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Memory and thinking

Not everyone who has multiple sclerosis (MS) will experience problems with memory and thinking, but mild difficulties are common. For example, many people with MS find it harder to recall information, follow conversations or think things through. These are examples of cognitive skills – and there are many ways to cope with difficulties, some of which we will look at in this booklet.

Contents

- 02** What is cognition?
 - 02** How might MS affect memory and thinking?
 - 03** Am I the only one?
 - 03** What kinds of problems might I have?
 - 05** What impact might memory and thinking problems have on me?
 - 06** Can cognitive problems be predicted?
 - 06** Can problems get worse?
 - 07** What should I do if I suspect cognitive problems?
 - 08** Self-help or professional help?
 - 08** What is a neuropsychological assessment?
 - 10** Tips for dealing with problems with memory and thinking
 - 14** The effects on other people
 - 16** Further information
-

What is cognition?

Cognition refers to attention, language, perception, memory and thinking. It describes the way we:

- concentrate and focus attention
- multitask – do more than one thing at a time
- learn and remember new things
- reason and solve problems
- plan, carry out and monitor our own activities
- understand and use language
- recognise objects, assemble things together and judge distances

These skills vary naturally in different people – we all have different strengths and weaknesses. Our cognitive powers are considered to be normal if our skills allow us to cope adequately with everyday life.

How might MS affect memory and thinking?

Thought processes (such as remembering, concentrating and thinking) rely on messages being passed along nerves to different areas of the brain, and MS lesions can stop or slow down these impulses.

What kinds of things can affect memory and thinking?

- tiredness and fatigue
- relapses
- other MS symptoms (such as pain)
- trying to do two things at once, for example walking and talking (multitasking)
- emotional states, including depression, anxiety, stress, fear or anger
- brain lesions

Problems with cognition can be both temporary and permanent. Other things that can affect concentration, memory and thinking include high alcohol consumption, poor nutrition, infections and other illnesses, as well as medication that affects the central nervous system, such as tranquilisers, sleeping pills and painkillers.

Many people find that cognitive problems, like physical symptoms, seem worse when they are tired or fatigued. When you are very tired it becomes difficult to concentrate or take in new information. However, when your tiredness or fatigue is over, your memory should return to normal.

As with other symptoms, heat and fevers can cause memory and thinking problems to become temporarily worse. Depression, anxiety and distress can cause similar problems – if you feel low or depressed, you may find your memory and concentration are not as good as usual. As mood improves, these difficulties can also improve.

There's more information on pain, managing a relapse, fatigue, mood, depression and emotions and other symptoms on our website and in our information booklets.

A number of people with MS have to devote a good deal of thinking to how they will carry out physical activities. Most people don't have to think about how they walk or do other physical tasks – the body is usually on automatic pilot and the mind is free to think about other things. If you are giving more concentration to physical activities than usual, then it can be hard to maintain concentration elsewhere.

Am I the only one?

Not everyone with MS will experience cognitive difficulties. However, as many as 65 per cent of people with MS do have some form of cognitive changes. Mostly, the changes are mild to moderate rather than severe.

What kinds of problems might I have?

Like other symptoms of MS, cognitive symptoms vary greatly from person to person. Just because you have some cognitive symptoms, it does not mean that you will experience all of them.

Problems with language, visual perception (recognising what you see) and spatial relations (judging distances and position) are less common in people with MS. The most common difficulties are with:

Learning and memory

There are different types of memory and the brain organises these in different ways. MS most commonly affects remembering recent events and remembering to do things. Some people with MS also

say that it may take more time and effort to actively search for a memory. This is known as recall and it can often be affected. Fortunately there are lots of ways that you can compensate for these kinds of problems (see pages 10-13).

In contrast, recognition is rarely affected in MS. Recognition is the power to instantly remember something when you see or hear it remembering both what it is and the memories attached to it, without actually trying to remember.

People with MS rarely have problems with other types of memory and can remember skills (like riding a bike – things that are ‘second nature’), general knowledge or things about the past. Memory difficulties experienced by people with MS are not like the types of problems experienced by people who suffer from Alzheimer’s. Most often, people with memory problems due to MS continue to know who they are, have no major difficulties with communication and are able to carry out normal daily activities.

**Attention,
concentration and
mental speed**

Some people find it more difficult to concentrate for long periods of time or have trouble keeping track of what they are doing if they are interrupted (they ‘lose the thread’). It may also be more difficult to do several jobs at once or carry on a conversation while the TV or radio is on.

Many people describe feeling as though they can’t function as quickly as usual. They can still achieve tasks but it requires more time and effort than before. Research also suggests that the ability to process information may slow down.

