Condition Insight Report (CIR)

Multiple Sclerosis (MS)

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Overview

What is the condition usually called / any abbreviations used?

Multiple Sclerosis is abbreviated to MS and grouped into three main types/categories:

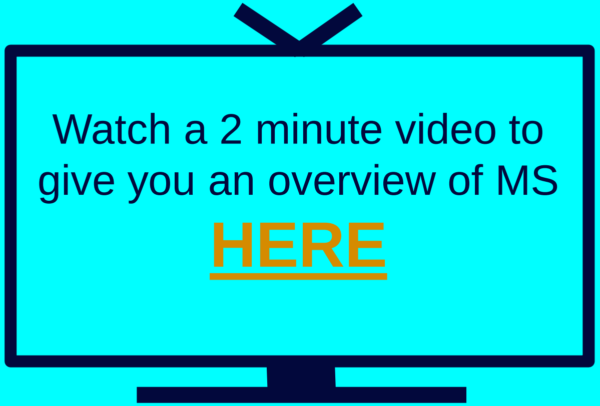
1. Relapsing-remitting,
2. Secondary progressive,
3. Primary progressive

Brief overview of the condition

Multiple sclerosis is a condition which causes damage to the nerves in your brain and spinal cord (the central nervous system).

'Sclerosis' means scarring and refers to the damage to the nerves caused by MS. 'Multiple' is added because this can happen in more than one place.

It is an incurable and progressive condition.



Watch a 2 minute video to give you an overview of MS **HERE**

Presenting Symptoms

No two people will have the same symptoms, and it's impossible to predict how someone will be affected. The only way to know how someone is affected is to ask them but some symptoms can be difficult to describe anecdotally. The list below includes some of the symptoms of MS but it is not exhaustive:

- **Fatigue** (watch video here)
- **Pain**
- **Vision problems** (watch video here)
- **Balance problems**
- **Dizziness**
- **Bladder problems**
- **Bowel problems**
- **Stiffness** and/or **spasms**
- **Muscle weakness**
- **Tremor**
- **Swallowing**
- **Speech**
- **Cognitive problems** (read more here)
  Problems with memory, thinking and communicating

Other symptoms such as **anxiety** and **depression** are more also common in people with MS.

Whilst medical evidence is not always available, for those with specialist input who give consent, it is critical to attempt to speak to their Neurologist, MS Nurse, Physiotherapist and/or Occupational Therapist for additional information.

Typically clinicians will measure disability in MS using the **Expanded Disability Status Scale (EDSS)**. This scale ranges from 0 to 10 in 0.5 unit increments and 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 steps 5.0 to 9.5 are defined by impairment to walking. The scale is based on measures of impairment in eight functional systems (FS):

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

The symptoms of MS are different for every individual and can be very unpredictable. How someone with MS presents on any given day may not reflect their symptoms the rest of the time.

Find out what the how the EDSS categorises disability in MS **HERE**.

Living with Multiple Sclerosis-Video accounts

Fatigue & MS

In this video we hear from Tom, Anna and Simon, who each speak about fatigue that’s secondary to their MS, and how it impacts their ability to function day-to-day. Watch the video HERE

Mental health & MS

In this video Tom, Anna and Simon speak about their mental health problems secondary to their MS. Tom reminds us that “most people with MS suffer with anxiety and depression and that it has twice the suicide rate of the general population.” Simon adds that “he had a life before MS which he no longer has”. Watch the video HERE

Pain & MS

In this video we hear Anna and Simon speak about how pain secondary to their MS impacts their ability to function day to day. Anna references that ‘the pain feels like the poisonous pain from a wasp sting, that irritating pain you cannot ignore, which just gets worse. Except, imagine that seeping out of your bones.” Watch the video HERE

Cognition & MS

In this video Tom speaks about the cognitive difficulties he faces secondary to MS. He tells us about how he struggles to hold conversations because of his fatigue and cognition. Watch the video HERE

Insight from a neuro-physiotherapist

In this video Rachel Flinn, a neuro-physiotherapist, speaks about working with people with MS. She tells us about the different types of MS and vast number of symptoms a patient may experience. She also provides some useful insight into how she assesses people with MS, including observations and questioning, specifically around the ‘hidden’ areas of their condition. Watch the video HERE

Expanded Disability Status Scale (EDSS)

Be mindful this cannot necessarily be directly applied to PIP but serves to support your understanding of medical information available.

