



Multiple sclerosis information

for health and social care professionals

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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

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 recorded⁵.

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 area⁶.

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

1. Compston A, Coles A. Multiple sclerosis. *Lancet* 2008;372(9648):1502-17.
2. Orton SM, Herrera BM, Yee IM, et al. Sex ratio of multiple sclerosis in Canada: a longitudinal study. *Lancet Neurol* 2006;5(11):932-6.
3. Burgess M. Shedding greater light on the natural history and prevalence of multiple sclerosis. *Br J Neurosci Nurs* 2010;6(1):7-11.
4. Richards RG, Sampson FC, Beard SM, et al. A review of the natural history and epidemiology of multiple sclerosis: implications for resource allocation and health economic models. *Health Technol Assess* 2002;6(10):1-73.
5. Cook SD, MacDonald J, Tapp W, et al. Multiple sclerosis in the Shetland Islands: an update. *Acta Neurol Scand* 1988;77(2):148-51.
6. Compston A. The genetic epidemiology of multiple sclerosis. *Philos Trans R Soc Lond B Biol Sci* 1999;354(1390):1623-34.

MS Trust resources

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



Further resources

Compston A, Confavreux C, Lassman H, et al. editors. *McAlpine's multiple sclerosis*. 4th ed. Philadelphia: Churchill Livingstone; 2006.

Ebers GC. Environmental factors and multiple sclerosis. *Lancet Neurol* 2008;7:268-277.

Diagnosis

Myelin is a fatty substance, which coats the axon of nerves in the central nervous system (CNS) and has an insulating effect enabling electrical impulses to move faster. Damage to myelin results in a disturbed transfer of information along the axons. In MS, patches of inflammation may occur in the myelin, this can result in the myelin itself becoming damaged. If the inflammation covers a wide area it can leave a scar (sclerosis); a lesion. These lesions can appear in many sites throughout the CNS - hence 'multiple'. Demyelination occurs when myelin around axons deteriorates and is lost.

There is also an increasing body of evidence to demonstrate that the axons themselves become damaged, this axonal loss is a cause of impairment. Once lost, an axon can never regenerate and this is thought to account for the progressive disability which is often part of the condition. Axonal loss is now believed to occur much earlier in the disease process than was once thought.

MS can affect any part of the CNS, giving rise to a variety of physical and sometimes cognitive symptoms, in addition to the psychosocial problems that can also result.

Onset

Onset of MS rarely occurs before puberty and is usually in early adult life. The incidence of onset rises during the 20s, reaching its peak in the late 20s and early 30s. Initial symptoms are, most commonly, visual disturbances, including pain in

and around the eyes, blurred or double vision, sensory problems that take the form of 'pins and needles' in the hands and feet, weakness, numbness, balance disorders and fatigue. Symptoms vary enormously, not only from one person to another, but also in the same person from one time of day to another.

Clinically isolated syndrome

85% of people experience an initial onset of symptoms that is known as clinically isolated syndrome (CIS). This inaugural event is defined as an individual's first episode of neurological symptoms lasting at least 24 hours. Damage may be monofocal resulting in the experience of a single symptom (eg optic neuritis) or multifocal when multiple symptoms might be experienced (eg incoordination and bladder problems).

Not everyone who experiences CIS will go on to develop MS and for some there may be no further symptoms. However, if MRI findings show brain lesions that are indicative of MS then the chances of having further relapses and a definite diagnosis of MS are high¹.

Paediatric MS

The onset of MS in childhood and adolescence is being increasingly recognised². 3-5% of patients have onset of MS before the age of 16 with 1% before the age of 11. Male to female ratio is equal before puberty, after which it is most common in females and mirrors the adult ratio of 3:1. 95% of patients with paediatric MS follow a relapsing remitting course. Diagnosis in this age group can however be problematic as symptoms often resemble acute disseminated encephalomyelitis (ADEM).



Diagnosis

Diagnosis

A diagnosis of definite MS is based upon objective evidence of lesions separated in time and space, ie relapsing and remitting symptoms affecting at least two separate areas of the brain or spinal cord. MS can be difficult to diagnose since there is no single test, or clinical feature which is exclusive to the condition, and so other possible causes must be eliminated. Confirmation of the condition can therefore take some time.

There are established criteria that have to be met to positively identify MS. These are known as the 'McDonald Criteria' and are relevant in diagnosis of both relapsing remitting and primary progressive MS³. Revision of these criteria in 2010⁴ allows for earlier diagnosis of MS without any loss of accuracy. This facilitates earlier use of disease modifying drugs that may have an impact on later accumulation of disability for people experiencing relapses.

NICE guidance⁵ states that the individual should be involved in the diagnostic process and should be informed as soon as a diagnosis of MS is considered reasonably likely. In a study of patient satisfaction and timing of diagnosis patients themselves preferred early diagnosis⁶. See page 10 - *Delivering a diagnosis of MS*.

The typical diagnostic process

The GP is usually the first health professional a person will consult when they are experiencing neurological problems. GPs see on average one new diagnosis of MS every 15 years and are likely to have only three or four patients with MS in their case load. There is no single clinical feature exclusive to MS and where there are unexplained neurological symptoms the GP will refer the patient to a neurologist for full neurological examination and paraclinical tests. The neurologist will make the diagnosis of MS.

There are specialist MS centres throughout the UK with access to neurologists who have expertise in treating MS and a specialist MS team including MS specialist nurses. Find these on the *MS Trust map of MS services* www.mstrust.org.uk/map.