**Problem solving –
planning, performing
and evaluating tasks**

Some people experience difficulties when making plans and solving problems. They know what they want to do but find it difficult to know where to begin, or find it difficult to work out the steps involved to achieve their goals. This can lead to confusion and stress, which in turn can hamper learning and memory.

Word finding

People with MS may also experience difficulties finding the right word. (‘It’s on the tip of my tongue’ – you know the word but just can’t think of it.) It may be difficult to take part in a discussion because it takes too long to express an opinion or find the correct word, by which time the discussion has already moved on.

What impact might memory and thinking problems have on me?

Cognitive problems have different meanings for different people, and this can affect the way they react.

- It can be frightening for some people to feel that they do not have a grip on things that used to come more easily.
- Sometimes people worry that they are 'losing it' or going mad, or that they are becoming stupid.
- It can cause problems in relationships or with family life.
- Some people feel that no-one will like them if they aren't as quick as they used to be.
- Some people fear they will lose their job, or that they won't achieve their career goals.

Cognitive changes can be worrying, and even mild changes might need specific coping strategies. If cognitive symptoms are not recognised, people can often feel very frightened about what is happening to them. Having good accurate information for you and those around you about the problems is usually the best form of defence.

Even when the changes are gradual, people can go through a grieving process when they first realise their mental abilities are affected by MS. It may take time before you can bear to think about ways of dealing with the problems, though there may be simple strategies that make a real difference.

For more on adapting to loss, see the MS Society booklet *Mood, depression and emotions*.

Employment

Even early on in MS, problems with cognition can have an impact at work. In fact, research has shown that cognitive issues are a major reason why people with MS might stop working.

As a person with MS, you have certain rights at work, which are set out in the Equality Act 2010 (if you live in England, Scotland or Wales) and the Disability Discrimination Act 1995 (if you live in Northern Ireland).

These laws state that if the symptoms of MS are affecting you and your ability to do your job, you have the right to ask your employer for 'reasonable adjustments' so you can continue to work.

There is more information about reasonable adjustments in the MS Society booklet *Work and MS*.

You may also find the tips for dealing with problems with memory and thinking on pages 10-13 of this booklet helpful.

Education

The same laws also apply if you are studying at college or university. They ensure that you are not discriminated against because of your MS, for example, by giving you more time to complete assignments or by providing study areas that are free from distractions. Most universities and colleges now have a dedicated member of staff to help with any issues you may have.

If your cognitive problems mean you need to buy extra equipment to help you with your studies, there are grants available, called Disabled Students Allowances. To apply, contact Student Finance (England Northern Ireland and Wales) or the Student Awards Agency (Scotland). [i](#)

Can cognitive problems be predicted?

Studies into cognitive problems in MS have shown conflicting results. It is not clear whether there is a link between cognitive problems and other symptoms of MS, how long you have had MS, how severe your MS is, or what type of MS you may have.

Cognitive problems are therefore difficult to predict and may occur in individuals who are newly diagnosed as well as those who have had MS for some time. Some people may have mild physical symptoms but have significant cognitive problems.

Can problems get worse?

Cognitive problems do not always get worse. Like other MS symptoms, cognitive difficulties may become worse, or stay about the same. For some people, they might improve. Some people may eventually develop severe cognitive problems, but most people do not.

If they do become worse, the rate of progression is usually fairly slow. This means that you can develop strategies to help you manage your symptoms.

Physical symptoms such as poor speech, poor coordination or rapid involuntary movements of the eye (nystagmus), are sometimes mistaken as visible signs of cognitive symptoms. No connection has been shown between these symptoms and cognitive performance.

What should I do if I suspect cognitive problems?

The first signs of cognitive dysfunction may be subtle. You may have difficulty in finding the right words to say, or trouble remembering what to do on the job or during daily routines at home. It may be that your family or friends become aware of the problem first, noticing changes in your behaviour or personal habits.

Even mild cognitive disturbances can cause uncertainty and fear. It is worth remembering that these are symptoms of MS and that there are ways of managing them.

If you are aware of even mild symptoms, you can try to find ways to cope with and compensate for them. On the other hand, the knowledge that MS can cause problems with memory and thinking may result in being too aware of minor memory lapses. Everyone forgets things from time to time; it's only a problem when the forgetfulness becomes more frequent than usual and has an impact on what you would like to do.

If you have repeated difficulties with your memory (for example, forgetting names and places, losing objects, struggling to remember familiar words), in ways that did not happen before, a first step may be to discuss this with your GP. It may be a symptom of MS or it may be due to other causes.

