

Task force on minimum standards for health care of people with multiple sclerosis: June 1999

M. P. Barnes^a, N. E. Gilhus^b and M. Wender^c

On behalf of the EFNS Scientist Panels on Neurorehabilitation, Neuroimmunology and Demyelinating Disease

^aUniversity of Newcastle upon Tyne, Hunters Moor Regional Neurorehabilitation Centre, Hunters Road, Newcastle upon Tyne, UK;

^bDepartment of Neurology, University of Bergen, Haukeland Hospital, Bergen, Norway; and ^cNeuroimmunological Unit, Medical Research Centre, Polish Academy of Science, Poznan, Poland

Keywords:

clinical guidelines, clinical standards, EFNS Task Force, multiple sclerosis, rehabilitation

Received 29 September 1999

Accepted 30 November 2000

Aim

This document is produced by three Scientific Panels of the European Federation of Neurological Societies – Neurorehabilitation, Neuroimmunology and Demyelinating disease. The aim is to produce minimum standards for the health care of people with multiple sclerosis (MS). The document is not intended to be a definitive article on all aspects of MS. We are aware that it is difficult to write a document that is applicable to all countries within Europe given the significant variations in resources found across the continent. Some standards are more easily achievable than others. Magnetic resonance imaging (MRI) facilities are, for example, a longer term aim in some countries. However, we firmly believe that these are reasonable minimum standards to which all countries should aspire. We hope the document will be helpful to health professionals, to people with MS and their families and to government health departments in monitoring current provision and working towards improved standards for the health care of people with multiple sclerosis.

Present situation

As part of preparing this document the Task Force asked members to annotate the extent and nature of the health services for people with MS and to provide copies of any country specific guide-lines. Regrettably this survey has made it clear that services for MS across Europe are very patchy and in many places non-existent. In most

countries there is a system for the diagnosis of MS usually based around major neurological centres. However, even at the diagnostic phase it is clear that many countries do not have adequate access to proper diagnostic facilities, particularly MRI scanning. The situation after the diagnostic phase is even worse. Virtually no country has a co-ordinated and structured system for the long-term support of people with MS. Individuals with MS will generally only come to the attention of health services after diagnosis when they have developed significant disability and unnecessary complications. At that point access is still patchy. Some individuals will access the neurological service, others will access a rehabilitation service whilst many people will have no access at all to any co-ordinated health care. Health care for people with MS even at the latter stages is usually Hospital orientated and very few countries have a comprehensive community support service. Obviously there are examples of good practice throughout Europe and it is particularly encouraging to see the developing concept of the MS nurse. Other countries have developed community based MS teams and there are a number of examples of Hospital based MS teams that provide outreach support to people with MS in the community. However, examples of good practice are sparse.

Overall, most countries in Europe have a neurological diagnostic service but there is virtually no co-ordinated follow-up after diagnosis and certainly no co-ordinated mechanism of longer term support within the community.

Epidemiology

Multiple sclerosis is one of the commoner disabling neurological disorders. The mean age of onset is in the

Correspondence: M. P. Barnes, Academic Unit of Neurological Rehabilitation, Hunters Moor, Regional Neurorehabilitation Centre, Hunters Road, Newcastle Upon Tyne, NE2 4NR, UK (fax: +44 191 219 5690; e-mail: m.p.barnes@btinternet.com).

early 30's and thus the disorder not only affects those individuals with the diagnosis but will often have a major economic and psychological impact on the whole family (Sadovnick and Ebers, 1993) The prevalence is known to increase from south to north across Europe. In the northern parts of Europe the prevalence is around 120 per 100 000 population (Roberts *et al.*, 1991). In the far north (e.g. Scotland, Scandinavia) prevalence is reported to be even higher at over 170 per 100 000. The disorder is obviously less common in southern Europe and Mediterranean countries (around 20 per 100 000 population) but nevertheless this figure still represents a significant number of disabled people. The incidence, in Northern Europe, is about 5–8 new cases per 100 000 population per annum (British Society of Rehabilitation Medicine, 1993).

The life expectancy in MS is now virtually normal except in those few individuals with rapidly progressive disease (Williams *et al.*, 1991). About 25% of those with MS are aged over 60 years and thus the disorder not only has implications for the younger population but has an impact on geriatric services.

