





Multiple Sclerosis & Cognition

The aim of this guidance is to help you understand the common cognitive changes that can occur with MS.

There is a lot of information and advice in this leaflet so please pace yourself. Pick a time when you can give your full attention, and read one page at a time.



What is cognition?

Cognition refers to attention, memory, processing speed, language, visuospatial, and organisational skills. These processes are what allow us to:

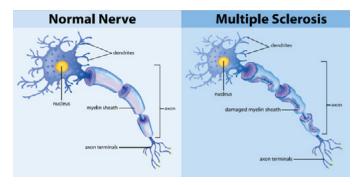
- Concentrate/focus attention
- Multi-task
- Learn and remember new things
- Plan, carry out and monitor activities
- Understand and use language
- Recognise objects, assemble things together and judge distances

We all have our own natural strengths and weaknesses in each of these areas. Often we know what these are, and play to our own strengths at home, in school/college, or at work.

MS and the brain

Myelin is often called "white matter", and is the protective covering of the nerve connections which help messages travel quickly and efficiently across the brain. MS attacks the myelin (white matter) that insulates nerves within the brain and spinal cord (see figure).

Damage to the white matter can disrupt connections in the brain and can cause physical (such as sensory, balance and mobility problems) and cognitive symptoms.



National MS Society www.nationalmssociety.org/understanding-ms



How common are cognitive changes in MS?

Not everyone with MS will experience difficulties with cognition, and most changes are mild to moderate in their severity. 35% to 70% of people living with MS are estimated to experience cognitive changes.

Cognitive changes vary from person to person. Changes can be noticeable at the time of diagnosis for some people, and for others not. Problems can be temporary or more persistent. Difficulties can recover after a relapse, or may remain. Cognition does not necessarily get worse over time in MS. If problems do become worse, the progression is slow, which means strategies can be developed to work around any problems.

Symptoms in MS tend to be individual and unpredictable. This can cause stress and uncertainty

A number of things can make cognitive problems feel worse:



By managing these factors, you may see an improvement in cognition. There are some strategies and suggestions for this, starting on page 7.



What cognitive changes might people with MS experience?

Speed of information processing

Slowed thinking speed is one of the earliest and most common cognitive changes that people with MS can experience. Speed is involved in all cognitive functions - so slowness can impact on memory recall or finding the right word for example. It can take longer to recall things from memory because of changes to neural pathways across the brain. Many people living with MS describe that they can still do all the things they need to - but that tasks take more time and effort than before. This can be frustrating if you are used to working at speed.

Executive function

Executive function is a term used to describe complex organisation and problem solving. This function is often described as similar to the "Chief Executive" of a business - who analyses a situation, plans, organises, problem solves, thinks carefully before acting, supports decision making, is able to juggle lots of different demands all at one time (multi-tasking), prioritises tasks and carries them out. The frontal lobe areas of the brain are known to have a big role in executive function. Frontal lobe white matter changes can often be seen in MS, and connectivity to this area can be disrupted by demyelination.

Attention

There are different types of attention, often closely linked with organisational function. Changes in attention could involve difficulty concentrating for long periods of time (sustained attention). Divided attention is the ability to focus on a task when there is more than one thing fighting for your attention. For example, trying to have a conversation while cooking dinner. Some people call this "multi-tasking". People living with MS often describe problems with this – such as difficulties doing two things at once, or getting back on track after interruptions.

Memory

Problems with memory are commonly reported in MS and are usually related to memory for recent events. For example, problems recalling a recent conversation or finding it hard to remember a new PIN or the name of a person you have just met. Often, we find that memory problems in MS are more related to processing speed and attention, rather than a difficulty with memory function itself. Strategies to slow down, repeat learning and reduce demands and distractions often help with memory encoding and recall.

Verbal fluency / word finding

People with MS sometimes notice that they struggle to find a word during conversation, having the feeling like the word is "on the tip of the tongue". It may feel like it takes too long to find the word and the conversation has moved on by the time it comes back. This can be frustrating. People sometimes put a lot of pressure on themselves to find the word which, in turn, can make it even more difficult to find. The word usually comes to mind in the end. It has not been lost to memory. Instead, slower speed and impacts on brain connectivity are making it take longer to bring to mind.



