Cognition

Multiple sclerosis information
Welcome to this Choices booklet about cognition

MS-UK believes we must listen to the voices of people affected by multiple sclerosis (MS) to shape the information and support we provide. It is these people that bring us perspectives that no one else can give.

For every Choices booklet we produce, MS-UK consults the wider MS community to gather feedback and uses this to inform our content. All of our Choices booklets are then reviewed by the MS-UK Virtual Insight Panel before they are published.

This Choices booklet has been designed with you in mind. We hope it will answer some of your questions and also provide some first-hand experience from those who have been in your position - people who can truly understand and empathise with your current thoughts and feelings.

"Every time you find bold text with quotation marks like this, it is a quote directly from someone affected by multiple sclerosis"
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What does cognition mean?
In very simple terms, cognition is the process of certain mental functions. These functions include identifying knowledge, processing and understanding, learning and planning, problem solving, concentration, and memory.

In MS this process can become difficult. This is known as cognitive dysfunction, or cognitive challenges and often referred to as ‘cog-fog’. Around 50 per cent of people diagnosed with MS will experience cognitive dysfunction to some degree (1).

We asked the MS community to describe how cognition affects them, they said…

• Can be embarrassing, but luckily when I’m with friends and family they help and I can laugh about it
• I’m slow to think and speak to express my thoughts and feelings
• I cannot think quickly. If I were a computer, I feel like it’s my RAM that is slow
• It takes longer to apply myself to dealing with life’s issues
• I get easily distracted, lose my train of thought, brain fog, memory holes
• Forgetting the start of a book by the time I’ve reached the end

Signs can initially be so subtle that they are not even really noticeable. They are easily attributable to feeling tired, or perhaps getting older. It can also have much more impact as the condition progresses and can interfere with work, personal life, how a person feels about themselves, or other situations that require more complex thinking. Social situations
can become difficult which can cause an increase in anxiety as a result.

I think most of my difficulty with cognition is due to fatigue so later in the day it is worse. I have to plan carefully and tackle complicated tasks when I am not fatigued. If I am struggling I will leave a task until I feel more able to tackle it.

Jeffrey Gingold, author of ‘Facing the cognitive challenges of multiple sclerosis’ states in his book how in some cases, cognitive issues have the potential to be just as disabling as the physical difficulties of MS (2).

As cognitive dysfunction is an invisible symptom it can often be overlooked, hard to recognise and understand by family, friends, co-workers and even health professionals. The difficulties people can face can be misunderstood. Equally, cognitive dysfunction can be a difficult symptom to talk about and it can be hard to admit you are having problems.

Cognitive dysfunction profoundly affects one’s sense of self. You feel as though your brain is failing you (which, with MS, it is!) and when you can’t rely on your own mind, where do you go?
Healthcare professionals need to have a flexible approach and be creative when providing new information to a person with MS-related cognitive difficulties. It is important for anyone, whether they are a health professional or a personal assistant working directly with people with MS, to understand the cognitive challenges that many people face.

**What causes cognitive issues?**

MS is an autoimmune condition where the body’s immune system attacks its own nerve cells. This means that it can affect any part of the brain therefore any cognitive function can be affected. Along with lesions, MS can cause brain atrophy (loss of brain cells) and shrinkage in certain areas (3).

In MS, the protective coating that surrounds the brain and spinal cord cells – myelin - becomes damaged, causing messages to not be transmitted through the nerves effectively.

The parts of the brain that control cognitive ability can be exposed and that’s when problems can start to appear.

People with lesions in the cerebrum and the cerebellum parts of the brain will more often have problems with cognitive function compared to those who have lesions in the cerebellum, brain stem and spinal cord (3).

The cerebrum is the largest part of the brain, contributing to nearly 80 per cent of the total weight of the brain. The cerebellum makes up the remaining part.

**What are the most common cognitive problems?**

Symptoms can vary from person to person and the level can fluctuate greatly. Symptoms can come and go and be dependent on
other factors such as heat intolerance, fatigue, infections, emotional stress, relapses and medication. Whereas for others, cognitive difficulties can be very persistent and debilitating.

"The words eventually come to me, once I relax"

Symptoms include

- Difficulty learning and remembering new things – memory can be less reliable, issues with short-term memory (long-term is often unaffected)
- Processing lots of information at once or multitasking can be tricky and slow
- Having poor concentration and being easily distracted (for example difficulty holding a conversation if there is background noise such as from a television)
- Inability to get the right words out – the word may be on the ‘tip of the tongue’ but you just cannot think of it
- Planning and problem solving can be more challenging. Often you know what you want to do but cannot figure out how to do it
- Slowed information processing – it can take much longer to process what you are reading, hearing and experiencing through senses. This can lead to getting lost as you are less able to process spatial information
- Less able to comprehend social cues in conversation or meetings
A number of these symptoms are not just specific to MS. They can be caused by other conditions such as depression and anxiety. Even some medications can interfere with cognition. Therefore, it can be difficult to assess and diagnose that cognitive issues are definitely MS related (4).