Background to the disease

It is not the purpose of this report to provide a complete resume on the causation or natural history of MS. However, we wish to make a few important points of relevance to this document.

1 The cause of MS is not known. There is epidemiological evidence that environmental factors have a role to play and there is also clear evidence of the role of genetic factors. Until a more specific cause or causes can be found it is unlikely that the incidence of MS will reduce. Thus, as the population of Europe increases and rehabilitation techniques improve there will be increasing numbers of people with MS throughout Europe for the foreseeable future.

2 A diagnosis of MS can now be made with reasonable certainty using modern techniques, particularly MRI scanning. The wider availability of MRI scanning is likely to increase the number of people who are diagnosed at an earlier stage. These people will be in need of early support, information and counselling.

3 Although the pattern of the disease over the first 5 years tends to predict the natural history there is no accurate prognostic indicator for disease progression. Thus it is not currently possible to design an MS service that addresses the needs of those more probable to need long-term support. Until such prognostic indicators are found all people with MS need to be kept under review. It is important to emphasize the highly variable course of the disorder. Around 10% of the MS population have a benign disease with normal

life expectancy and little or no disability. In general terms an average course would be around a 5-year period of relapses and remissions followed by a longer period of gradually progressive disability. Around 10% of people never experience relapses and remissions but progress steadily from the outset. A small number of these people have severe and rapidly progressive MS leading to profound disability in 1–2 years and shortened life expectancy. Overall, a person newly diagnosed with MS has a one in two chance of needing aids for walking in 15 years time (British Society of Rehabilitation Medicine, 1993).

4 Modern rehabilitation techniques have greatly improved the potential for the management of significant disabilities. Neurological rehabilitation specialists are now slowly becoming more widely available throughout Europe. At the same time management techniques are improving (e.g. management of spasticity). The need for co-ordinated and long-term support is becoming more important as we are able to manage symptoms earlier and thus improve quality of life and prevent longer term complications.

Economic impact

Multiple sclerosis has a major impact on health care resources as well as overall economic resources for the state. The disease usually manifests itself in the early 30's at a time when the individual is economically active and often with a family to support. Thus, people with MS are major consumers of state benefits and represent a significant loss of economic and employment activity. Furthermore MS has a significant cost implication for health services in the diagnostic phase, around the time of relapses and more particularly in the latter stages when severe disability is incurring health and social care costs. A recent prevalence based cost of illness survey produced in the UK illustrated that the annual cost was £1.2 billion including the cost of health care, social support and economic impact of the disease (Holmes *et al.*, 1995). The largest share of this cost was borne by individuals through lost earnings – both the person with MS as well as their carers and partners.

Research

In recent years there has been significant progress regarding disease modifying treatment for MS as well as treatments for many of the disabling symptoms. However, there is a clear need for active ongoing research into the basic cause of the disorder as well as applied research into management of the various physical and psychological disabilities. More research work is also required on the best way to deliver a service for people

with MS. The Task Force encourages every country to have at least one active centre of excellence for MS encompassing not only clinical and research needs but also the education and training needs of health professionals and those with MS and their families.

Minimum standards in MS

This document will now address the minimum standards for multiple sclerosis. The Task Force believes it is logical to divide these standards into three phases.

- Diagnostic phase
- Minimal disability and relapse phase
- Severe disability

Diagnostic phase

This is obviously an important time for people with MS and if this phase is not managed properly this may have significant negative long-term effects both on the individual and family. We believe a number of standards are pertinent at this point.

1. Primary care physicians should be fully conversant with common presentation patterns

Referral patterns vary widely throughout Europe. Some individuals are able to refer themselves directly to a neurologist whilst in other countries the primary care physician (general practitioner) or other general medical specialist will be the first physician to have contact with the patient. The diagnosis of MS may be straightforward but initial symptoms can be vague and variable. Primary care physicians may have only occasional contact with someone with MS and thus their state of knowledge may well be inadequate to make appropriate onward referral. A delay in diagnosis can have significant implications both in psychological and physical terms. The Task Force recommends that an active educational programme for primary care physicians/general practitioners should be in place in each country in order to make more certain that such doctors are fully aware of the possible range of presenting symptoms. An education programme in some countries should also involve therapy and nursing staff who may have initial contact with patients.