Clinical evidence

A thorough physical examination of the current function of the nervous system is made. Specifically, signs of weakness or stiffness in the limbs and areas of abnormal/reduced sensitivity on the body surface will be looked for. Evidence of current or previous damage in the optic nerve is important (and can be detected through an ophthalmoscope) as this is a common site of lesions in MS. However, it is rare to make a certain diagnosis of MS on clinical evidence alone, since in many cases such evidence is subjective.

Diagnostic tests

There are three major investigations, all or some of which may be carried out when MS is suspected though none are 100% conclusive without supporting clinical evidence and robust clinical history:

- magnetic resonance imaging (MRI)
- neurophysiological tests
- examination of cerebrospinal fluid (CSF).

Magnetic resonance imaging (MRI)

MRI is the most sensitive investigation with the ability to highlight areas of active and non-active demyelination. MRI creates images by using magnetic fields and radio waves to monitor the behavior of hydrogen atoms in the body, these are converted to create cross-sectional images. The chemical make up of the scars caused by MS means that they show up as white patches on MRI images, giving a very clear picture of the effects of MS on the brain and spinal cord (Figure 1).



The use of an enhancing agent, such as gadolinium, will show whether a lesion is active or not. In active inflammatory lesions the blood-brain barrier is disrupted and the gadolinium leaks into the surrounding brain tissue and can be detected on the MRI image.

It can be problematic to establish a correlation between the lesions as revealed by MRI and the clinical presentation at any given time.

Neurologists use MRI for the following purposes:

- to observe abnormalities that are suggestive of multiple sclerosis
- to rule out alternative diagnoses such as tumours or stroke
- to help in the evaluation of patients who have subjective complaints but few objective signs of abnormality
- as a surrogate marker for disease activity in clinical trials.

The 2010 revised McDonald criteria for diagnosis of MS⁴

Clinical presentation (person presenting to neurologist)	Additional data needed for MS diagnosis
Two or more attacks; objective clinical evidence of two or more lesions	None
Two or more attacks; objective clinical evidence of one lesion	Dissemination in space shown on MRI or Up to two MRI detected lesions typical of MS plus positive cerebrospinal fluid. or Await a further relapse suggestive of dissemination in space (ie affecting another part of the body)
One attack; objective clinical evidence of two or more lesions	Dissemination in time demonstrated by MRI or Second clinical attack (relapse)
One attack; objective clinical evidence of one lesion (known as 'clinically isolated syndrome')	Dissemination in space demonstrated by MRI or Up to two MRI detected lesions typical of MS plus positive cerebrospinal fluid AND dissemination in time demonstrated by MRI or Dissemination in time demonstrated by MRI (ie new lesion seen on MRI at least three months after the original scan) or Second clinical attack (relapse)
Insidious neurological progression suggestive of multiple sclerosis (typical for primary progressive MS)	Positive cerebrospinal fluid AND dissemination in space, shown on MRI or Abnormal visual evoked potential plus abnormal MRI AND dissemination in time demonstrated by MRI or Continued progression for one year (determined retrospectively or by ongoing observation)

Diagnosis

Neurophysiological tests

These relatively simple, non-invasive investigations are carried out on vision, hearing or sensation to look specifically for delay in the conduction of nerve impulses to and from the brain.

The most common test is the visual evoked potential (VEP). Visual tests involve watching a television screen that has alternating black and white squares. An electrode is placed over the visual cortex and a computer analyses the received visual signal from the television set. The length of time it takes for the signal to leave the television set and reach the visual cortex is known and thus a delay in the signal transmission can be identified. Such a delay may be indicative of damage due to an MS lesion.

Cerebrospinal fluid examination

Examination of the cerebrospinal fluid (CSF) used to be an important diagnostic aid but the increased use of MRI has reduced the need for this invasive procedure. Fluid is drawn off the spinal cord by means of a lumbar puncture. NICE guidance states that this should only be used when the situation is clinically uncertain; however it is still of importance in the diagnosis of primary progressive MS.

The sample of CSF is analysed by electrophoresis for its protein level and leucocyte count. Approximately 80% of people with MS have an elevated immunoglobulin G (IgG) index or oligoclonal immunoglobulin bands present in the spinal fluid but not in the serum, indicating inflammation and immunological disturbance.

Delivering a diagnosis of MS

A critical element in the diagnostic process is the provision and pacing of information. It is recognised that how a diagnosis is communicated and the information and support received at this time will impact on subsequent adjustment to MS⁷. The health professional should find out how much and what information the individual wants to receive⁸. Explanations of diagnostic tests should be given. A diagnosis given badly will be remembered throughout the life of a patient and can impact negatively on their adjustment to living with MS.

The importance of patient information in the management of MS is further highlighted in the recommendation by NICE that:

'People with MS should be enabled to play an active part in making informed decisions in all

aspects of their MS healthcare by being given relevant and accurate information about each choice and decision'.

The Information Standard was devised by the Department of Health to allow people to recognise organisations that produce information that is accurate, evidence-based and unbiased. Certified organisations can be recognised by the quality mark below. The MS Trust is a certified organisation.