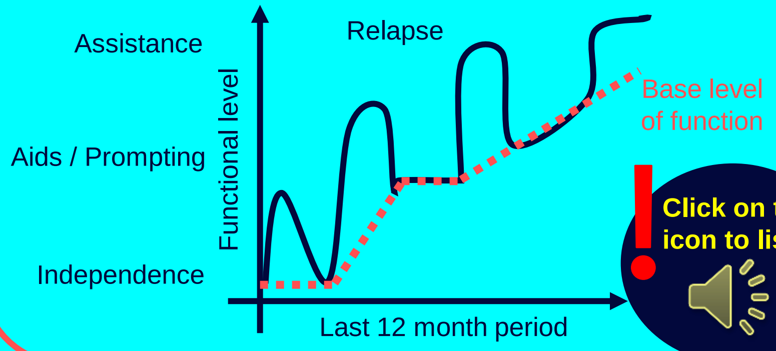
0	Normal neurological exam, no disability in any functions	**5.5**	Disability rules out full daily activities. Can walk 100 metres without an aid
1.0	No disability, very small sign that one function isn't normal	**6.0**	Can walk 100 metres with a stick or crutch, with or without rests
1.5	No disability, very small signs that more than one function isn't normal	**6.5**	Can walk 20 metres with the two aids (crutches or sticks) without stopping for rests
2.0	Very small disability in one function	**7.0**	Essentially restricted to a wheelchair but active all day; can't walk more than 5 metres even with an aid
2.5	Mild disability in one function or very small disability in two functions	**7.5**	Can only take a few steps. Restricted to wheelchair and may need help getting in and out of it. May need a motorised wheelchair
3.0	Moderate disability in one function or mild disability in three or four functions. No restrictions walking	**8.0**	Need to be in a chair, wheelchair or bed. May be out of bed much of the day. Still have use of the arms.
3.5	Moderate disability in one function and mild or moderate disability in several other functions. No restrictions walking	**8.5**	In bed much of the day. Still have some use of arms
4.0	Significant disability but you can walk without an aid for 500 metres	**9.0**	In bed all the time but can communicate and eat/swallow
4.5	Significant disability but up for much of the day. May still work but might need some help. Can walk 300 metres without an aid	**9.5**	In bed but you can't communicate or eat/swallow
5.0	Disability gets in the way of daily activities but can walk without an aid for 200 metres	**10.**	Death due to MS

MS Society report the scale is sometimes criticised for its reliance on walking as the main measure of disability, where non-mobility symptoms also have a big impact on everyday life. Review the scale on the MS Society website here.

Fluctuations

MS symptoms can vary enormously from one day to the next – even from one hour to the next. They might last for a few hours, days, weeks or even months.

Here is an example of relapsing remitting MS fluctuation over 12 months but remember there are **other forms of MS which will present differently** and this is an **illustrative example only**.



Click on the icon to listen

Some people find certain triggers such as heat (change in core body temperature), stress, exertion or tiredness make their symptoms worse, or make old symptoms reappear.

- **How has the condition been over the past 12 months?** What changes have they seen, over what period of time did they experience any deterioration, what has this meant for their functional ability now compared to previous?

Where pain / fatigue are reported:

- **What level of?** Can they quantify this, do they use a scale and can they describe it? What level of severity? Can they discuss this in this way over what might be a 'typical' day for them?
- **Triggers?** Exertion to varying levels might be a trigger for increased fatigue and pain. Can they describe what level of exertion has what impact? How do they manage this trigger, or others?

Reliability

What specific areas should be covered to ensure a complete, reflective report?

SAFETY

Do they have any symptoms which could cause a safety consideration?

Depending on the reported symptoms, where it is appropriate cover how risks are mitigated and if there is a history of incidents within activities 1, 2, 3, 4, 5, 9, 11 and 12 to ensure you have addressed the needs of the individual claimant.

Safety considerations can be a result of physical and psychological symptoms.

TIMELY

For any activities where restriction is reported how long does it take them to complete these activities? Has how long it takes them changed over time?

Pain, fatigue, spasms/ stiffness can all affect time frames of how long it takes an individual to complete a task.

This will vary for each individual, but there are no specific time frames outlined for what is reasonable.

Ensure to ask:

- How long it takes to complete tasks such as 1,4,5,6 and 12.
- Why they feel it takes them this long?
- Where they report having any breaks in task, why, how long are these breaks and how frequent?

ACCEPTABLE STANDARD

How have they adapted to completing tasks over time – is this different to what might be considered 'normal'?

As MS progresses for the individual, how they have adapted will become their 'normal'. This may mean they do not raise these during superficial questioning.

Exploring **HOW** they complete the task in depth can help to draw out any compensation strategies which can then be explored further.

Ask about the pain and fatigue experienced whilst carrying out activities and the impact on daily life.

REPEATEDLY

Are they able to repeat a task as often as reasonably required? Is this the same every day?

The complex variability of MS symptoms must be properly explored. They may have good days and bad days. How they are on any given day is not how they are going to be all the time. You need to try and establish what is the majority of times for them.

For example, someone with cognitive difficulties may be able to explain an action but be unable to carry it out when asked so may not be reliable.