2. An individual with suspected MS should be referred immediately to a neurologist

The Task Force believes there is a clear need for specialist referral immediately a diagnosis of multiple sclerosis is suspected. A neurologist should organize the

battery of necessary investigations. MRI is the single most useful investigation currently available to support the diagnosis of MS (Miller *et al.*, 1997). and referrals should preferably be made to a neurological centre which has MRI scanning capability. We are aware that this may not be possible in all countries at the present time. We would further recommend that a MRI scan should be assessed and interpreted by a neuroradiologist and/or a neurologist.

3. Referral time to a neurological service should be short. Investigations should be completed and results communicated to the patient within as short a time-scale as possible

The Task Force is aware that there are highly varying referral waiting times for neurological services across Europe. However, ideally individuals with suspected MS should be referred to the neurologist immediately after suspicion has been aroused and the neurological service should be able to see that individual quickly – and certainly within a few weeks of referral. Investigations for MS are now relatively straightforward and should, as far as possible, be completed in a few days. Investigations should be started as soon as possible after referral and the results of such investigations should be communicated to the patient as quickly as possible after the results have been seen and reviewed. It is clearly difficult to place an acceptable time-scale on this given the variation of resources and facilities across Europe. However, the Task Force would recommend a maximum of 4 weeks from referral to completion of investigations.

4. Sufficient time should be made available to impart the diagnosis and to give the person sufficient information about multiple sclerosis

Diagnosis is obviously a particularly stressful time for the person with MS and the family. Individuals are often only able to absorb a limited amount of information at the initial consultation. The Task Force believes it is important to give the patient and family time to come back at least once after the initial diagnosis, within a week or so, in order to ask further questions and receive further information. Clear information written in lay language should be available in the clinic. Such literature is often best produced by the lay MS societies. There is now a range of literature available which covers commonly asked questions. The individual should have time to absorb the information and have access to an expert who should be able to answer further questions. The Task Force believes that ideally the patient and family should be able to access

the neurologist. However, if this is not possible then a fully trained and expert non-medical specialist could be involved at this stage. In a number of countries this role is now being taken on by a trained MS nurse.

Minimal disability and relapse phase

5. Post-diagnostic contact should be maintained with the neurological service

Further questions often arise in the months after diagnosis and further management may be required for control of early symptoms and disabilities. The Task Force believe that ongoing contact is essential. This should preferably be with the neurological service but if this is not possible then there should be a clear contact point available with the local health services, who in turn may refer back to the neurological service as appropriate. Many countries are now developing ongoing support through a network of MS nurses who are able to deal directly with the patient and family. The Task Force also believes that contact should be suggested with local MS societies who can often offer peer and social support as well as a useful range of literature and information. The Task Force believes that no individual with MS should be left without the ability to contact relevant health professionals directly.

6. All people with multiple sclerosis should have access to a multidisciplinary rehabilitation team with expertise in MS

As the disease progresses it is probable there will be an increasing range of troublesome symptoms. Many of these are transient but others may produce longer term and more significant disability. A number of such symptoms and disabilities can now be managed effectively by a range of interventions. The Task Force firmly believes that all individuals should have access to a multidisciplinary rehabilitation team. Ideally this team should include a physiotherapist, occupational therapist, nurse and a clinical psychologist. The team itself will need access to a broader range of health professionals, particularly including continence advice, medical support, social care support, speech and language therapy and an individual that can advise on state benefits and employment rehabilitation systems. The Task Force is well aware that this standard has significant resource implications and is unlikely to be achieved in the short term across Europe. However, we firmly believe that access to a full multidisciplinary team is vital for the best management of the individual, both in physical and psychological terms. If the person

with MS is not able to access such a team directly we believe the local contact professional should have access to appropriate advice and information from such a team. The reader is referred to the related EFNS Task Force document on Minimum Standards in Neurological Rehabilitation (Barnes *et al.*, 1997).

7. Individuals with acute relapses should have immediate access to appropriate therapy

Multiple sclerosis patients recover more effectively from relapses following the rapid administration of steroids (Martin and Hohlfeld, 1996). The use of intravenous methylprednisolone may be preferable but if this is not available then a course of oral corticosteroids is acceptable. Individuals should have access to such steroid therapy as soon as possible after confirmation of a relapse and preferably within 48 h. The health care professional with responsibility for ongoing contact (see Standard 5) should have the ability to deliver, prescribe or at least have access to this therapy.

