

Multiple sclerosis information

for health and social care professionals

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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.

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MS Trust resources

Health professional resources

www.mstrust.org.uk/professionals



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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