References

1. Miller D, Barkhof F, Montalban X, et al. Clinically isolated syndromes suggestive of multiple sclerosis, part 1: natural history, pathogenesis, diagnosis and prognosis. *Lancet Neuro* 2005;4(6):281-8.
2. Huppke P, Gartner J. A practical guide to paediatric multiple sclerosis. *Neuropediatrics* 2010;41(4):157-62.
3. McDonald WI, Compston A, Edan G, et al. Recommended diagnostic criteria for multiple sclerosis: guidelines from the International Panel on the diagnosis of multiple sclerosis. *Ann Neurol* 2001;50(1):121-7.
4. Polman CH, Reingold SC, Banwell B, et al. Diagnostic criteria for multiple sclerosis: 2010 revisions to the McDonald criteria. *Ann Neurol* 2011;69(2):292-302.
5. 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.
6. Janssens ACJW, de Boer JB, Kalkers NF, et al. Patients with multiple sclerosis prefer early diagnosis. *Eur J Neurol* 2004;11(5):335-7.
7. Burgess M. The process of adjustment: providing support after a diagnosis of multiple sclerosis. *Br J Neurosci Nurs* 2010;6(4):156-60.
8. Box V, Hepworth M, Harrison J. Identifying the information needs of people with multiple sclerosis. *Nurs Times* 2003;99(49):32-6.

MS Trust resources

MS Explained
MS: What does it mean for me?



Clinically isolated syndrome (CIS) factsheet

Map of services www.mstrust.org.uk/map

Further resources

Compston A, Coles A. Multiple sclerosis. *Lancet* 2008;372(9648):1502-17.

Zajicek J, Freeman J, Porter B. Multiple sclerosis care: a practical manual. Oxford: Oxford University Press; 2007.

Types of MS

Relapsing remitting MS

About 85% of people are diagnosed with the type of MS that manifests in a series of relapses (sometimes called an attack or exacerbation) followed by periods of good or complete recovery - a remission.

A relapse is defined as; the appearance of a new symptom or the reappearance of old symptoms that last more than 24 hours. A relapse can last for considerably longer and may persist for weeks or months, the average length of a relapse has been reported as 55 days. The frequency of relapses, the severity of symptoms experienced and the length of the gap between attacks are unpredictable. Similarly, it may sometimes be difficult to determine what is a fluctuation in symptoms (a day to day worsening or improvement) and what is a relapse.

On average people with relapsing remitting MS have one or two attacks a year, but this can vary. It is possible for symptoms to worsen gradually over time as recovery from relapses becomes less complete. The term rapidly evolving severe relapsing remitting MS is sometimes used for someone who has two or more disabling relapses in one year and evidence of increasing lesions on two consecutive MRI scans.

Secondary progressive MS

About 75% of people whose disease pattern begins with relapsing and remitting symptoms later develop secondary progressive MS (50% of those with relapsing remitting MS develop secondary progressive MS within ten years from diagnosis). The accepted definition of secondary progressive MS is that a person must have shown continued deterioration for the past six months whether or not they have continued to experience relapses. The transition to secondary progressive MS is psychologically difficult as people recognise they have moved into another phase of the disease and disease modifying medications may no longer be useful.

Some people find that the increase or progression of disability is very gradual, whilst for others it can occur more quickly.

Primary progressive MS

About 10% - 15% of people with MS are diagnosed with a form of MS in which disability increases from the outset. This is known as primary progressive MS (or, less commonly, chronic progressive MS). Some

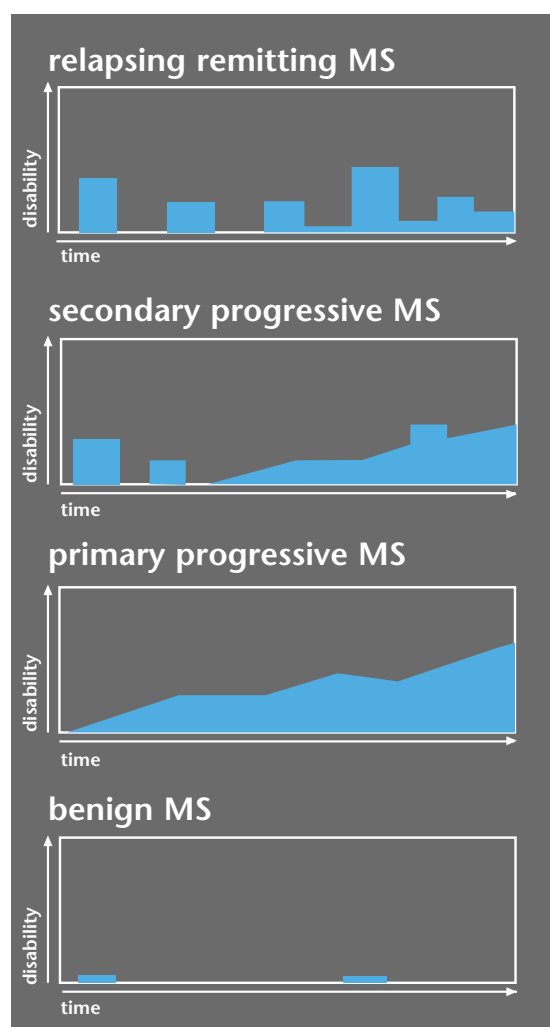
people can have a persistent increase in disability whilst others may experience plateaux or a more gradual worsening of symptoms.

Some people whose MS has been progressive from onset may also experience occasional relapses, this is sometimes referred to as relapsing progressive MS.

Benign MS

People with benign MS experience attacks separated by long periods with no symptoms. The phrase is sometimes used inaccurately to describe a period of mild symptoms following diagnosis. As the defining characteristic of benign MS is the long-term absence of symptoms, it can only be diagnosed retrospectively after ten or more years.

Some people with an initial benign course will eventually start to experience more frequent relapses and may eventually develop secondary progressive MS.



Adapted from Lublin FD¹.