8. People with MS should have access to disease modifying treatment

Interferon therapy and other disease modifying therapies [e.g. glatiramer acetate (IFNB Multiple Sclerosis Study Group, 1993)] produce a reduction in relapse rate and reduce the disabling impact of the disease (Paty *et al.*, 1993; Johnson *et al.*, 1995; Jacobs *et al.*, 1996; Prevention of Relapses and Disability by Interferon Beta-1a Subcutaneously in Multiple Sclerosis (PRISMS) Study Group, 1998). The Task Force realizes this is a controversial area and there is a wide variation in the use of such therapies world-wide (Multiple Sclerosis Society, 1999). One in five people with MS in the United States is treated with disease modifying therapy compared with 15% of people in Austria, 6.3% in Germany and <1% in the UK. The Task Force is aware that these therapies have major resource implications. The cost of 1-year therapy is significant and, in UK terms, is equivalent to approximately £10 000 per annum. We firmly believe that there should be clear guide-lines and equitable access to such therapies and encourage health Departments across Europe to draw up guidance for prescription of these agents within their own country taking into account the health resources available but bearing in mind the significant lessening of disease impact for the individual. Recent guidelines for the prescription of interferon therapies have recently been published (Association of British Neurologists, 1999; Paty and Hartung, 1999).

Severe disability

9. Individuals with advancing and severe disability should have access to a multidisciplinary rehabilitation team

This standard overlaps with Standard 6. In earlier phases if resources are limited access to a multidisciplinary team may not be available directly to the individual but via a contact professional. However, at the stage of severe and advanced disability it becomes of more direct importance for the individual to access a comprehensive multidisciplinary rehabilitation team. A significant range of symptoms are now amenable to interventions. Such symptoms and disabilities include spasticity, incontinence, problems with communication and swallowing, aspects of sexual function, management of pressure sores, fatigue, pain, mood disturbance and assessment and advice on deficits of cognitive function (British Society of Rehabilitation Medicine, 1993). This list is by no means complete but indicates the range of effective interventions that are now possible through a comprehensive rehabilitation team. Advice and information can be offered even for those symptoms that are not particularly amenable to intervention such as dizziness and unsteadiness, disturbance of sensation and ataxia. Core members of the team will be the physiotherapist, occupational therapist, nurse and clinical psychologist, with ready access to advice and information from a continence advisor, medical rehabilitation specialist, social worker, speech and language therapist and an appropriate advisor on state benefits (Barnes *et al.*, 1997). Easy referrals should be possible to other specialists as required including pain specialists, urological surgeons, orthopaedic surgeons and plastic and reconstructive surgeons. The Task Force is aware that such comprehensive teams are rarely available in Europe. However, we still feel that the lack of a team is a significant detriment to people with MS and their families and would encourage health departments and key centres to develop such teams. There is emerging evidence of the effectiveness of multidisciplinary rehabilitation teams in multiple sclerosis (Freeman *et al.*, 1997; R. W. Makepeace, M. P. Barnes and J. K. Semlyen: Establishment of a community multiple sclerosis team, personal communication). Ideally we believe these teams should have a community focus and be able to see, assess and advise individuals within or near their own homes. However, if this is not possible then, as a minimum, such teams should be based around relevant Hospital Departments such as neurology or rehabilitation.

10. People with MS should have access to regular respite facilities and appropriate long-term care facilities

As disability in MS advances the role of the carer becomes more stressful and time consuming. In many countries it is only the spouse or other informal carer that has any regular contact with the person with MS. Long-term care facilities and support are sparse and in many countries completely absent. Ideally the carers should have the ability to have a break and access to appropriate respite facilities is important. Respite facilities can also be used for a reappraisal of the needs of the person with MS. We believe that access to such facilities will enable the person with MS to stay at home for as long as possible. Eventually it may not be possible for the individual to stay at home and at this stage access to appropriate long-term residential and/or hospice facilities is important. Preferably such facilities should be as near to the home as possible and be in an Institution with people with similar problems. Sharing long-term facilities with those with other difficulties (e.g. learning disabilities or elderly people) is not appropriate. Even in long-term facilities individuals should still have access to an appropriate multidisciplinary team. At this stage information, advice and support to the family is also important (Multiple Sclerosis Society, 1998).

