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**MS** and cognitive function. Top tips for promoting selfcare



# Cognitive change in MS

Cognitive change in MS is a complex issue. People with MS want to understand what cognition is, why they are experiencing problems and how they can help themselves. Many healthcare professionals feel they can't answer these questions and so this book has been written as a guide to provide answers and suggest strategies to help patients. It is not meant to be a comprehensive resource but a pocket book of ideas.

## **What is cognition?**

*Cognition is how we think, reason and remember. It describes how we concentrate, maintain and divide attention, learn and remember new things, plan, problem-solve, reason and monitor our own behavior. In other words, it is the process of thinking and acting.*

Approximately 45-65% of people with MS report cognitive changes. The most commonly reported

difficulties are short-term (recent) memory, concentration, slowed information processing, abstract reasoning and problem solving. These can vary from person to person and in extent to which they affect a person.

## **Why does cognitive change happen?**

MS is a demyelinating disease. Demyelination is a word used for the loss of myelin - the fatty sheath which protects the nerve fibres in your brain. MS causes the myelin to become damaged and causes the messages to and from the brain to become slowed down or distorted. The myelin sheath is like the protective covering on electrical wire- when it is damaged, the flow of electricity to the attached appliance is interrupted, causing intermittent problems or causing the appliance not to work at all. Due to the changes to the myelin, changes occur in parts of the brain and spinal cord and sometimes these can affect a person's memory and thinking.



Many people with MS describe cognitive changes as an **“invisible symptom”** and this leads to distress and fear.



# The brain

The brain is made up of several areas including the cerebrum, cerebellum and the brain stem.

The Cerebrum has two hemispheres, and each consists of four lobes; frontal, temporal parietal and occipital.

## Parietal Lobe

Important for:

- Integrating sensory information - Reading - Writing - Drawing - Spatial judging

## Occipital Lobe

Important for:

- Vision - Identifying colour - Recognising objects

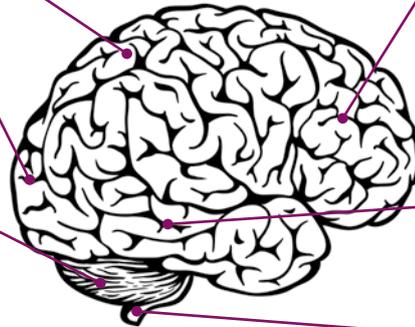
## The Cerebellum

The cerebellum is located below the back of the cerebrum and has a role in co-ordination, balance and walking

## The Hemispheres

The right hemisphere is responsible for controlling movement and monitoring sensation on the left-hand side of the body, and the left hemisphere controls the right-hand side of the body. For the majority of people, the left hemisphere is important for verbal skills and the right hemisphere is important for visual skills.

The two hemispheres are connected by a large bundle of nerve fibres called the Corpus Callosum. Its role is to help both sides of the brain to communicate with each other.



## Frontal Lobe

Important for:

- Planning - Organisation - Initiation - Problem-solving - Judgement - Personality - Abstract thinking - Mood - Speech - Attention to task - Reflection - Movement

## Temporal Lobe

Important for:

- Auditory and Visual memory - Hearing - Sense of identity - Understanding speech

## The brain Stem

Connects the Cerebrum to the Spinal Cord and has a number of areas with its own function. It is important in automatic activities such as breathing and swallowing and has a significant role in maintaining alertness.

All sensory and movement messages pass through this area going to the body from the brain and vice versa.

“

I have the attention span of a **goldfish**.

”

# What is attention?

*Attention* is a complex thinking skill that has many different parts. It includes the ability to focus on a task or a thought, and to return to a task or a thought after doing or thinking about something else. Problems with attention can affect the ability to remember new things. If you can't focus long enough, you may struggle to take new information.

## **Why does MS affect attention?**

Changes in the brain caused by MS can affect attention. Different parts of the brain help manage different kinds of attention, such as being able to:

- Keep your focus on a task or thought
- Direct attention to a specific task or thought
- Notice visual detail in your environment
- Focus on only one thing and ignore distractions
- Switch your attention from one thing to another
- Focus on more than one thing at a time

## **Attention problems**

People with MS and attention problems may find it hard to:

- Listen to other people talk
- Read a story, a magazine article or a chapter in a book from start to finish
- Tune out distractions
- Watch a TV program or movie
- Drive

## What can make attention problems worse?

- Fatigue and lack of sleep
- Stress or illness
- Doing something you are not interested in
- Medicine side effects
- Depression



## Strategies to help

### 1. Take care of your body

- Exercise regularly
- Eat a well-balanced diet
- Get plenty of sleep
- Take breaks during the day
- Try to do only one thing at the time
- Follow a daily, weekly, and monthly routine; this can help you be less distracted