Prognosis

One of the chief characteristics of MS is its unpredictability from one person to another, from one day to another, from one time of day to another. However, some prognostications can be made from the pattern of the disease over the first five years. For example, early problems with sensation and eyesight (as opposed to problems related to the cerebellum such as unsteadiness and clumsiness) usually indicate a more favorable form of MS. Younger age at onset is also a good prognostic sign².

Factors that influence prognosis³

Favourable

- Female
- Low rate of relapses per year (1-5 in five years)
- Complete recovery from the first attack
- Long interval between first and second attack
- Symptoms predominantly sensory eg optic neuritis
- Younger age of onset - less than 35 years
- Low disability at five years from onset.

Unfavourable

- Male
- High rate of relapses per year (3 or more in first five years)
- Incomplete recovery from the first attack
- Short interval between first and second attack
- Symptoms predominantly of motor involvement eg balance, weakness, ataxia
- Older age of onset - over 35 years
- Significant disability at five years from onset

After 15 years with MS, about half of the population will still be independent in terms of walking and the remaining half will need help with mobility. When people reach the point of requiring help with walking (EDSS 6.0) they are likely to progress, irrespective of whether they are having relapses, or if they have primary or secondary MS⁴.

Long-term studies suggest that MS only has a small impact on life expectancy of five to ten years compared to the general population. One study found that people with more complex disability (EDSS greater than or equal to 7.5) were more at risk of potentially life threatening complications - such as respiratory or cardiovascular problems - that can result from reduced mobility, and this affected the overall life expectancy figures⁵. Frequency of death by suicide has been found to be 7.5 times higher among patients with MS compared to the general population⁶.

The uncertainty of prognosis can be hard to deal with. Many people ask if there is any way of identifying 'triggers' which will cause the condition to worsen but there is very little proof that any particular event or circumstance can be identified. There is some evidence that stressful life events, such as a car accident or severe emotional stress, can make deterioration more likely. A meta-analysis⁷ concluded that there is a consistent association between stressful life events and subsequent exacerbation in multiple sclerosis. However even this is controversial and there is usually little that can be done to prevent such stresses occurring.

There is no known reason why someone with MS should avoid either immunisation⁸ or a necessary surgical operation. NICE guidance recommends people with MS should be offered immunisation against influenza and have any other immunisations and surgery that they need.

References

1. Lublin FD, Reingold SC. Defining the clinical course of multiple sclerosis: results of an international survey. *Neurology* 1996;46(4):907-11.
2. Vukusic S, Confavreux C. Natural history of multiple sclerosis: risk factors and prognostic indicators. *Curr Opin Neurol* 2007;20(3):269-74.
3. Hutchinson M. Predicting and preventing the future: actively managing multiple sclerosis. *Pract Neurol* 2009;9(3):133-43.
4. Cottrell DA, Kremenchutzky M, Rice GP, et al. The natural history of multiple sclerosis: a geographically based study. 5. The clinical features and natural history of primary progressive multiple sclerosis. *Brain* 1999;122(4):625-39.
5. Sadovnick AD, Ebers GW, Wilson RW, et al. Life expectancy in patients attending multiple sclerosis clinics. *Neurology* 1992;42(5):991-4.
6. Sadovnick AD, Eisen K, Ebers GC, et al. Cause of death in patients attending multiple sclerosis clinics. *Neurology* 1991;41(8):1193-6.
7. Mohr DC, Hart SL, Julian L. Association between stressful life events and exacerbation in multiple sclerosis: a meta-analysis. *BMJ* 2004;328(7442):731.
8. Farez MF, Correale J. Immunisations and risk of multiple sclerosis: systematic review and meta-analysis. *J Neurol* 2011;258(7):1197-1206.

MS Trust resources

MS Explained
Primary progressive MS exposed



Clinical measures

Measurement of a condition as variable as MS is notoriously difficult but the need for evidence-based decisions has highlighted the importance of the development of adequate measures¹. Monitoring disease status, evaluating clinical practice outcomes and interpreting the results of research interventions require robust measurements. However choosing the most useful outcome measure can be problematic².

For any measure to be acceptable it must be reliable, reproducible and valid. Reliability concerns the extent to which scores produced by a scale are free from measurement error and are able to be reproduced, validity concerns the extent to which an instrument measures what was intended. In the field of health another parameter is also necessary: whether the measure can detect clinical change in the attribute being measured even if the change is small. This property is termed responsiveness.

Clinically useful scales therefore:

- reflect the extent of the disease process
- are multi-dimensional to reflect the main ways in which the disease affects an individual
- are scientifically sound
- are capable of reflecting change over time.

A further consideration is also necessary - are the aspects of life considered important by the person with MS the same as those which the clinician considers important? Assessment of patient reported outcome measures (PROMs) has become increasingly common as these provide a means of collecting the patients views on a treatment efficacy or outcome³. The ability to detect improvement is also important but studies in this area have been limited⁴.

In multiple sclerosis the most commonly used measure remains the Expanded Disability Status Scale (EDSS). This is a method of quantifying disability in multiple sclerosis and monitoring changes in the level of disability over time. It is widely used in clinical trials and in the assessment of people with MS.

The EDSS scale ranges from 0 to 10 in 0.5 unit increments that represent higher levels of

disability. Scoring is based on an examination by a neurologist. EDSS steps 1.0 to 4.5 refer to people with MS who are able to walk without any aid and is based on measures of impairment in eight functional systems:

- pyramidal - weakness or difficulty moving limbs
- cerebellar - ataxia, loss of coordination or tremor
- brainstem - problems with speech, swallowing and nystagmus
- sensory - numbness or loss of sensations
- bowel and bladder function
- visual function
- cerebral (or mental) functions
- other.

