

Information for people living with multiple sclerosis

Symptoms



- Multiple sclerosis and cognitive symptoms
- What should I do if I experience cognitive problems?
- What can I do to manage these symptoms?
- General information and assistance



About half of all people living with multiple sclerosis experience issues with aspects of thinking or 'cognition' – memory, attention span, planning, decision making, understanding or concentration. For most, these symptoms – known as cognitive problems – are quite mild and can change from day to day. For others, these issues can be made worse by other multiple sclerosis symptoms. With the right information and support, cognitive symptoms can be minimised effectively to maintain a productive, healthy and active life at work and at home.

Multiple sclerosis and cognitive symptoms

If you experience some form of cognitive change, you're not alone. This change typically manifests as poor memory and trouble concentrating, and is often described by people living with multiple sclerosis as 'fuzziness' or 'brain fog'.

You may have difficulty finding the right words to say, or trouble remembering work tasks or home routines. Some people forget appointments, take longer to solve problems or need things repeated.

Cognitive issues can arise early in the course of the condition, but the longer you've had multiple sclerosis the more likely problems are to occur.

For most people living with multiple sclerosis, cognitive change is mild and can fluctuate. In fact, rather than recognising these symptoms as an aspect of your multiple sclerosis, you may link them to stress, overwork, tiredness or just getting older.

For people living with multiple sclerosis, invisible symptoms such as cognitive issues can be frustrating, because others may not notice how you feel. The most common cognitive problems are linked with:

- **Memory** Difficulty remembering recent events or information, or forgetting to do things.
- Word finding A word is 'on the tip of your tongue' but you can't recall it
- **Concentration and attention** Hard to concentrate, follow conversations, your mind wanders or feels overloaded (especially if lots of people are talking at once).
- Information processing Hard to follow a series of complex instructions (especially if rapid).
- **Visuospatial abilities** How you judge for example, distance, speed and where things are.
- **Planning and problem solving** Everyday tasks, thinking through implications of actions or decisions may become harder.



Other factors related to your multiple sclerosis, which can worsen cognitive issues include:

- **Emotions** stress, anxiety and depression can impact cognition and can also be difficult to tell apart from other multiple sclerosis symptoms. For example, depression can be confused with fatigue as it can make you tired and uninterested in life. A psychologist assessment may help in this case.
- Fatigue or poor sleep slows everything down and can also affect short term memory, concentration or word finding. People report it's harder to 'think straight' when fatigued. Pacing yourself and planning demanding activities for when you've got the most energy can help.
- Infections and other illnesses can worsen cognitive problems.
- **Medications** including some used to treat multiple sclerosis symptoms such as bladder problems, spasticity and pain can impact cognition. An MS nurse or GP can advise on the likely effects of medications.

- **Physical effort** if you have balance or mobility issues, you may need to concentrate more while moving about, to ensure you don't trip or fall. This can lessen your capacity to concentrate on other things, such as talking while walking. Balancing physical and cognitive activities so you only have to concentrate on one thing at a time can help.
- Other things such as heat, tense or exciting situations can impact cognition. Staying cool in hot weather, or using relaxation techniques, can be useful.

Cognitive symptoms appear to stay the same over several years, or only very gradually worsen, giving you time to develop strategies to compensate for any difficulties.

With the right advice, you can manage or reduce these symptoms. Like multiple sclerosis, cognitive symptoms vary from person to person, so an individual approach is best.

What should I do if I experience cognitive problems?

If you have cognition concerns talk to your MS nurse or GP, and at your next visit, tell your neurologist. Some things to think about and discuss with your MS nurse might include:

- At what point in a conversation you can keep up with what's being said. And if you ever struggle to find the appropriate words to say.
- If you sometimes forget things, even straight after receiving information. And if so, when does this happen e.g. when you're fatigued or stressed?
- Whether it seems you need more time to take in information or learn new things than before.

If your decision making or ability to do tasks at work has declined, your neurologist may refer you to a neurophysiologist for assessment.

It can be helpful to talk to others with memory/ learning/new task problems (at peer or other support meetings), who have developed some useful strategies.



What can I do to manage these symptoms?

Compensatory strategies

Managing cognitive symptoms often involves finding strategies to minimise the effects of symptoms. Compensatory strategies may include:

- Starting a fixed routine keeping things in the same place, or doing things in a certain order.
- Using verbal tricks to help you remember things such as when clocks change for daylight saving.
- Visual and verbal associations can help for example picturing 'Ms Glass' as 'the woman with spectacles on', or putting meaningful tags onto words or names such as 'Jack, the man who works in the bank'.
- Using diaries or smartphones for reminders, planning or memory prompts.
- Prioritising tasks to allow you to focus on one thing at a time and where possible, removing distractions, for example sitting in a quieter part of the office or turning the TV down.
- Breaking down longer tasks into smaller chunks and carrying them out over a few days.
- If you can, avoid doing things when you're tired or anxious so you have more chance of staying focused.

If your cognitive problems worsen due to your other multiple sclerosis symptoms, getting those symptoms treated can help. For example, if heat's an issue, using cooling therapies such as fans or air-conditioning can assist. Equally, stress, anxiety and other symptom management can help, by way of for example:

- guided relaxation mindfulness
- aromatherapy
 meditation
- breathing exercises
 yoga

Talk to your healthcare team about tailored options to improve your individual situation.