When cognitive issues are undiagnosed and unrecognised it can be an emotional and distressing experience. It can also have an impact on relationships and employment, and a person can lose their sense of self and feel vulnerable. In some cases a person may compare their cognitive issues to that of a form of dementia, although the use of this term in MS isn’t necessarily supported in a health care setting (5).

It is important to talk through these thoughts and fears with a health professional, counsellor, MS-UK Helpline or a friend. It may be that coping strategies can be created together and in turn this will help reduce further stresses and anxiety.

**How to measure cognition in MS?**

There is no one test that can diagnose cognitive dysfunction, or even necessarily confirm it. However, there is ongoing research into finding better tools to acknowledge and assess the symptom and therefore allowing for better management (6).

The NICE guidelines state that cognition should be discussed fully by MS clinic staff and referrals should be considered to both an occupational therapist (OT) and a neuropsychologist to fully assess and manage the symptom (7).

A full assessment is required to determine the level of cognitive problems that a person is experiencing. However, there are tools that other health professionals (such as MS nurses) can use too,
as access to neuropsychology in some areas can be quite limited. An assessment will likely include a number of different tasks that will test your ability to remember, concentrate and do things that would ordinarily be easy.

The assessment will take into consideration whether a person is having a relapse, may be experiencing depression or high levels of stress, as all will have an impact on cognitive ability.

After the assessment the health professional and patient will work together to set individual goals and find ways in which to make improvements where needed. This might include things like creating new strategies and techniques, referring on for cognitive rehabilitation, counselling, finding alternative approaches to perform tasks, and so on.

Professional help

There are various ways in which a person can manage their cognitive difficulties but sometimes guidance is needed by a professional.

Unfortunately there are no prescribable drugs that can help with MS-related cognition although some disease modifying therapies (DMT) have shown some improvements in clinical trials. However, a DMT wouldn’t be prescribed solely for cognition, they all have eligibility criteria that needs to be met.

GPs or MS nurses can refer you to a neuropsychologist but if there isn’t one in your area then an occupational therapist (OT) can help too. An OT can work with a person to help design some strategies to help manage specific issues.

Visit www.ms-uk.org to find out more
The neuropsychologist was very helpful in giving me strategies to get through and not panic, and to be open about how it affects me so people understand, most importantly not to be ashamed of it.

An OT may suggest certain pieces of equipment and aids or even some apps to use on your mobile phone or tablet.

**Cognitive rehabilitation therapy (CRT)**
Cognitive rehabilitation therapy can be offered by an OT or psychologist either individually or in a group setting. This type of therapy works by learning new cognitive strategies aimed at compensating for cognitive problems. It can have a positive impact on memory and problem solving and also help to improve attention and a person’s mood (8).

**Mindfulness-based cognitive therapy (MBCT)**
MBCT is mindfulness training combined with elements of cognitive behavioural therapy. Studies have shown that mindfulness-based interventions can have a positive effect on cognitive function. More studies are required to evidence this further (8).

**Self-management techniques**
Professor Dawn Langdon, neuropsychologist, says there are a number of things people with MS can do to help protect their cognition. Positive lifestyle choices, some of which may be hard to
action but are important to consider include

- Less (or better no) smoking
- Limiting the use of alcohol
- Regular exercise
- Maintain a healthy weight

Other factors that may or may not be available to you are to take disease modifying medication and to also be prescribed optimum treatment for all other diseases, especially cardiovascular and diabetes.

Professor Langdon also says that regular challenging mental activities can help to maintain clear and fast thinking (5).

**Having time to take in information and to respond to questions is very important**

**Managing depression**

Moderate and severe depression can have a significant impact on cognitive function and is a symptom experienced by up to 50 per cent of people diagnosed with MS (9). Depression can slow down a person’s thinking. The decline of cognitive function is interlinked with both depression and fatigue. Depression can increase fatigue, which can lead to cognitive decline. Fatigue is associated with increasing levels of depression, which can also lead to a decline in cognition. Each symptom impacts negatively on the others.
It is important that depression is recognised and treated to prevent any potential impact on a person’s cognitive ability. Accessing counselling, cognitive behavioural therapy, and taking anti-depressant medication can all help. Speaking to a GP and/or MS nurse about any low mood can open up the conversation in finding the best form of treatment. Treating just one of those symptoms has a significant improvement on the others (9).