Each functional system is scored on a scale of 0 (no disability) to 5 or 6 (more severe disability). EDSS steps 5.0 to 9.5 are defined by the impairment to walking. The scale is sometimes criticised for its reliance on walking as the main measure of disability.

Although the scale takes account of the disability associated with advanced MS, most people will never reach these scores.

EDSS is of limited reliability and is not very responsive to change. There is a bias towards physical (especially ambulatory) rather than cognitive effects of MS. It is not a linear scale and people with MS spend more time at some levels on the scale than others. Despite its limitations EDSS remains the most widely used impairment assessment scale in MS, particularly in clinical trials.

Scales to monitor impairment:

- **Expanded Disability Status Scale (EDSS).** This is an observer-rated scale, usually performed by a neurologist.
- **Scripps Neurological Rating Scale** is based on the standard neurological examination with an extra category for bladder, bowel and sexual dysfunction. Correlation between the Scripps scale and EDSS is not good and further psychometric evaluation is necessary.

Expanded Disability Status Scale (EDSS)

Score	Description
1.0	No disability, minimal signs in one functional system (FS)
1.5	No disability, minimal signs in more than one FS
2.0	Minimal disability in one FS
2.5	Mild disability in one FS or minimal disability in two FS
3.0	Moderate disability in one FS, or mild disability in three or four FS. No impairment to walking
3.5	Moderate disability in one FS and more than minimal disability in several others. No impairment to walking
4.0	Significant disability but self-sufficient and up and about some 12 hours a day. Able to walk without aid or rest for 500m
4.5	Significant disability but up and about much of the day, able to work a full day, may otherwise have some limitation of full activity or require minimal assistance. Able to walk without aid or rest for 300m
5.0	Disability severe enough to impair full daily activities and ability to work a full day without special provisions. Able to walk without aid or rest for 200m
5.5	Disability severe enough to preclude full daily activities. Able to walk without aid or rest for 100m
6.0	Requires a walking aid - cane, crutch, etc - to walk about 100m with or without resting
6.5	Requires two walking aids - pair of canes, crutches, etc - to walk about 20m without resting
7.0	Unable to walk beyond approximately 5m even with aid. Essentially restricted to wheelchair; though wheels self in standard wheelchair and transfers alone. Up and about in wheelchair some 12 hours a day
7.5	Unable to take more than a few steps. Restricted to wheelchair and may need aid in transferring. Can wheel self but cannot carry on in standard wheelchair for a full day and may require a motorised wheelchair
8.0	Essentially restricted to bed or chair or pushed in wheelchair. May be out of bed itself much of the day. Retains many self-care functions. Generally has effective use of arms
8.5	Essentially restricted to bed much of day. Has some effective use of arms retains some self care functions
9.0	Confined to bed. Can still communicate and eat
9.5	Confined to bed and totally dependent. Unable to communicate effectively or eat/swallow

Scales to monitor a person's need for care:

- **Extended Barthel Index** is well-established, monitoring ten areas of activities of daily living: bowel, bladder, grooming, toilet use, feeding, transfer, mobility, dressing, stairs, and bathing on 0-3 point scales. It does not however include cognition or communication.
- **Functional Independence Measure (FIM)** is more detailed than the Barthel scale in that it includes an assessment of communication and social cognition and uses 1-7 point rating scales.

Health status scales:

All the scales listed in this section are questionnaires and would be completed by the person with MS following an introduction from a health professional.

- **Multiple Sclerosis Impact Scale (MSIS-29)** measures 20 physical and nine psychological items assessing how much impact they have on life from the patient's perspective. This combines both quality of life issues and psychometric testing. High scores indicate greater disability.
- **Study Short Form 36 Health Survey (SF36)** measures the health status in eight dimensions including physical function, pain, general health, vitality, and social functioning. This scale is widely used but, because it is not MS specific, its usefulness can be limited. However this can allow comparisons of the impact of MS with other conditions.
- **MS Quality of Life Instrument (MSQOL 54)** is a variant of the SF36 with an additional 18 items that are specific to MS. Low scores indicate lower quality of life.
- **MS Quality of Life Inventory (MSQLI)** is composed of SF36 plus pre-existing established symptom related scales, this allows comparisons of specific symptoms across subject samples and with other illness groups.
- **Functional Assessment of Multiple Sclerosis (FAMS)** is a quality of life instrument based on a scale developed within the oncology environment.

- **Fatigue Severity Scale (FSS)** consists of nine questions focusing on physical symptoms with an average score ranging from 1-7. Lower scores indicate less fatigue.
- **Modified Fatigue Impact Scale (MFIS)** a 21 item scale covering physical, cognitive and psychosocial functioning. Lower scores indicate less fatigue.
- **Leeds MS Quality of Life Scale (LMSQoL)** is a recent development and is MS specific.
- **UK Neurological Disability Scale**, formerly known as the Guys Neurological Disability Scale (UKNDS/GNDS) is based on 12 areas which are considered important by neurologists. This captures many aspects of disabilities that can be experienced by people with MS and is commonly used by health professionals in practice as a basis for assessment.

Mobility scales:

- The **A1** scale is similar to EDSS but gives a more precise measure within levels 4-6.
- **Ten metre timed walk.** Individual walks without assistance 10 m and the time is measured for the intermediate 6m to allow for acceleration and deceleration.
- **Rivermead** mobility scale covers mobility, including bed mobility, lying to sitting, transfer and gait.

Upper limb function:

Nine hole peg test involves the subject placing nine dowels in nine holes. Subjects are scored on the amount of time it takes to place and remove all 9 pegs.

