

Introduction

This fourth edition of *Multiple sclerosis information for health and social care professionals* has been compiled by the MS Trust with the help of specialist health and social care professionals, and people affected personally by multiple sclerosis (MS). The aim of the book - and of the MS Trust - is to improve the level of understanding of MS amongst those who work with, and care for, people who have the condition. We recognise the challenge that MS presents for professionals but hope that professionals will also acknowledge the challenge for a person receiving a diagnosis of MS, knowing that they will live for the rest of their life with the condition, yet having no idea how it might progress.

The ambition of this book is to:

- offer an overview of MS
- provide a resource for professionals who work with people with MS
- answer some of the questions about the management of MS and its symptoms
- offer directions for further information through references and bibliographies.

There have been two national documents that should have impacted on the management of MS in the UK. The first of these was *Multiple sclerosis: management of multiple sclerosis in primary and secondary care* issued by the National Institute for Health and Clinical Excellence (NICE) in 2003. The second was the *National Service Framework for long-term conditions* launched in 2005. Both documents enshrined principles for good management which included:

- the provision of person centred services
- early recognition, prompt diagnosis and treatment from specialised services
- emergency and acute management
- early and specialist rehabilitation
- community rehabilitation and support
- vocational rehabilitation

- the provision of equipment and accommodation
- the provision of personal care and support
- palliative care to enable people to make choices about end of life care
- support for families and carers
- the provision of seamless, responsive services.

How successful has implementation of these principles been? The MS Trust, in partnership with the Royal College of Physicians, has now carried out three national audits of NHS MS services in England and Wales. The findings show real progress with the development of specialist centres but little progress with regard to access to rehabilitation, the provision of equipment, access to palliative care, or joined up services. Much work clearly remains to be done and we hope that this publication will support the professionals who can help to change the situation and improve the management of MS.

The arrival of disease modifying drugs in the UK goes back to 1995. NICE assessed the drugs in 2002 and following this the Department of Health Risk-sharing Scheme was set up also in 2002. The UK has however been slow to adopt the disease modifying drugs into routine practice and we still lag well behind the USA and Europe. The Department of Health Risk-sharing Scheme allows all people eligible for the four original disease modifying drugs to be treated within the NHS and the Scheme has also been the catalyst for the establishment of specialist centres and a significant increase in the number of MS specialist nurses. The long-term cost efficacy data is being collected and analysed on an ongoing basis.

Two further drugs have also been licensed: natalizumab for people with highly active relapsing remitting MS and fingolimod for people with rapidly evolving severe relapsing remitting MS or with high disease activity despite treatment with a beta interferon. In both cases these drugs offer a greater reduction of relapses than the original disease modifying drugs but have more complex side effects. Further drugs are also in research and development.

MS the disease remains poorly understood by commissioners and NHS managers. The complexity of the condition and the management strategies means that MS will remain a condition managed in partnership between specialist centres and MS specialist nurses alongside the primary care teams.

Joined up services to address both health and social issues are an aspiration for the future.

Further resources

National Institute for Health and Clinical Excellence. Multiple sclerosis - management of multiple sclerosis in primary and secondary care. NICE Clinical Guideline 8. London: NICE; 2003.

National Institute for Health and Clinical Excellence. Multiple sclerosis - beta interferon and glatiramer acetate for treatment of multiple sclerosis. NICE Technology Appraisal Guidance No. 32. London: NICE; 2002.

Department of Health. Cost effective provision of disease modifying therapies for people with multiple sclerosis. Health Service Circular (2002/04) London: Stationery Office; 2002.

Department of Health. The National Service Framework for long-term conditions. London: Department of Health; 2005.

Royal College of Physicians, MS Trust. NHS services for people with multiple sclerosis: a national survey. London: RCP; 2006, 2008, 2011.

Section 1

MS: an overview

100,000 people in the UK are estimated to have multiple sclerosis (MS), a chronic neurological disorder and the most common cause of neurological disability in young adults¹. It is sometimes benign, frequently remitting, but often progressive with gradually increasing disability. Although that disability will vary, the uncertainty and unpredictability is universal. For most, MS does not have a significant effect on life expectancy but for some it may mean facing 50 years of disability and distress.

Multiple sclerosis was first described in the 1860s by the French neurologist Jean Martin Charcot yet for virtually a century little research was carried out into the condition. Despite much research over recent years the cause of MS is as yet unproven and the cure remains elusive. However, much can be done to manage symptoms and, with the advent of disease modifying drugs, it is believed that incremental disability may be slowed.

Good management of MS is a huge challenge to health and social care professionals because the disease course is unpredictable, symptoms endlessly variable and the psychosocial consequences can impact as profoundly as the physical symptoms. MS affects all aspects of life, work, social and family life. People continually have to readapt to changes in their condition and live with a lifetime of uncertainty that multiple sclerosis brings. For this reason, a holistic approach, with the person with MS and their family at the centre of managing MS, is essential.

Prevalence

MS is the most common condition of the central nervous system (CNS) which is made up of the brain and spinal cord. It is generally diagnosed between the age of 20 and 40, with women outnumbering men in a ratio of about 3:1². Though MS can be diagnosed in very young children and in people over 65, this is unusual³.

Areas of low, medium and high prevalence of MS can be identified. It is commonest in temperate countries (50-120/100,000) decreasing with proximity to the equator (<5/100,000)⁴. In the UK, prevalence is approximately 100-140 per 100,000⁵

We hope you find the information in this book helpful. If you would like to speak with someone about any aspect of MS, contact the MS Trust information team and they will help find answers to your questions.

This book has been provided free by the Multiple Sclerosis Trust, a small UK charity which works to improve the lives of people affected by MS. We rely on donations, fundraising and gifts in wills to be able to fund our services and are extremely grateful for every donation received, no matter what size.

MS Trust information service

Helping you find the information you need

The MS Trust offers a wide range of publications, including a newsletter for health and social care professionals Way Ahead and the MS Information Update, which provides an ongoing update on research and developments in MS management.

For a full list of MS Trust publications, to sign up for Way Ahead and much more visit our website at www.mstrust.org.uk



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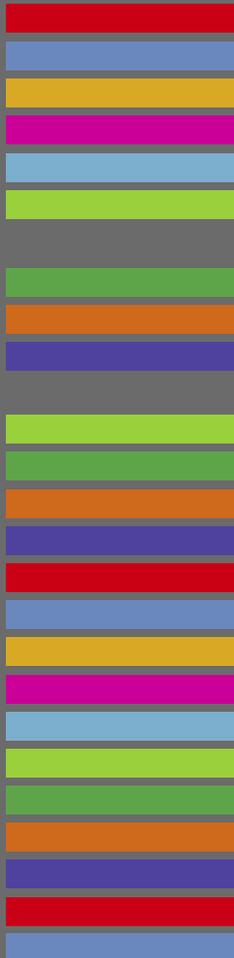
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This publication will be reviewed in three years

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