**Brain training**

A 2016 study looking at brain training versus ordinary computer games showed that both improved overall cognitive function. Training consisted of one hour a day, five days a week for 12 weeks (10). The brain training group used a cognitive remediation training program where patients were instructed to play a series of games and tasks, compared to a placebo program of ordinary computer games. The brain training group showed nearly three times the improvement than the computer games group. Both groups were able to take part from their own homes rather than attend a clinic, which was beneficial to all.

Cognitive remediation therapy is a form of rehabilitation offering exercises that aim to improve attention, memory, language and/or executive functions. It can also teach specific strategies to help find the best ways of working with cognitive impairments.

**StayingSmart**

StayingSmart is a website designed by the MS Trust for people affected by MS who want to know more about how MS can affect thinking. The main aims of the resource is to support learning about cognition in MS, to help build confidence in managing cognition and to encourage the sharing of knowledge about, and experiences of cognition.
It looks at everyday problems and provides guides, videos and tips and tricks, full of a variety of ways to manage cognition. They also include videos from people sharing their own personal experiences. www.stayingsmart.org.uk

I have learnt to manage my issues through planning, recording, scheduling, giving myself time and finding a job more suited to my ability

Tips and tricks for memory

StayingSmart has some useful suggestions when dealing with memory issues, they include (11):

• Paper diaries and electronic organisers are unobtrusive and very useful

• For important appointments and dates (such as hospital appointments or birthdays), a reminder in advance can be helpful. For example, a reminder to book leave from work or transport a week before an appointment. A reminder to buy a card or present a week before a birthday

• Writing small prompts or cues on sticky notes, for example just writing ‘dry cleaning’ will probably be enough to remind you to stop to pick up the cleaning

• Check in with family members and friends to see if they have noticed any problems with your memory. It helps to be open and honest as they will then feel more able to be honest with you too

Visit www.ms-uk.org to find out more
I avoid meetings at work. I tend to catch up and email thoughts and ideas later as I find thinking on the spot too hard, especially when lots of ideas and comments are being thrown around.

**Daily reminders**

There are other daily reminders that can really improve quality of life and are simple to implement. These include:

- **Dosette boxes** are such a simple piece of equipment that help people to remember to take medication at the right time of the day. Sometimes they can even be arranged via the pharmacy to come prefilled with prescribed medications too.

- **Use a family calendar or organiser** to track everyone’s activities each day of the week. This can really help to alleviate confusion and keep on top of where everyone is.

- **Assign a specific place** for storing important frequently used things such as car keys, encouraging family members to make sure they put things back where they belong.

- **Plan your most challenging cognitive tasks** for your best time of day. If you experience fatigue around 3pm each day, make sure you have completed more taxing tasks in the morning.

- **Smart phones** are great tools for alarms and reminders, and using the notes app to keep track of to-do lists is helpful. They are also good for brain training if you use certain game apps such as sudoku.
My iPad is my ‘bible’. It goes with me everywhere, so that I can diarise events or make lists as necessary

**Tips for living**

In Jeffrey Gingold’s book ‘Facing the Cognitive Challenges of Multiple Sclerosis’ he talks about tips for living (2). He says,

- Maintaining clear thinking spaces in your life means saying ‘no’ to some requests which can often be difficult
- If a situation appears confusing, don’t be afraid to ask for clarification, reminders and direction
- When faced with a moment of ‘befuddlement’, don’t force it. Give yourself permission to pause and breathe calmly, relax and patiently gather your thinking focus. Allow yourself the time and mental space to ride out your temporary lapses in thinking
- Limit visual distractions and live an uncluttered life. Clear floors and table tops; organise shelves and drawers
- Keep lists for daily responsibilities and activities. Also keep a long term and a short term list for projects

I need to try and schedule “concentration” times to earlier in the day, when less tired
Each day

• Prioritise your activities
• Have a sense of purpose and accomplish something
• Renew and maintain bonds with family and friends
• Establish a minimum exercise routine
• Find ways to relax and soothe your mind to prevent or ease stress
• Remember to have fun and make it part of your daily routine
• Be patient with yourself by taking breaks and extra time to complete projects if necessary

“I was advised to start writing things in a notebook. I like to do crosswords to challenge my vocabulary skills.”

These are all important points to remember to begin to take control and manage your own cognitive function. Keeping your brain active with hobbies you enjoy such as reading, crafts, painting to name a few can really help to keep your brain healthy. Crosswords and jigsaw puzzles are a great tool to exercise your brain. It is important that these activities stretch your mind somewhat though. Reading is great, talking about the subject with others is better, writing about it is best.
Why stopping smoking is important

According to MS Brain Health, it is important to stop smoking when affected by cognitive issues. Cigarette smoking in people with MS is associated with decreased brain volume as well as higher relapse rates, increased disability progression, more cognitive problems and reduced survival compared with not smoking (12).