How might cognitive changes impact me?

Cognitive changes are very individual, and can vary over time. They can have different meanings for different people.

- For mild changes, many people easily find "work arounds", tools and strategies which help them.
- More moderate changes sometimes cause worry; or impact home, work or education. In this case, more careful thinking with the family or a line manager/learning advisor might be helpful to find adjustments and strategies to cope. Some of the suggestions in this information leaflet will also help.
- It is rare for problems to become more severe. For bigger changes or concerns, we suggest you ask your MS Specialist Nurse for advice.

Employment

Changes in cognition can impact work. It is important to remember that you have rights at work under the **Equality Act 2010.**

These laws state that if the symptoms of MS are affecting your ability to work, you have the right to ask your employer for **'reasonable adjustments'** so you can continue to work. Employers must ensure that you are not discriminated against because of MS.

See MS and your rights | MS Society for more information.



Education

The same laws apply if you are studying at college or university. Reasonable adjustments might include more time to complete examinations or study areas free from distraction.

Your education department may also have a dedicated member of staff or Learning Support service who might help.

If you need extra equipment to help with your studies, there are grants available to help with this, called Disabled Students Allowance. You can apply for this through the Student Awards Agency.

Ask your director of studies or learning support service for advice.

More information on both study and work can be found on the MS Trust website, along with helpline information:

Managing work and study | MS Trust



What should I do if I suspect cognitive changes?

Mild cognitive changes (e.g. struggling to think of the right word or forgetting your keys) are common in MS. Although changes can cause worry, they are often manageable and strategies can help. There are some evidence-based tried and tested strategies on the next few pages. This can be a "toolbox" of ideas for you to try at home and work.

Read through the strategies on the following pages a box at a time. Take your time doing this. Discuss the ideas with friends and family, or at work.

See what works for you.



Improving general wellbeing

Talk about it with others

- Explain to family what you are experiencing and how they might be able to help.
- Be open with people at work, your manager, or advisor for your studies. A few strategies might be enough to help you cope.
- Talk to others that may be experiencing something similar (e.g. a friend or a support group). Details of MS support groups can be found in the websites below.

Keep yourself informed

See the websites such as:

- Revive MS | Support For People Living With MS | Scotland (revivemssupport.org.uk)
- Scotland | MS Society
- Here for everyone with MS | MS Society
- Home | MS Trust

Manage fatigue or pain symptoms

- Pace yourself and prioritise the things you value most.
- Alternate rest with activity.
- Eat healthily and regularly.
- Organise your day with a routine.
- Keep a diary to schedule or "budget" your time.
- Take gentle exercise (walking or yoga).
- Speak to a health professional (MS Specialist Nurse or GP) about fatigue or pain management.
- For more information see:
- Managing MS Fatigue Help & Support | MS Society
- Fatigue | MS Trust

Tips to improve sleep

Sleep is very important to help process information and support memory.

- Make sure your bedroom is comfortable consider your mattress, pillows, covers, temperature and bedroom atmosphere.
- Darkness helps sleep use curtains or black out blinds to help block out light.
- Don't look at screens in bed (TV, laptop, or smart phone). This stimulates the brain and keeps you "switched on"!
- Set a regular bedtime and "getting up" time. Maintain the same sleep and wake times every day (even weekends).
- Eat breakfast when you get up.
- Get some natural daylight and light exercise during the day (not evenings).
- Don't drink caffeine after 3pm
- Don't nap after 3pm

Reduce stress

Stress makes cognitive tasks more difficult.

- Relaxation, yoga, or mindfulness can help regulate emotions; consider taking a yoga or mindfulness class.
- More information on managing stress:
- www.nhs.uk/every-mind-matters
- Highland mental health and wellbeing
- Talk to others that may be experiencing something similar (e.g. a friend or support group).
- There are MS Counselling services, which your MS Specialist Nurse can direct you to Counselling | Revive MS | Scotland
- If you are experiencing anxiety or depression symptoms, speak with your GP about treatment options.



