Multiple Sclerosis Trust

Multiple sclerosis information

for health and social care professionals

Fourth Edition

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.

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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 adults[1]. 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 3:1[2]. Though MS can be diagnosed in very young children and in people over 65, this is unusual[3].

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 100,000[5] in England and Wales. This figure is higher still in Scotland, especially Shetland and Orkney, where the highest known prevalence, 200 per 100,000 has been recorded[5].

Cause

The cause of MS remains unproven, but the evidence is pointing toward a complex interplay of epigenetic, environmental and genetic factors that provoke the immune system to produce an autoimmune inflammatory response characterised by transient attacks on those cells that form myelin. Over time axonal loss and neurodegeneration leads to accruing disability.

This loss and degeneration starts very early with a subclinical phase and additional risk factors have evidence to support their influence. Month and place of birth, familial risk, gender, diet and levels of circulating vitamin D3 and UVB exposure together with smoking associated with HLADRB1 may all play a part. Migration influences risk and positive Epstein Barr serology, particularly accompanied by early infectious mononucleosis, is also likely to increase risk.

The most common, but still speculative, explanation is that some environmental agent (probably infective) gains access to the genetically susceptible person before puberty. Evidence supporting this theory is that an individual living in the tropics is unlikely to develop MS but if that person moves to a temperate environment before the age of puberty they then take on the risk of the area to which they moved.

Chronic cerebro-spinal venous insufficiency (CCSVI) is a recent theory proposing that people with multiple sclerosis have an abnormal narrowing in veins taking blood from the brain and that this causes a build up of iron which crosses the blood brain barrier and damages cells in the central nervous system. CCSVI needs further research and if a valid link is found it will need to be established whether the narrowing is a cause of MS, or alternatively due to the effect of MS. Treatment, by percutaneous venoplasty, is as yet based on incomplete evidence.

Although a genetic component is likely MS is not hereditary in the conventional sense. Families who already have a member with MS have a greater risk of developing the condition than families where no one has MS. If a parent has MS, the risk for their children is 15-20 times greater than that of the general population though the risk is still relatively low.

Putting MS risk in context

- 1 in 700 people will develop MS
- 1 in 40 people will develop MS if they have a first degree relative with the condition (parent, sibling)
- 1 in 3 people will develop some form of cancer
- 1 in 22 people have chronic heart disease
- 1 in 33 people have diabetes
- 1 in 500 people have Parkinson's Disease.

So far there are no conclusive results to explain what the hereditary process could be, though there is ongoing work in this area[6].

What we do have is evidence that treating early is critical as it can influence the long-term outcome for people with MS who may have otherwise faced a lifetime of disability.

References

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MS Trust resources

MS Explained
Kids' guide to MS
The young person's guide to MS
Talking with your kids about MS

Further resources

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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.

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