Box and block. A number of small wooden blocks are placed in one side of a box. The subject being tested is required to use the dominant hand to grasp one block at a time and transport it over a partition and release it into the opposite side. The test is then repeated with the non-dominant hand.

Both are tests of manual dexterity with the former requiring greater dexterity and can be administered in less than ten minutes.

Clinical measures

Spasticity scales:

- **Ashworth Scale** is most frequently used with a clinical rating being given after an assessor tests the passive resistance to passive movement of a joint. A physiotherapist would normally administer this scale.

Cognition scales:

- **Paced Auditory Serial Addition Test (PASAT)**. Two variations of this test are used: a two or three minute version.
- **Symbol-digit Modalities Test (SDMT)**.

Both these cognition tests need to be administered by trained personnel.

Composite assessment scores:

The complexity of the disease and the range of measures available have now led to research with the aim of validating composite measures which encompass the major clinical dimensions that are of relevance both to the clinician and to the person with MS.

MS Functional Composite (MSFC) is an example and includes:

1. Timed walk of 25ft
2. Nine hole peg test
3. PASAT 3 minute version

Each of the test results is standardised using a reference population and the resulting scores are averaged to provide a single score. The MSFC is measured by a unique Z score where an increase or decrease represents improvement or deterioration in neurological function.

The MS population is complex and MS requires sensitive clinical outcome measures that can detect small changes in disability whilst reliably reflecting long-term changes in sustained disease progression. Integration of current and new outcome measures may be most appropriate and utilisation of different measures depending on the MS population and stage of the disease may be most useful.

References

1. Thompson AJ, Hobart JC. Multiple sclerosis: assessment of disability and disability scales. *J Neurol* 1998;245(4):189-96.
2. Laidler D. The outcome measure minefield. *Way Ahead* 2008;12(4):12.
3. Doward LC, McKenna SP, Meads DM, et al. The development of patient-reported outcome indices for multiple sclerosis (PRIMUS) *Mult Scler* 2009;15(9):1092-102.
4. van Winsen, Kragt JJ, Hoogervorst ELJ. Outcome measurement in multiple sclerosis: detection of clinically relevant improvement. *Mult Scler* 2010;16(5):604-10.
5. Rothwell PM, McDowell Z, Wong CK, et al. Doctors and patients don't agree: cross sectional study of patients' and doctors' perceptions and assessments of disability in multiple sclerosis. *BMJ* 1997;314(7094):1580-3.

MS Trust resources

Health professional resources

www.mstrust.org.uk/professionals



A multidisciplinary approach to MS care

Current and emerging disease modifying drug therapies impact on the course of MS by targeting immune responses and slowing down the course of MS. They are an investment for the long-term future but do not address the impact of symptoms felt.

Expert and effective symptom management remains key to optimising quality of life for those living with MS¹. Lesions characteristic of MS can occur anywhere within the central nervous system resulting in a wide range of diverse symptoms that may present in many combinations, with variable intensity and are often difficult to describe. No two people with MS have exactly the same symptoms.

It is important to consider that most people with MS may experience only a few of these symptoms and that the intensity and frequency can vary; either at any one time or throughout the duration of the condition. Symptoms can also be influenced by a number of mediators and moderators such as core body temperature, stress, concomitant illness, infection, pressures sores and general health and wellbeing.

It is essential to discriminate between cause, effect and association in MS. Understanding the relationships between primary symptoms, secondary effects and additional factors will ensure effective symptom management.

Secondary complications will worsen primary symptoms. Take pressure sores as an example. They may be the consequence of untreated continence problems rather than a symptom of MS. They will then become a focus for worsening spasm if spasticity is present as a primary problem. Less clear perhaps is pain, which may be either a primary symptom deriving from damage to the central nervous system or a secondary symptom such as the effect of bad posture.

Symptoms can be visible and invisible; they may present an obvious problem or be misattributed, even missed. The less overt and invisible such as depression, fatigue, cognitive problems or sexual dysfunction are often not considered, assessed or

identified and yet impact on quality of life and capacity to remain in employment as profoundly as some more apparent symptoms such as impaired mobility.

The diversity and range of symptoms often necessitates many health and social care professionals being involved in the care of a person with MS. A study reported up to 60 workers from different sources visiting the home of a person with MS². NICE guidelines³ state that 'when several healthcare professionals are involved with a person with MS they should work together with the person and his or her family as a team towards common agreed goals and using an agreed common therapeutic approach.'

MS can result in very complex multidisciplinary needs, often with subtle problems remaining unrecognised and misunderstood. Successful outcomes need true multidisciplinary working with shared goals. GP, neurologist, radiologist, rehabilitationist, physiotherapist, occupational therapist, psychologist, counsellor, orthotist, dietitian, nurse, continence adviser, speech and language therapist, pain specialist, social worker, complementary therapist - all can have a role to play in helping the person with MS remain fully engaged with daily life and able to manage effectively.

Successful management of one symptom may require the input from several different professionals and goals that encompass whole lived experience not just a disparate collection of symptoms.

The MS specialist health professional is pivotal to collaborative and coordinated care and support for people with MS. "The role involves acting as a consultant and educational resource for staff striving towards greater awareness and knowledge of MS in the health and social arena"⁴. The MS specialist can support people with MS to maximise their self-management skills.

Provision of specialist MS services remains inequitable and for some lack of access to an MS specialist team may result in not being able to obtain the right advice at the right time with resultant poor outcomes. People living with MS may not always know what is available, useful, and accessible; often they are young and have a life yet to be lived. The MS Trust and other voluntary organisations can provide information to people with MS and signpost to local services available.