What strategies can help cognition?

It may feel difficult or upsetting to rely on strategies if you have not needed to use them before. However, many people find that once they get used to using them, they quickly become part of their daily routine and help them feel more confident in managing their symptoms.

Pace yourself

There is a lot of information and advice in this leaflet. Take it step by step and perhaps read a page a day. Try one strategy at a time to see what works for you. Discuss it with others to help try out strategies – you may want someone close to you to read it too.

Memory

- Write things down. Use your smart phone or a notepad. Keep this handy so that you can access it as soon as you think of something to remember or you are given information.
- Use a calendar to record appointments as soon as you get them. If someone is on the phone giving you information, ask them to stay on the line and repeat the information while you write it down.
- Use reminders and alarms this can be on your phone or using a smart speaker.
- An electronic calendar on your phone can be set with reminders and alarms.
- Photos can be used as reminders too. For example, take a photo of where your car is parked, perhaps landmarks on a new route, or events you want to recall.
- Create meaningful connections with information to be remembered regularly; such as a song, story or image. For example, remember your PIN by singing it to yourself to a well-known tune such as 'Happy birthday'.

Set up a "memory station" at home

- ✓ Place a whiteboard / corkboard somewhere that you will regularly see it (on the fridge, next to the kettle, in the hall as you come home).
- ✓ Note on the white board what you have to do that day or week (the priority tasks).



- ✓ The cork board can be used to pin up appointment letters or bills as they come in. Try to get into the habit of only opening letters when standing by the memory station.
- ✓ You can add a calendar/planner to note future appointments or deadlines.
- ✓ Get in the habit of checking and updating the memory station every evening before bed and every morning when you get up. Set an alarm on your phone to remind you until you get into the habit.
- ✓ Try to anchor checking into your routine: Always check it in the morning when you make breakfast, and set it up in the evening before you brush your teeth. Perhaps place it by the kettle and check it every time you make a cup of tea.
- ✓ Try to set a weekly planning session when you set up the white board for the week ahead.

Organise your space

- Have a dedicated place to keep things you need. It is a good idea if this is by the memory station, or perhaps by the way you enter or leave home or work.
- Check in/check out system: When you get home, have a regular way to "check in". Don't rush ahead to the next thing. Stop and put items in their places, perhaps near the door.
- Perhaps keep keys in a bowl near the door, a bag needed for work hanging next to the door, a checklist or pictures of what you need on the door - "keys, wallet, mobile".



Planning and organising

- Use lists to plan out all the activities /tasks that you need to do that day. It may help to use an organiser, calendar, alarms, smart speaker, or mobile phone apps. Perhaps you can use a "To do" App or a voice recorder to record these.
- Step by step: Prioritise the tasks that you need to do and record these in the order that you are going to do them so that you can refer back to them later.
- For more complex tasks, it might help to do this with the help of someone else.
- For common daily tasks you might like to have a checklist on the wall at home or on your desk at work with step-by-step instructions.
- Try to establish a routine for daily activities so that you don't need to actively remember them.

Finding words or following conversations



- Relax and give yourself time, the word might come back to you. Stressing about finding the exact word makes it harder to find it.
- Try to use an alternative word.
- Describe the word that you are trying to think of to others they may be able to help you.
- If you feel comfortable, tell others that you have difficulty finding words at times and how you would like them to help you. For example:
 - **o** Do you want them to give you more time, or offer a prompt/suggestion?
 - **o** Or do you prefer them to stay quiet and not finish your sentences for you?
- Try to talk one-on-one for important information.
- Take time to gather your thoughts before responding.

'On the spot' thinking

- Do what you can to slow things down take a breath, relax.
- Ask people to talk more slowly. Tell people that you need more time to process information or answer questions.
- Try to plan ahead as much as possible to avoid situations where you will have to respond quickly.



Neuropsychology | NHS Highland

Issue 1 Date of issue: Jan 2025 Review Date: Jan 2027

Devised by: Dr Emma Neilson, Clinical Psychologist in Neuropsychology, Dr Ruth Sumpter, Consultant Clinical Neuropsychologist

