neurologist, a clinical nurse specialist with expertise in MS (see below) and close links with hospital diagnostic departments such as radiology, neurophysiology and the MS society. In this way the patient will have access to all of the essential services needed during the diagnostic phase. At present the investigation of MS usually takes place on an inpatient basis. This is not necessary in the majority of cases, and if tests are suitably coordinated they could potentially be performed at a single outpatient attendance. This would be facilitated by a dedicated diagnostic clinic and could have implications for improved patient quality of life as well as for allocation of scarce inpatient resources. Each patient may require either noninvasive tests alone or in combination with invasive tests. All of these investigations (including MRI, VEP and CSF analysis) can be performed in the outpatient setting. Previous reservations about performing lumbar puncture as a day case probably have more basis in tradition than fact. Of course, each patient must be considered as an individual case, and clinical features may change over time, so that it is not always possible to arrange a battery of tests in this way.

It is clear that there is considerable scope to improve the way in which diagnostic tests are presently coordinated, and diagnostic clinics are one promising possibility. It is perhaps reasonable to suggest that all tests are completed within 1 month and that the results be communicated to the patient within a further 2-4 weeks (18).

A recent report asked patients what they thought were the most important elements in providing a quality clinical service (19) and found that an explanation of investigations was perceived to be extremely valuable. The natural anxiety and concern that accompany tests such as an MRI scan could easily be reduced by a simple explanation of what is involved, perhaps in conjunction with an opportunity to see the equipment beforehand or an information booklet.

**Telling the diagnosis**

Little data is available concerning the way in which people are told the diagnosis of MS and their satisfaction with the process. Furthermore, a study will necessarily be retrospective, and patients may not be reliable in reporting events that are both emotionally charged and in the distant past. Despite these reservations, it is useful to consider the available information. A number of points emerge from one such retrospective study undertaken in Southampton, U.K. (20). Firstly, 6% of patients did not suspect that MS was the diagnosis and so were not prepared for it. This suggests that the consultants concerned did not explain that MS was a possibility before performing the investigations and emphasizes the importance of a full and open discussion at the initial consultation. Secondly, in only 17% of cases was a relative present at the time of diagnosis. The great majority of those told without relatives would have preferred to have been told together. In 7% of cases it was actually a spouse or relative who told the patient the diagnosis, and this, not surprisingly, was reported as being unsatisfactory. Thirdly, in half of the population the news was learned from hospital doctors, and in 6% of cases this was a junior doctor. Relatives told by a junior doctor reported dissatisfaction because they felt that the responsibility should have been taken by the consultant. Thus, there are clear practical messages arising from this study that could be relatively easily put into practice.

1) Guidelines for imparting the diagnosis

Partly based on the evidence cited above, a working party report on MS for the MS society (17) has suggested the following guidelines, which provide a useful framework for communicating the diagnosis of MS.

(i) The patient should be provided with a clear explanation for their symptoms, including some information about the nature of the disease.

(ii) In most cases, the specific diagnosis of MS should be communicated and ideally supplemented with written information.

(iii) The diagnosis should be given by someone with adequate specialist knowledge of the condition. This will usually be a consultant neurologist. Sufficient time should be allocated for the purpose, and information should be conveyed carefully and slowly, bearing in mind that not everything may be taken in on a single occasion.

(iv) A majority of patients would prefer to have someone else present, such as a close relative, so this should be offered (but not assumed). The diagnosis should always be given directly to the patient rather than via another person.
A working prognosis or range of prognoses should be given, though these will often be imprecise given the nature of MS. This is generally felt to be less harmful than providing no such information.

A further appointment should be offered to discuss any specific points arising from the initial consultation.

The MS society should be made known to the patient, and the local branch address provided. Appropriate written information as provided in booklets provided by the MS society may be most useful.

**Support and counseling at the time of diagnosis**

The time of diagnosis is one of the most stressful periods in the course of the illness, and difficulties may be compounded by a lack of access to both information and counseling. The Southampton survey (20) found that approximately 60% of the MS population felt that they had not received sufficient information at the time of diagnosis, although satisfaction was greater in the group diagnosed in the previous 10 years compared to the 20-year cohort. General explanation of the nature of the illness together with some prediction of possible symptoms were the types of information most commonly sought.

A large qualitative survey (21) has identified similar problems in obtaining appropriate information about the illness as "the major single difficulty which almost all people with MS have". A number of related recurrent themes also emerged from the survey. Patients often felt as though information had to be fought for from many disparate sources, and that in spite of these efforts they were unlikely to obtain all the relevant information. Another apparently common experience was that information seemed often to come from serendipitous meetings and contacts rather than in a controlled or structured manner.

The understanding of the nature of information itself was found to differ between health care professionals and patients: professionals were thought to see information as a series of facts to be dispensed to the patient, while patients viewed information as something to be provided via an ongoing process of interactive dialogue and negotiation. One suggestion resulting from this survey was the concept of a centralized, regularly updated source of information for people with MS, which might be particularly helpful for those without the education, energy, verbal skills or perseverance to seek out such information for themselves.

Another recent report (17) found that of the existing sources of information, the most valuable was felt to be the MS society, with 25% of patients citing this as the most useful source. 20% felt books to be the most useful source, while 18% thought doctors (equally divided between GPs and consultants) the most helpful source. 10% cited others with MS or friends, but only 3% thought allied health care professionals, including therapists, nurses or social workers, to be their best source of information.