In a recent study presented at ECTRIMS 2019, it was found that smokers have reduced Processing Speed Test (PST) scores (which are used to assess cognitive functioning), compared to non-smokers. They also have more brain atrophy (13). The study looked at ex-smokers as well as current smokers. It was found that ex-smokers had significantly greater brain atrophy than those who had never smoked. This was an effect that was much greater in current smokers.

The doctor behind the study said how important it is for clinicians to discuss smoking management at every appointment and provide patients with the data to encourage them to stop smoking to reduce the risks and the negative impact on disease progression.

Planning for the future

If cognitive issues are becoming a problem in terms of managing your finances there are a few things you can do to help plan for the future.

Third Party Access and financial support

Third Party Access is when a trusted person is given access to your accounts to help you sort out your day-to-day banking. They can make sure your bills are paid on time by arranging direct debits for example; access to mobile or online banking can be helpful so you can go through it together.
Another option would be for a standing order to be set up where a fixed amount is paid regularly to your third party so they can withdraw money and pay bills for you whilst keeping a record of what they spend on your behalf.

Third Party Access can be set up at your bank and can be cancelled at any time.

**Lasting Power of Attorney (LPA)**

In some cases where cognitive issues have a significant impact on quality of life and can be a very disabling symptom, things can become more difficult. Life can become confusing, overwhelming and very isolating. In this instance it may be a good idea to have a LPA.

A LPA is a legal document that allows you to appoint one or more people, (or ‘attorneys’) to have the authority to help you make decisions or to make decisions on your behalf. The person/people appointed do not have to have any legal experience. They can be a family member, friend or people you trust who will always consider your preferences and to help you make your own decisions as much as you can. They should always make decisions in your best interests.

If there are high levels of cognitive issues meaning you cannot make your own decisions easily, you may be seen to ‘lack mental capacity’. Health professionals and social workers would be able to assess whether or not an individual lacks mental capacity. Therefore a LPA will be important in having control over what happens to you and your future.

**There are two types of LPA:**

- health and welfare
- property and financial affairs
You can choose to just have one LPA, or both. You can arrange LPAs via a solicitor or for people living in England, Wales and Scotland the forms are available online from the Office of Public Guardian. For people living in Northern Ireland you can contact the Office for Care and Protection.

Forms can be completed online and there is a fee to register each LPA made. Reductions and exemptions are available to those in receipt of certain benefits.

To read more, please visit the gov.uk website.
www.gov.uk/power-of-attorney

For more information on Third Party Access and LPAs please visit the following webpage from Citizens Advice.
www.citizensadvice.org.uk/family/looking-after-people/managing-affairs-for-someone-else/#h-ordinary-power-of-attorney
About MS-UK

MS-UK is a national charity formed in 1993 supporting anyone affected by multiple sclerosis. Our hope for the future is a world where people affected by MS live healthier and happier lives.

MS-UK has always been at the forefront of promoting choice, of providing people with all the information and support they need to live life as they wish to with multiple sclerosis; whether that be through drugs, complementary therapies, lifestyle changes, a mixture of these or none at all.

We will always respect people’s rights to make informed decisions for themselves.

The MS-UK Helpline

We believe that nobody should face multiple sclerosis alone and our helpline staff are here to support you every step of the way.

Our service is informed by the lived experience of real people living with MS, so we can discuss any treatments and lifestyle choices that are of benefit, whether they are clinically evidenced or not.
New Pathways

Our bi-monthly magazine, New Pathways, is full of the latest MS news regarding trials, drug development and research as well as competitions, special offers and product reviews. The magazine connects you to thousands of other people living with MS across the country.

Available in print, audio version, large print and digitally.

MS-UK Counselling

MS-UK Counselling is open to anyone living with MS and is the only service of its kind available in the UK. Whether you want support coming to terms with a diagnosis or to improve your mental wellbeing, our counselling service is focused on helping you.

All of our MS-UK counsellors are BACP registered or accredited with an in depth knowledge of MS.
Sources


(8) BMC Neurology. Nauta, Ilse M. Cognitive rehabilitation and mindfulness in multiple sclerosis (REMIND-MS): a study
Call 0800 783 0518       www.ms-uk.org/choicesleaflets

Visit www.ms-uk.org to find out more

www.acnr.co.uk/SO08/ACNRSO08_cognition.pdf


www.stayingsmart.org.uk/memory/tips-and-tricks


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