Conclusion

The Task Force believes the application of these standards will produce significantly improved care and support to people with MS and their families. The key standards are the provision of continuity of support, probably through ongoing contact with a single health professional, as well as ability to access a multidisciplinary rehabilitation team. Ideally such teams should be associated with the local neurology and/or rehabilitation Departments. Provision of services for people with MS in Europe is patchy and fragmented and generally inadequate. The Task Force urges governments throughout Europe to make a commitment to introduce these standards to improve the quality of life for people with MS and their families.

References

- Association of British Neurologists (1999). *Guidelines for the Use of Beta Interferons in Multiple Sclerosis*. Association of British Neurologists, London.
- Barnes MP *et al.* (1997). Minimum standards in neurological rehabilitation. *Eur J Neurol* **4**:325–331.
- British Society of Rehabilitation Medicine (1993). *Multiple Sclerosis: a Working Party Report of the British Society of*

- Rehabilitation Medicine*. British Society of Rehabilitation Medicine, London.
- Freeman JA, Langdon DW, Hobart JC, Thompson AJ (1997). The impact of inpatient rehabilitation on progressive multiple sclerosis. *Ann Neurol* **42**:244.
- Holmes J, Madgwick T, Bates D (1995). The cost of multiple sclerosis. *Br J Med Econ* **8**:181–193.
- IFNB Multiple Sclerosis Study Group (1993). Interferon beta-1b is effective in relapsing/remitting multiple sclerosis. I. Clinical results of a multi-centre, randomised, double blind, placebo controlled trial. *Neurology* **43**:655–661.
- Jacobs LD, Cookfair DL, Ruddle RA *et al.* (1996). Intramuscular interferon beta-1a for disease progression in relapsing multiple sclerosis. *Ann Neurol* **39**:285–294.
- Johnson KP, Brooks BR, Cohen JA *et al.* (1995). Co-polymer 1 reduces relapse rate and improves disability in relapsing/remitting multiple sclerosis: results of a phase III multi-centre, double-blind, placebo-controlled trial. *Neurology* **45**:1268–1276.
- Martin R, Hohlfeld R (1996). Current immunotherapy in multiple sclerosis. A review of clinical experience. *Clin Immuno Th* **5**:12–21.
- Miller DH, Kesselring J, McDonald WI *et al.* (1997). *Magnetic Resonance in Multiple Sclerosis*. Cambridge University Press, Cambridge.
- Multiple Sclerosis Society (1998). *People with MS in Long Term Care: Good Practice Guide-Lines for Service Providers*. Multiple Sclerosis Society of Great Britain and Northern Ireland & The Leonard Cheshire, London.
- Multiple Sclerosis Society (1999). *Basics of Best Practice in the Management of Multiple Sclerosis*. Multiple Sclerosis Society of Great Britain and Northern Ireland, London.
- Paty DW, Hartung HP (1999). Management of relapsing/remitting multiple sclerosis: diagnosis and treatment guidelines. *Eur J Neurol* **6**:s1–s35.
- Paty DW, Li DKB, The UBS MS/MRI Study Group, IFNB Multiple Sclerosis Study Group (1993). Interferon beta-1b is effective in relapsing/remitting multiple sclerosis. II. MRI analysis results of a multi-centre, randomised, double blind, placebo controlled trial. *Neurology* **43**:662–667.
- Prevention of Relapses and Disability by Interferon Beta-1a Subcutaneously in Multiple Sclerosis (PRISMS) Study Group (1998). A randomised, double-blind, placebo-controlled study of interferon beta-1a in relapsing/remitting multiple sclerosis. *Lancet* **352**:1498–1504.
- Roberts MHW, Spackman AJ, McIntosh-Michaelis S *et al.* (1991). Prevalence of multiple sclerosis in the Southampton and South West Hampshire Health District. *J Neurol Neurosurg Psychiatry* **54**:55–59.
- Sadovnick AD, Ebers GC (1993). Epidemiology of multiple sclerosis: a critical overview. *Can J Neurol Sci* **20**:17–29.
- Williams ES, Jones DR, McKernan RO (1991). Mortality rates in multiple sclerosis: geographical and temporal variations revisited. *J Neurol Neurosurg Psychiatry* **54**:104–109.