More severe difficulties

For some people, cognitive problems can become more serious – they may not even be aware of the true extent of their difficulties and need more help than the above compensatory strategies. In this case, it may help to be referred to a neuropsychologist who may look at a retraining approach with gradually more challenging exercises, to help strengthen impaired function. A speech pathologist or occupational therapist may also be involved.

In many cases, cognitive training or rehabilitation can be of benefit. This involves structured activities designed to maintain or retrain someone's ability to use their judgement and make decisions.

Treatments

Two small studies on Ginkgo Biloba (2002/05) suggested it may have some effect in enhancing cognition, however a larger study published in 2012 concluded it doesn't improve cognition. At present, there isn't enough scientific evidence to make a recommendation either way on the use of Ginkgo to improve cognition in multiple sclerosis.^{1.2}

There's some evidence that disease modifying therapies can have beneficial effects on cognition, ^{1,2} as it's believed that some multiple sclerosis medications may reduce the amount of brain volume loss, in turn slowing down the progress of potential cognitive issues.

Everyone's different so you may need to try a range of options (or several at once) before you find what works best for you.



General information and assistance

There is support available to help you manage your multiple sclerosis:

- Contact your state MS organisation (details below) to access services such as MS nurses, peer support and other resources.
- Speak to your neurologist and other healthcare providers about the best approach to treatment management for your individual circumstances.
- For information about multiple sclerosis and multiple sclerosis treatments, visit **www.msplus.org.au**

State MS organisations

MS Plus (Victoria, NSW, ACT and Tasmania)



1800 042 138 connect@msplus.org.au www.msplus.org.au

MSWA (Western Australia)



1300 097 989 communications@mswa.org.au www.mswa.org.au

MS Society SA & NT (South Australia and NT)



1800 812 311 msassist@ms.asn.au www.ms.asn.au

MS Queensland



Other organisations

The following support services may be able to provide lifestyle, wellbeing, or other advice:

Carers Australia 1800 242 636

www.carersaustralia.com.au

Information and advice for carers, their friends and families about carer support and services.

Independent Living Centres Australia 1300 885 886 www.ilcaustralia.org.au

Products to assist with day-to-day living.

• For advice about Acquired Brain Injury (ABI), services and/or fact sheets, contact your local Brain Injury Australia state/territory member organisation: <u>www.braininjuryaustralia.org.au/</u> <u>services/</u>

Service focus differs across organisations. For example, Victoria's **BrainLink 1800 677 579 www.brainlink.org.au** assists families and friends of people affected by ABIs (including progressive neurological diseases such as multiple sclerosis). And among its many programs, **Brain Injury SA (08) 8217 7600 www.braininjurysa.org.au** helps people in their early 20s living with conditions that impact cognitive functioning, to connect into employment, education and the community.





- The MS Trust StayingSmart website www.stayingsmart.org.uk is for people who want to know (or know more) about how multiple sclerosis can affect thinking.
- Home care recipients with moderate to severe levels of cognitive impairment associated with dementia or other conditions may be eligible for the federal dementia and cognition supplement: agedcare.health.gov.au/aged-care-funding/ residential-care-subsidy/supplements/thedementia-and-cognition-supplement-in-homecare
- Some local hospitals have cognitive services or departments such as this example at the Royal Melbourne Hospital in Victoria, for people aged 50+ experiencing changes in their memory or thinking: https://www.thermh.org.au/healthprofessionals/clinical-services/aged-care/ cognitive-dementia-memory-service
- The Brain Health Guide (for people living with multiple sclerosis) has some terrific information about cognitive issues (including tips and positive actions you can take) – see pages 3, 4 and 7 – such as:
 - Keep your mind active. Education, reading, hobbies and artistic or creative pastimes help to protect against cognitive problems in multiple sclerosis when pursued over a lifetime.

- Avoid smoking. Cigarette smoking is associated with decreased brain volume in people living with multiple sclerosis, as well as with higher relapse rates, increased disability progression, more cognitive problems and reduced survival compared with not smoking.
- In multiple sclerosis, the body's immune system mistakenly attacks and damages tissue in the brain, spinal cord and optic nerve (the central nervous system). Although it is normal for healthy adults to lose small amounts of brain tissue as they get older, this process happens more quickly in people living with multiple sclerosis. For many people with the disease, this causes physical disability, fatigue and cognitive problems (e.g. difficulties with concentration, memory and learning new things).
- The Australian government's online HealthDirect portal has general information on cognitive impairment and cognition, which you may find useful:

www.healthdirect.gov.au/cognitive-impairment

References

1. www.ncbi.nlm.nih.gov/pubmed/26884145

2. www.ncbi.nlm.nih.gov/pubmed/29063244

Sources

This fact sheet comprises material from previously published Australian MS organisation leaflets plus Multiple Sclerosis (MS) UK Trust online resources. The Brain Health Guide (and associated references), and has been endorsed by a medical expert, an MS Nurse and a person living with multiple sclerosis.

Disclaimer

Information prepared by MS Australia. It is intended to provide useful and accurate information of a general nature and is not a substitute for medical advice.