### 2. Change your environment

- Make sure you have enough light to see what you are doing
- Do activities in a quiet place
- Turn off the TV or radio
- Work in a clean and uncluttered environment
- Do things that need your attention at times of the day when you have the most energy

- Wear ear plugs when you are reading or looking at something
- Ask people to speak slowly and clearly
- In a busy place, face away from the crowd

### 3. Practice paying attention

- Face the person you are speaking with
- When talking with another person, summarise or repeat the key ideas to them
- Take notes
- Say the steps of a task out loud while you do the task
- Set aside distracting thoughts when you are trying to focus
- Practice doing the things that are hard for you by breaking them down into small steps
- Remind your brain to focus as you are doing an activity. In other words, when you are

trying to complete a task and notice your attention is wandering, try to bring yourself back. It may help if you prompt yourself by saying “focus”.





We have so many packets and tins in our cupboards because I **forget what I need to buy** and just buy things I think we need.



# What is memory?

Memory enables you to make links between the past and the future. It informs your judgement, guides your behavior, influences your ability to learn skills and contributes to your personal identity.

Memory is a system for registration, storage and retrieval of information and can be compared to a filing system or a music system in which cassettes and CDs are recorded, stored and then retrieved and replayed when required.

## Memory and MS

People with MS can have particular difficulty with short term or recent memory. You may generally be able to remember what happened a few days, weeks or years ago but can't always remember a conversation 15 minutes earlier. You may go into a room for something and then forget why you are there.

People *without* MS experience this type of difficulty too, especially if they are distracted or tired, but for people with MS it is more of a regular occurrence.



## Strategies to help

Not all strategies help all people, so it is important to experiment and find out what works for you.

### Modify your environment

- Reduce clutter
- Try to keep things in a consistent place, particularly items that often get lost eg keys, mobile phone, glasses, purse, etc.

### Be aware

- Get organised and plan for tasks or events by having 'to-do' lists and setting reminders

- Stop and think. When you are struggling, give yourself time, don't panic and you may find things come to you more easily
- Be extra vigilant. Be mindful and learn to recognise those situations where you may struggle to remember information

### Routines

- Set up Standing Orders
- Perform certain activities on certain days
- Create timetables for activities

### Break tasks down

- Write tasks down, breaking them into the steps needed to complete the task
- Tick items off as you complete each part

### Remembering important conversations

- Write down what people say, or use a recorder
- Keep a diary of important events
- Write things down in a organised way
  - Use headings
  - Underline
  - Bullit points
  - Capital letters

### Diaries

- Diaries are useful for both forward planning and remembering past events

- Use a 'page-a-day' diary
- Diary entries can act as cues or triggers
- Check your diary regularly
  - Cross out things you have done
  - Write in future activities/events

### Memory aids

There are various products available that you might find useful, such as post-it notes, timers, key-finders, etc.

### Memory Techniques

Memory techniques such as Visualisation and Association can be very helpful

“

... hang on, **the word** is there,  
on the tip of my tonque...

”

# What is memory?

## Language and MS

At times you might notice some changes in your language ability which can be quite frustrating.

You may have difficulty finding the word you are looking for, an 'on the tip of your tongue' experience. You might know the word you want to use but just can't seem to get it out. You may notice you misname words, or you may be able to describe the function of an item but not its actual name.

Some people with MS find difficulty with verbal fluency, that is being able to choose the best words to express themselves quickly. Sometimes you may start to answer a question and then get sidetracked.



People get so annoyed with me  
because I find I am always saying,

“What did you just say?”

## Strategies to help

Not all strategies help all people so it is important to experiment and adapt, and find out what works for you.

### Talk around the subject

- Don't get hung up on finding the right word
- Getting the message across is what's important
- Describe what you want to say
- Use gestures

### If you lose your train of thought:

- Take some deep breaths and start again
- Visualise what word you are trying to remember. Some people find it helpful to visualise a blackboard with the word written on it
- Try and get a picture in your mind of the object, person or idea you want to retrieve

### Self-cueing

- Try thinking of the first letter of the word you are trying to remember
- Working through categories and sub-categories which describe the word or object may lead you to it

### Finishing sentences

Encourage people you know not to tell you the word you are finding it hard to say. This can be very frustrating and cause arguments because people all too often give the wrong word. It may also encourage you to stop trying to find words and allow others to speak for you.

### Try 'chunking' information

Grouping different pieces of information into manageable blocks can make it easier to remember and recall.

### Before sitting down to write..

Using key thoughts or words like 'why', 'what', 'where' and 'how' can help you structure your thoughts.

... and be patient!



“

I hate driving to **new places**  
because I always get lost.

”

# Visual Perception and Spatial Difficulties

MS can affect the speed at which visual information is processed. Sometimes it can be difficult for people with MS to make sense of what they see, or when they see an item it might not appear as they expected.