A multidisciplinary approach to MS care

References

1. Thompson AJ, Toosy AT, Ciccarelli O. Pharmacological management of symptoms in multiple sclerosis: current approaches and future directions. *Lancet Neurol* 2010;9(12):1182-99.
2. Thompson A, Johnston S, Harrison J, et al. Service delivery in multiple sclerosis: the need for co-ordinated community care. *MS Management* 1997;4(1):11-8.
3. 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.
4. MS Trust, RCN, UKMSSNA, TiMS. A competency framework for MS specialist services. Letchworth: MS Trust; 2009.

MS Trust resources

Way Ahead – newsletter for health and social care professionals who support people with MS



Health professional resources
www.mstrust.org.uk/professionals

Map of services
www.mstrust.org.uk/map

Self-management

Self-management is about dealing with the impact that a long-term condition has on a person's daily life. The concept of self-management has caused some confusion within clinical practice over many years, and is not always well defined or understood¹.

There are a number of related terms and definitions which may be useful.

Self-management - refers to an individual's ability to take control of their health and effectively manage their chronic illness, with a strong emphasis on self-efficacy. Understanding a patient's attitude to health and knowledge in this context is important for health professionals.

Self-care - traditionally indicated the performance of activities or tasks by the patient or family, which were previously carried out by professionals. Self-care requires knowledge, skills and understanding of a condition and its management². Whilst self-care and self-management are inextricably linked they are not the same.

Self-help - traditionally has been seen as the act of helping or improving oneself without relying on anyone else, it differs from self-management which is undertaken in partnership.

Self-efficacy - has been described as the belief that one is capable of performing in a certain manner to attain certain goals³. The feeling of self worth and competence to intrinsically motivate an individual's self-efficacy relates to a person's ability to have optimistic beliefs, but in contrast to other features of optimism, perceived self-efficacy explicitly refers to one's ability to deal with challenging encounters.

Self-management is a concept now evident in Department of Health initiatives, for example the *Expert patient⁴* and *Supporting people with long term conditions to self-care⁵*. The aim of promoting self-management is to enable patients to help themselves to manage their long-term conditions, whilst working in partnership with the support of services provided by the National Health Service⁶. A more recent report recognises the benefits of self-management⁷ finding that investment in targeted self-management interventions, particularly for people with long-term conditions, can increase people's confidence to manage their health and well-being and improve their quality of life. The cost effectiveness of this strategy has also been explored⁸.

The estimated 100,000 people in the UK who live with multiple sclerosis require specific skills to live life to the full and successfully manage their condition. Equally, health professionals have the responsibility through Quality, Innovation, Productivity and Prevention (QIPP) to promote and support self-management and to reduce the need for unscheduled acute admissions. The Department of Health⁷ recognises the need for a systematic transfer of knowledge and power to patients to empower them to maximise self-management and choice, engage in decision-making and ensure that there is 'no decision about me without me' so that patients are active participants in all decisions about their care.

The concept of self-management began in the 1960s and it was seen as a method of finding better solutions to illness¹. Today self-management is seen as an integral part of the health care system. With the concept of the Expert Patient arising early in the new century, the Department of Health began to endorse the initiative seeking to empower those with chronic health needs, to take control of their own care and recognised that professionals can support and provide expertise to maintain independence⁹.

Benefits of self-management

80-90% of all care for people with long-term conditions is undertaken by the person themselves or their families. This self-management includes eating well, exercising, taking medicines, keeping in good mental health, watching for changes, coping if symptoms get worse and recognising when to seek help from health professionals.

Supporting self-management in MS involves educating people about their condition and care, and motivating people to look after themselves effectively. Self-management support can be seen in two ways: as a portfolio of techniques and tools that help people to choose healthy behavior and a fundamental transforming of the patient caregiver relationship into a collaborative partnership⁹. The very nature of chronic disease management requires a dynamic, positive approach, encouraging patients to move from a 'passive' helpless role to a 'proactive' one¹⁰. Education is central in re-establishing a sense of control over the condition^{11,12}.

Key attributes to self management include:

- self-efficacy
- resource utilisation
- collaborative partnerships with health and social care professionals
- education

Self-management

- goal setting and monitoring
- problem solving and decision-making.

Research has identified that self-management improves health and quality of life, including: reduced pain (despite increasing levels of functional disability); improved mood; reduced visits to the general practitioner; improved levels of self-efficacy. Changes were noticed within one month of self-management intervention and resulted in sustained improvement in the study groups for up to four years post-intervention¹³.

Self-management in multiple sclerosis

In 2009, the Consortium of Multiple Sclerosis Centers¹⁴ issued a white paper analysing patient self-management in multiple sclerosis and offering guidelines for best practices aimed at empowering patients. These include:

- raising awareness among professionals expert in and providing for patients with MS concerning the needs for patient self-management
- formally evaluating the unmet needs in MS, considering both patient and provider perspectives
- encouraging research on a broad range of MS self-management strategies and outcomes, including assessment of the specific components of self-management programs that are most effective for patients with MS, as well as their optimal delivery eg in-person or via telephone, type of leadership, number of sessions
- eliminating any practice barriers to self-management. This should include engaging patients in all aspects of developing and administering interventions, such as implementation, testing and research, dissemination, and sustainability
- developing evidence-based practice.

In MS self-management includes:

- dealing with symptoms and relapses
- making informed choices about medication
- making best use of available resources
- being a partner with health professionals in making decisions about treatment
- living well and accommodation of MS into everyday life.