Sensitivities

What areas might they find difficult to mention or perhaps understate the impact of?

Some individuals with MS may have cognitive difficulties, which may mean they find it difficult to take in and process information. They may need longer than other people to respond to questions.

Others may have speech difficulties which make it harder for them to speak clearly.

Depression and anxiety are 50% more common amongst people with MS than the general population. Someone with low mood, anxiety or other negative effects on their psychological wellbeing may be reluctant to talk about it.

Those living with bladder and bowel issues can be amongst the most difficult area to discuss.

What is the generally preferred term for someone with this condition?

A person living with MS.

Watch **Alistair** talk about his experience of living with MS **HERE**

Customer Care

How is it best to ask about any sensitive topics and what are the common courtesies?

In general

- Be proactive in offering a break in the session. They may feel uncomfortable about asking for this as bladder problems and fatigue are very common
- Ensure any companion is made to feel welcome and allowed to contribute to the assessment
- Give the person time and wait for their response. Some people with MS find it difficult to think properly when they're put on the spot – so try to put them at ease, and don't pressure them to answer immediately
- Make your questions as clear as possible, and be prepared to repeat a question if necessary. Also consider asking the question in a different way
- Don't assume that because someone has speech difficulties that they have cognitive difficulties
- If you haven't understood something, say so. If necessary, repeat it back to them to make sure you've understood
- Remember that speaking can be tiring for someone with MS, particularly if they have speech difficulties.
- If someone has a carer or supporter with them, ask them for clarification on anything you don't understand or the person with MS is unable to explain

During face to face interactions

- On arrival, advise on location of basic facilities including accessible toilet and rest areas
- If someone appears to be in discomfort while waiting ask if any assistance can be provided
- Make eye contact and speak to both person with MS and companion even if the companion is providing most of the information

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 1: Preparing food

Fatigue, visual changes, changes in balance, dizziness, stiffness and spasms, muscle weakness, tremors can all affect the physical ability to stand, prepare and cook items and changes to cognition and any anxiety and depression can affect timings, motivation and safety in the kitchen area.

Remember in PIP…

Can someone prepare a meal reliably? Someone's physical ability to complete an activity is not the only area to be considered here. If there is evidence of cognitive deficit, are they safe cooking? Can they tell if food is cooked? Are they safe around knives and flames? Furthermore, if there is a lack of motivation, do they require prompting to cook? Are they cooking the majority of days? Do they require support or supervision? If there are issues with motor skills, can they safely cut food or hold pans? Do they require physical assistance?

Activity 2: Taking nutrition

Changes to ability to swallow due to muscle weakness can cause coughing whilst eating and creates higher risk of choking and aspiration, this may cause fear or reduced motivation to eat. Weight loss may be a feature.

Remember in PIP…

You need to have established the individual's ability to be nourished, either by cutting food into pieces, conveying it to the mouth and chewing and swallowing; or through the use of therapeutic sources. Spilling food, motivation to eat and risk of choking should be explored alongside extent of any support.

Activity 3: Managing therapy and monitoring a health condition

Changes to cognition can make managing medication and treatment regimes more difficult, as can low mood and reduced motivation.

Due to the physical restrictions that can occur there may be need for assistance taking medication and/or participating in therapy such as physiotherapy.

Remember in PIP...

You must establish how they are managing their treatment. Do they require prompting or support to administer their medication? Do they have poor compliance?
Furthermore, if they receive therapy in the home environment, do they require assistance with this? How long does this assistance take?

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 4: Washing and Bathing

Fatigue, visual changes, changes in balance, dizziness, stiffness and spasms, muscle weakness, tremors can all affect the safety of individuals getting in and out of an unadapted bath/shower and ability with bending and reaching to all areas of the body.

Changes to cognition and mood can impact motivation, sequencing and ability to carry out the task.

Remember in PIP…

You must not only consider physical ability to complete the activity, but also recognition of the requirement to wash and motivation. Do they require prompting to wash regularly? In the absence of prompting, how often would they wash? If they have a physical restriction, how are they managing to wash their entire body? Can they physically get in and out of an unadapted bath? How long can they stand for? Do they require assistance to wash their body? If so, is this their entire body? How long would it take them to wash unassisted? Would this be acceptable when considering the extent of their symptoms?.

Activity 5: Managing toileting needs and incontinence

Bladder and bowel problems are common in people with MS, but many people don't feel comfortable talking about them. Some people may be reluctant to leave their house for fear of having a bladder or bowel accident. Muscle weakness, stiffness and spasms means some people need assistance in going to the toilet. Listen to a lived experience of this HERE.

Remember in PIP…

If the claimant is incontinent, how frequent is it bladder and bowel? Can this be managed with pads independently or do they need assistance to maintain hygiene?

How do they transfer on/off the toilet?

