

### Abstract

Multiple Sclerosis (MS) often starts in early adult life and occurs in over 1:1,000 of the population of the United Kingdom. Because of its prolonged course and the disability that can result from it, it often affects the lives of others in the person's family and makes major demands upon the Health Service and upon resources for community rehabilitation and care.

The complexities of MS call for help from many different medical specialties and health professions, with all the opportunities for misunderstandings, duplication of effort, delay and muddle that this implies. The outcome of recent proposals to change the way that the United Kingdom health service, social services and voluntary sector work together will depend upon the priority afforded to resources for disabled people in the reorganised services and the level to which decision making, responsibility and resource allocation are devolved.

The working party shares the view of the British Society of Rehabilitation Medicine that the medical and therapeutic measures capable of promoting health and independence, relieving discomfort and preventing the medical complications of MS are not put into practice as often or as effectively as they should be. Too often people are simply told '*There is no medical treatment for MS*'. We hope that the information and guidelines in this report will help to remedy this.

Because MS is complex, it is difficult to find many professional staff, especially those working in the community, who have extensive experience and understanding of it. On the other hand, those with the greatest knowledge of the disease process, such as neurologists, are rarely members of the community teams that provide help on a day to day basis. The person with MS and their family often have to piece together the picture for themselves, partly from a neurologist who understands the disease but not their situation, and partly from those in the community who may understand their situation but not the disease.

This report is designed to help professional people of all disciplines working in health and social services to understand the needs of people with MS, their carers and their families, as seen from the viewpoint of rehabilitation medicine. We recognise that this is not the only viewpoint from which to appreciate all aspects of this complex subject. Nevertheless, we hope that this report will help members of the medical, therapy and other health related professions, including social workers, those involved in employment and training, and planners and managers of services to adopt the best practices and to order priorities in such a way that the handicap and suffering imposed by MS in the UK can be minimised.

One of the difficulties facing the working party was how to cover the essential points about MS without writing a text book. Neurological diseases account for much of the severest category of disability and MS in particular may lead, more often than other diseases, to situations in which life becomes so restricted that living in residential care becomes the preferred option. No consideration of MS can, therefore, be complete without an account of how the family life of the person with MS may be affected since this signals how community health, social and voluntary sector services can best help.

This report covers the epidemiology and possible causes of MS. It summarises what is known about the frequency with which symptoms and disabilities occur in MS. It briefly describes the way in which the disease tends to progress, including the thorny question of how to predict the way things will turn out for individual patients. It then describes how the diagnosis is made and gives guidelines as to how the diagnosis should be explained to the patient and family.

It goes on to summarise the position on treatments that are aimed at the actual disease process of MS. It then deals with a very much larger range of medical treatment and therapies available to deal with the impairment and disabilities caused by MS. These treatments do not attempt to cure the MS itself and are equally applicable to people with similar disabilities caused by other conditions.

The rest of the report deals with wider aspects of the effects of the disease and how services can best meet the needs of people with MS and their families. It summarises the way in which MS was affecting social activities and family life in the Southampton survey of 1987/9 then chronicles the coping strategies most frequently employed. This is important for those concerned with establishing community support and counselling services for MS.

Finally it provides a summary of the range of services needed and guidelines on their organisation. The report ends with a brief review of some of the unsolved problems of MS indicating what the priorities are for research and development.

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