Other studies have also found a dissatisfaction with information given by health care workers at the time of diagnosis. One such survey was undertaken at Manchester Royal Infirmary prior to the establishment of a specialist MS nurse post, in which a population of 55 MS patients, 80% of whom had had the disease for over 5 years, were studied (22). Only half of the patients considered themselves to be well-informed about the disease. Of these, half would have preferred explanation from a doctor, a third from a nurse, while 70% felt that written information would have been helpful.

The surveys mentioned are subject to the limitations of any retrospective study, and one must be wary of drawing firm conclusions from limited evidence. However, the consistent reported dissatisfaction with information and explanation given regarding diagnosis suggests that there is considerable room for improvement. Aside from the above guidelines for imparting the diagnosis, it has been suggested that an increasing role could be played by a specialist nurse in MS, who could ensure continuity of dialogue from the time of diagnosis onwards and who could help to provide ongoing access to appropriate information.

1) The specialist nurse in MS

The first such post in the U.K. was created in Lothian, Scotland in 1990 as part of a research project and was felt to be helpful in improving patient and family psychological well-being and reducing GP workload (23). Patients reported an improvement in their access to information compared to previous experience in a neurology outpatient clinic and felt that liaison in their own home was beneficial. The study concluded, however, that there was no evidence that the post had reduced overall spending, and it was discontinued in 1992. A more recent study found that the establishment of an MS nurse specialist post reduced
the duration of inpatient stays for MS patients (24), suggesting that such a post may in fact be cost-effective. This issue needs to be clarified with further studies.

Recently there has been further interest in the potential role of the specialist nurse, at least in part due to the licensing of beta-interferon-1b for relapsing-remitting MS in the U.K. and the subsequent need for monitoring treatment. Furthermore, the British Society of Rehabilitation Medicine report on MS (17) has suggested that a coordinating health worker with some specialist training in the disease would help to integrate currently rather fragmented MS services. The report identified an ineffective distribution of expertise, in that the primary health care workers providing day to day care for patients with MS had little knowledge or experience of the disease, whereas hospital staff with greater knowledge were playing a more limited role in ongoing patient care. It was therefore recommended that a role be defined for a health worker to help to integrate the available services for MS patients and to provide continuing advice in a liaison capacity. The specialist nurse would be ideally placed to take on this responsibility.

There remain reservations about the creation of such posts, however. Firstly, it is suggested that if a small number of nurses develop expertise in the management of MS, then general nurses and other health care workers will no longer feel a need to learn about the care of MS patients, leading to a loss of skills in these groups. Secondly, there is as yet little objective evidence that specialist nurses improve outcome, nor is there evidence that they reduce the overall cost of MS care provision.

Continuing education after diagnosis

Once the diagnosis has been established as definitively as possible and conveyed to the patient, the need for information, explanation and advice continues. Unfortunately, this early phase of the disease is often poorly managed, with the various health care workers lacking a coherent strategy. Communication between primary care and hospital departments is often poor, which may leave the patient not knowing the most appropriate place from which to seek help. Clearly, a specialist nurse could have an important part to play in this respect. The MS society may also be an invaluable resource in providing access to information. Ideally the opportunity for patients to meet with others who have recently been diagnosed should be available, perhaps facilitated by the local neurologist and the MS society. A recent study has highlighted some of the problems with the present structure of service provision (25). The authors concluded that many of the important service elements could be met by a community-based outpatient unit with strong links to a regional neurological center – the "hub and spoke" model. This would improve access to services and result in a greater degree of responsiveness to changing patient needs.

A number of pilot schemes involving ongoing study for patients have been started in the U.K. and have been felt to be beneficial, although no formal studies have been undertaken. These may take the form of regular informal teaching sessions or less frequent "study days" where a group of specialist professionals may provide education on different aspects of the disease and its management. It is desirable to involve the family or caretakers in any such education as many aspects will be of particular relevance to them.

The education of patients with MS should not, however, be limited simply to explanations of the nature of their condition and likely prognosis. Other factors may be of equal or greater importance to the management of their condition. For example, managing finances may be extremely difficult for patients with MS, partly because the ability to work may be limited or lost. It should be remembered that considerable time and effort are required to obtain relevant information about the range of financial assistance available, and this becomes increasingly difficult as disability progresses. One survey (21) identified a strong feeling among patients that information was being missed, and furthermore that agencies were resistant to providing them with their entitlements. This was thought in some cases to result in a feeling of guilt once benefits were finally obtained. Concerns were also voiced regarding the appropriateness of means testing, and it was felt that the government should review current procedures. Information should be provided in order to maximize the degree of financial security of patients with MS, including the implications of the disease for obtaining life insurance policies or mortgages.

Continuing education should aim to help maximize the potential quality of life of patients, particularly with respect to mobility. For example, the existence of agencies to assess the suitability of patients for continued driving should be pointed out (such as Bansted place in the U.K.). Mobility may also be improved by an awareness of subsi-
dized taxi schemes. Unfortunately, there is a continuing problem with disabled access to many public places, but people with MS should at least have the information available on which to base their leisure decisions.

Conclusions

The rationale and structure of current diagnostic pathways for multiple sclerosis have been discussed and some potential areas for improvement of the patient experience have been identified. An attempt has been made to place the process of investigation in a wider context to include related factors, including the timing and manner of communicating the diagnosis. Some of the limitations of patient access to information have been discussed and problems of relevant service provision after the time of diagnosis have been identified. It is clear that there is considerable room for improvement in many areas, and some possible solutions including a centralized information service and the development of specialist MS nurse posts have been proposed.

References