## **Difficulties may be experienced with:**

- Angle matching (judging angles and shapes eg door widths, edges of tables)
- Face recognition
- Misjudging depth and distance- eg walking into things
- Getting lost whilst driving, even when familiar with the place (this may also be due to memory problems)
- Becoming confused between right and left

- Having trouble assembling things from diagrams or written instructions
- Having difficulty visualising objects from a verbal description

**I am looking for my red t-shirt but  
can't find it,**

even though it is in front of  
me on top of the ironing pile

## Strategies to help

Not all strategies help all people so it is important to find out what works for you.

### Change your environment

- Reduce clutter
- Keep things in set places

### If you keep walking into doors:

Put lines of tape on the floor to walk between.

### If you find you are forgetting passages or missing the ends of sentences when reading:

Use a piece of paper to cover the text and guide your reading.

### Increase contrast

Dark objects on white backgrounds or vice-versa

### Place coloured tape on sharp corners

### Scanning

Scanning is moving the head and eyes to search for a target.

### Use written and visual cues

A written cue is a note you write to yourself to remind you of something - a shopping list is a familiar example of this.

### A visual cue

A visual cue could be a coloured tag in a book to remind you where you stopped reading.

A combination of a written and visual cue would be a brightly coloured sticker on the fridge reminding you to 'Buy some flowers'.

### Get your eyes checked

You may need glasses or a change of prescription.



“

I cannot think as quickly as I used to

”

## Attention in concentration

You may have difficulties in processing sentences, which can be due to slowed processing; you might also find that you need a little extra processing time when you are having conversations. You might be experiencing attention and concentration problems and therefore you are easy to distract (See attention section).

You may have to make a greater effort to concentrate. Because your information processing speed may be slower, you take in less information. Therefore you may think you have a memory problem.

People with MS report an overall slowing in their speed of information processing of visual information (eg making sense of lots of roads signs in a short distance) and of auditory information (eg following a set of verbal instructions or making

sense of a conversation happening at normal speed). If you are experiencing slowed processing, you will also notice you take longer to react to incoming information which can cause you to become frustrated.

**People with MS find they often need more time to take in information and to make sense of it.**

It can also take them longer to formulate an appropriate response.



## Not all strategies work for everyone

So it is important to find out what works for you.

- Give yourself permission to take more time
- Break information into small steps
- Try to avoid situations where you have to think on your feet
- Turn off distractions like TV/radio/mobile phone
- Try to avoid over-stimulating environments
- Have patience
- Set yourself small, achievable goals and practice tasks as this will help your speed. Brain training is helpful for this.

- Keep a positive mindset - say to yourself: I know I can do this when I have a little more time
- Be brave and tell others what you need: “can you say that a little slower please?”, “Please repeat what you said”
- Allow yourself preparation time. Make notes in advance to refer to during a conversation or meeting
- Plan tasks that require more energy when you know you are not fatigued for the best time or day for you
- Take notes of important conversations (either during the conversation, or immediately afterwards)

“

I start a task at work then  
I seem to get ‘lost’.

”

# Executive Functioning

Executive functioning is the term to describe the cognitive process that regulates a person's ability to organise their thoughts and activities, to prioritise tasks, to manage time efficiently and to make decisions.

**People with MS may find they experience difficulty with one more of the following executive skills:**

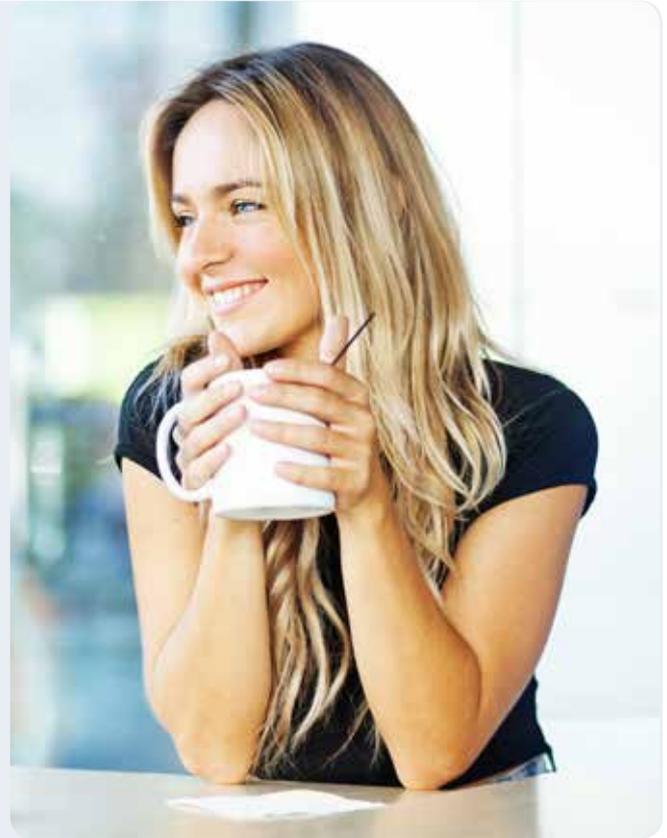
- Planning and organisation
- Sequencing - ie difficulty in completing complex tasks in the right order
- Flexible thinking - you may become more rigid in your thinking, ie wanting to stick to fixed routines
- Problem-solving
- Motivation/drive - an inability to start activities
- Self-monitoring
- Self-correction
- Distractibility