People who are most likely to successfully self-manage their MS:

- have a good understanding of MS
- manage the impact of MS on physical, emotional, social and working life and are able to make adjustment where necessary
- actively participate in making decisions with health professionals
- adopt healthy lifestyles
- take action.

Generic self-management programmes

The Expert Patients Programme (EPP) is a free six week course for people with chronic or long-term conditions. The course is delivered by trained and accredited tutors, most of whom are themselves living with a long-term health condition.

The EPP aims to give people the confidence to take more responsibility and self-manage their health and to be active participants in the treatment, management and care of their condition. Rather than focusing on health information about specific conditions, the course looks at general topics including healthy eating, dealing with pain and extreme tiredness, relaxation techniques and coping with feelings of depression.

Work carried out by Professor Julie Barlow of Coventry University evaluating the expert patient programme in people with MS found:

- reduced severity of symptoms
- significant decrease in pain
- improved quality of life control and activity
- improved resourcefulness and life satisfaction¹⁵.

Internal evaluation data⁸, self-reported from approximately 1,000 EPP participants, indicates that the programme provides significant numbers of people living with long-term conditions with the confidence and skills to better manage their condition on a daily basis:

- 45% felt more confident that they would not let common symptoms (pain, tiredness, depression and breathlessness) interfere with their lives

- 38% felt that such symptoms were less severe four to six months after completing the course
- 33% felt better prepared for consultations with health professionals.

MS specific self-management programmes

Some examples of self-management courses for people with MS include: Getting to grips with MS, Taking control and fatigue management programmes.

Getting to grips with MS, Taking control

These MS specific courses are designed for people newly diagnosed with MS but could be suitable for a person at any point along the MS trajectory. They cover disease specific education including research in MS, health promotion including nutrition, exercise and physical activity, positive lifestyle adjustments and managing MS in the workplace. The roles of other professionals involved in MS management such as occupational therapists, physiotherapists and psychologists are explored.

A study of a cohort of people with MS undertaking self-management programmes found 82% of participants felt they had been enabled to cope better as a result of the course, 64% felt they ate a better diet and 72% felt enabled to alter their lifestyles as a response to MS¹¹.

Fatigue management

Fatigue is experienced by 70-90% of people with multiple sclerosis and can have a major negative impact on people's lives. As efficacy of pharmaceutical treatment is modest, fatigue management strategies play a vital role. These include avoiding the build up of fatigue and conserving energy. Fatigue management education delivered in a face to face format in community settings has been found to significantly reduce impact of fatigue on daily life, improve quality of life and increase self-efficacy in randomised trials¹⁶. Other ways of delivering the course such as by teleconference were also successful¹⁷.

References

1. Schilling LS, Grey M, Knafel KA. The concept of self-management of type 1 diabetes in children and adolescents: an evolutionary concept analysis. *J Advan Nurs* 2002;37(1):87-99.
2. Department of Health. Improving care improving lives - self care - a real choice. London: DOH; 2005.
3. Bandura A. Self-efficacy: Toward a unifying theory of behavioral change. *Psych Rev* 1977; 84(2):191-215.
4. Department of Health. The expert patient - a new approach to chronic disease management for the 21st century. London: DOH; 2001.
5. Department of Health. Supporting people with long term conditions to self-care London: DOH; 2007
6. Kennedy A, Rogers A. Improving self-management skills: a whole systems approach. *Br J Nurs* 2010;10(1):734-8.
7. Expert patients programme. Healthy lives equal healthy communities - the social impact of self-management. London: EPP; 2011.
8. Expert patients programme. Self-care reduces costs and improves health - the evidence. London: EPP; 2010.
9. Hughes SA. Promoting self-management and patient independence. *Nurs Stand* 2004;19(10):47-52.
10. de Silva D. Helping people help themselves a review of the evidence considering whether it is worthwhile to support self-management. London: The Health Foundation ;2011.
11. Embrey N. Information provision for patients with a diagnosis of multiple sclerosis - do nurses have an impact on self-management? *Nurs Times* 2005;101(34):34-6.
12. Brechin M, Burgess M, Dunk J, et al. Taking Control - a pack to facilitate teaching people with newly diagnosed MS. *Way Ahead* 2001;5(2):7-8.
13. Lorig K, Ritter PL, Plant K. A disease-specific self-help program compared with a generalised chronic disease self-help program for arthritis patients. *Arthritis Rheum* 2005;15;53(6):950-7.
14. Fraser R, Johnson E, Ehde D, et al. Patient self-management in multiple sclerosis. Consortium of Multiple Sclerosis Centers White Paper. USA: CMSC; 2009.
15. Barlow J, Edwards R, Turner A. The experience of attending a lay-led, chronic disease self-management programme from the perspective of participants with multiple sclerosis. *Psychol Health* 2009;24(10):1167-80.
16. Mathiowetz V, Finlayson M, Matuska K, et al. A randomised trial of energy conservation for persons with multiple sclerosis. *Mult Scler* 2005;11(5):592-601.
17. Finlayson M, Preissner K, Cho C, et al. Randomised trial of a teleconference-delivered fatigue management program for people with multiple sclerosis. *Mult Scler* 2011;17(9):1130-40.

MS Trust resources

MS and me – a self-management guide to living with MS
At work with MS – managing life and work
Living with fatigue

Diet factsheet

Move it for MS – DVD

Exercises on the web

www.mstrust.org.uk/exercises

Stay active

www.mstrust.org.uk/stayactive

StayingSmart

www.stayingsmart.org.uk



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.

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