Activity 6: Dressing and undressing

Fatigue, visual changes, stiffness and spasms, muscle weakness, tremors can all affect the ability to get dressed and undressed. Understanding reliable level of grip to manage fastenings, clothing items and ability to bend and reach to all areas of the body.

Changes to cognition and mood can impact motivation, sequencing and ability to carry out the task.

Remember in PIP…

How do they manage to dress themselves? Are they capable of selecting appropriate clothing? Do they require prompting to do this? If they can dress, how long does it take? Can they manage fastenings, buttons and laces? How do they feel after? Do they require assistance or use any aids to dress?

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 7: Communicating Verbally

Where processing information can become challenging it can impair an individuals ability to understand and/or communicate their needs.

Remember in PIP...

The scope of the activity is to be able to both express **and** understand. It is not enough that someone can hear what another person is saying. Can they process it and respond appropriately and in a timely manner? How do they manage with communicating with others? Do they require support to do so?

Activity 8: Reading and understanding signs and symbols

Double vision can affect an individuals ability to read and processing can become more difficult. *Watch the video in the symptom section for more details.* Cognition problems (often referred to as brain fog) can also cause issues with understanding complex written information.

Remember in PIP…

Double vision needs to be effecting their ability to read on the majority of days. Simply being able to read information is not adequate to manage this activity. The information someone is reading must be **understood**. What level of information can they understand? Although retention of information is not considered, it is clinically reasonable that someone will have difficulties processing, and this should absolutely be explored during the assessment.

Activity 9: Engaging with others face to face

Anxiety and low mood can affect an individuals motivation to, and ability to form and maintain relationships. Difficulties with cognition, speech and any physical restrictions can be the trigger for this anxiety as they can feel vulnerable with their symptoms.

Remember in PIP…

If there are cognitive changes reported, you must explore their ability to safely engage with others. Are they vulnerable? Are they at risk when engaging? Do they require support? If they have anxiety, who can they engage with regularly? How do they manage engaging with unfamiliar people? Do they require support from a specific individual to do so? **REMEMBER: Just because someone reports they can mix with others, this does not me**

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 10: Budgeting

Low mood and anxiety, along with changes to cognitive processes can impair their ability to effectively budget.

Remember in PIP…

If someone has a cognitive deficit it may be that they are unable to prioritise finances. Could they reliably manage a household budget? Do they require support? How would they cope with an unexpected bill? Can they manage future financial planning? Also, could they understand change expected in a shop?

Lack of motivation and anxiety alongside impulsivity must also be considered here.

Activity 11: Planning and following a journey

Anxiety and changes to cognition can impact their ability to plan and follow a journey and in some cases they may need support to do so.

Double vision can impact safety and depth perception when out.

Remember in PIP…

You must explore safety in this activity. If someone is completing journeys, are they safe? Do they have road safety? Also could they maintain concentration when out of the home? Are they vulnerable? Could they manage a diversion or plan and follow a new route? How would they cope on public transport? What would they do if they got lost? Have there been any incidents when out of the home? Do they have OPD? Can they safely navigate kerbs?

Activity 12: Moving Around

Fatigue, balance, pain, dizziness, stiffness, spasms, weakness and tremors can all impair the distance and time it takes someone to move around. Due to the unpredictable nature of relapses reliability is variable. Being able to repeat a distance in the same way each time can be challenging and for some may be difficult to fully describe.

Remember in PIP...

Firstly, establish when someone is walking, do they require an aid? If so, what aid? Was this prescribed or self purchased? How often are they having falls? How do they manage this? What is their gait? How far can they walk and how long does this take? How does walking make them feel? Does pain/fatigue increase each time they walk? When they walk a second time, does pace reduce or distance reduce? If they experience fatigue, how do they feel later in the day? How many times could they repeat the distance they walk? How long does it take to recover from mobilising? #

Lived examples are also extremely beneficial. How do they manage up and down the stairs? How do they manage with chores? How do they manage their shopping? How many aisles can they walk and how long does it take? If they go to their GP surgery or hospital, how far is it from the car? How long does it take them to get to the required department and how far is this?

Additional reading or other resources

EXTERNAL

- MS Society 'What is MS?' : https://www.mssociety.org.uk/what-is-ms/
- National Institute for Health and Care Excellence (NICE): Clinical guideline [CG186]: Multiple sclerosis in adults: management www.nice.org.uk/guidance/cg186/chapter/Introduction
- MS Trust 'Types of MS': www.mstrust.org.uk/a-z/types-ms
- For further information see NHS Conditions and Treatments: https://www.nhs.uk/conditions/multiple-sclerosis/
- https://www.youtube.com/user/MSSociety/

INTERNAL

- Desktop Aids – Fatigue, Activity 12, Activity 6, Washing and Bathing, MSE, CSE

Version control