- Poorer decision making - diminished abstract reasoning



## Strategies to help

- Take a minute. If you are struggling with a task, take a minute and think about it before starting
- Set specific goals for specific times
- Schedule activities - use calendars, electronic devices, computers to help you plan and schedule activities
- If you find it difficult to plan meals and tend to be an impulsive shopper, try writing up meals plans for the coming week before going shopping
- Sequencing - make a list of steps needed to achieve a task
- Be kind to yourself and reward yourself for achieving a task



- Make checklists of the tasks you struggle with using the sequencing strategy mentioned on the previous page
  - When you are struggling to solve a problem, work it through with someone you trust and write down their alternative solutions
  - If you are making frequent errors take a step back and see if you can recognise the errors, then try to do the task differently
  - Each day write down the jobs you want to achieve, numbering them in order of priority, so you start with the most important ones
  - If you are struggling with your finances, try using a budget book to track money spent
- If family/friends tell you there is a problem, remain calm and ask for support in resolving it.



“

I found that by doing a little exercise  
I felt **‘smarter’** and **happier**

”

## Healthy living

If you are experiencing cognitive changes, these changes may not necessarily be due to MS but may be caused by factors listed here.

- Fatigue
- Stress & Anxiety
- Low mood
- Lack of sleep
- Excessive alcohol
- Medications
- Ageing

If, however, these changes are due to the MS, it is important to be aware that all these factors can worsen any cognitive changes, which is why it is so vital to think about living healthily.



## Fatigue

Fatigue is a common symptom of MS and it can affect both mental (cognitive) and physical function.

### Strategies

- Plan ahead - what is realistically achievable?
- Prioritise and delegate
- Use energy effectiveness strategies
  - think through how you can tackle tasks.Are there ways you could be saving energy?
- Pace yourself

## Stress

Being stressed has a significant impact on cognition

- whether a person has MS or not.

### Strategies

- Identify what is causing the stress
- Take action to reduce the stress - the following can be useful:
  - Guided relaxation
  - Aromatherapy
  - Breathing exercises
  - Yoga
- Try to keep things in perspective
- Be kind to yourself
- Ask for support

## Low mood

This can be common in MS.

### Strategies

- Prepare for change. Knowing and expecting that changes may occur will decrease their impact
- Find ways of maintaining enjoyable and rewarding life experiences, even if this means adapting them in some way - alternatively find new activities to enhance your enjoyment in life
- Challenge your negative thinking. Your situation may be bad, but is not 100% awful all of the time
- Use the fatigue strategies from the previous page. Fatigue and low mood appear to be linked in some way so helping your fatigue will help your low mood and your cognition as well



## Sleep

Look at your sleep pattern - is it a problem?

Here are some strategies for helping with a good night's sleep:

### Strategies

- Have a routine, as much as possible
- Try to avoid getting over-tired
- Having a short nap can be better than a long sleep during the day
- Keep bed for sleeping (and sex)
- Use relaxation or deep breath exercises
- Use mind games - eg counting sheep
- If your mind is full of thoughts/ideas/anxieties have a pad and pen next to the bed to write them down and then look at them in the morning

## Healthy eating

A healthy diet = a healthy brain!

- Eat plenty of fruit and vegetables plus complex carbohydrates
- Poor diet or eating habits mean the body and brain may not have enough fuel, which in turn causes cognitive problems
- Avoid high sugar food or drinks
- Drink sufficient fluids: especially water
- Try to maintain a healthy weight

## Alcohol

This affects the central nervous system and can worsen MS symptoms including cognition.



## Exercise

Exercise is important for keeping healthy, it can also lift mood and relieve stress, in turn helping with cognition.

Try to stay active, and if you are unsure what exercise you can do, physiotherapists can suggest exercises that take MS symptoms into account.



## Strategies

Speak to your GP before starting a new exercise program. If you are planning exercise, remember:

- You can build elements of exercise into everyday jobs
- Try to vary routines to keep them enjoyable
- Increase intensity gradually
- And take plenty of rests



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