If, as a relative, you notice signs of cognitive problems, you may find it hard to talk openly about them. However, it can often be a relief for the person with MS when someone else brings up the subject. It can help with identification of their difficulties (and yours) and make it possible to talk about them as well.

Once problems are spoken about, they may be easier to deal with. We list some tips on pages 10-13. You may find a professional evaluation helpful, to find the extent and limits of these problems.

Self-help or professional help?

There are various ways you can manage some of these symptoms. For example, if your problem is attention, recall, organisation or planning, you may be able to apply some of the tips on pages 10-13 to help.

There are apps available through your mobile phone to help you remember appointments and other bits of information. Or you may decide to start using a calendar or a diary.

These are simple changes to make if you know what the problem is. Sometimes, however, you may need a professional to help you identify the areas where you could use some help. If you decide to ask for professional help, your GP should be able to refer you to an occupational therapist, who can help you think about ways of managing your symptoms and suggestions on equipment and aids that may help. Or you can ask your GP or MS nurse to refer you for a neuropsychological assessment with a clinical psychologist.

What is a neuropsychological assessment?

A neuropsychological assessment is used to find out what cognitive problems you are having. It may include a number of different spoken and written tests on areas such as attention, memory and problem solving. For example, you may be given a list of words to remember and recall.

What happens in a neuropsychological assessment?

The assessment usually takes about two to three hours, with a follow-up session for feedback. You will be asked to perform a number of tasks that are designed to test your ability to remember, concentrate and do things that you used to find easy.

For each task the instructions are explained and then you try to complete the task. For example, the task may be to remember a story that is read out.

The assessment will try to identify both the specific problems you are experiencing as well as your personal strengths that you can use to help you overcome and manage any weaknesses.

A psychologist will take into account whether you are depressed, unusually stressed or undergoing a relapse.

What happens after the assessment?

After the assessment, you may be offered different ways to help you manage any problems identified. This could include:

- practising and improving any weakened skills

- making better use of your strengths
- finding alternative ways to perform tasks
- finding ways to cope with limited abilities (both practically and emotionally)
- counselling (for you or your relatives)

Individual goals may be set, for example, to restore or improve your ability to work, to encourage and support future education, or to improve your general performance on tasks.

You may be offered individual or group sessions. Often a partner or family member will also be invited to attend – people close to you may also have concerns about your difficulties and the effects on family life. They may be able to help you put in practice new strategies and techniques.

If your problems appear to be progressive, practising weakening skills may seem a waste of time. However, recognising and understanding what is going on and reorganising the way you do things may still make it easier to cope.

It is often useful to learn to make the most of the skills that you are good at and to practise using different types of aids to help you. For example, a memory aid like a diary may help you stop worrying that you have forgotten something. Also, writing things down or putting them in your mobile phone can help to fix them in your mind.

Cognitive rehabilitation

Cognitive rehabilitation is a way of relearning the cognitive skills you have lost. It is provided by occupational therapists and psychologists in either a group setting or one to one. There is some evidence to suggest it may improve attention, memory and problem solving. It can also have a positive effect on people's mood.

Drug treatment

Not much has been written on the effects of disease modifying drugs on cognitive problems. The possibility that they may slow cognitive decline, may support the move toward early treatment, but more research is needed to confirm this.

For more about disease modifying drugs see the MS Society booklet *Disease modifying drugs*.

There are no drugs licensed specifically for cognition problems in MS, but sometimes, drugs that have been licensed for Alzheimer's may be prescribed. There have been a few clinical trials to assess how effective they are in MS. They did not show conclusive evidence that these drugs benefit people with MS.

Tips for dealing with problems with memory and thinking

If you're having problems with memory and thinking, there are strategies that you can use to help.

It may feel upsetting or difficult to have to rely on these strategies if you have not done so before. But many people find that once they get used to using them, they feel more confident in managing these symptoms.

We've listed some common problems that people with MS might have, with tips for how to deal with them. Of course, your problems might not be exactly the same. It's important that you're aware of your own strengths and weaknesses, so you and your family can find ways around the difficulties. As you practise different strategies, they will soon become part of your everyday life.

I forget things easily

- Many people forget things and getting stressed or upset about it will make it even harder to remember things. Relax, take a few moments to calm down – try slow, deep breathing or other relaxation exercises. Your memory will sometimes clear.
- Different people remember things in different ways. As well as writing things down, you might find recording them onto a mobile phone or Dictaphone helps.
- Many modern mobile phones have built in reminders, alarms and calendars that you can use. You can also use emails to send reminders to yourself.
- Rhymes, rules or phrases may help you remember things. For example using a mnemonic such as 'Richard of York gave battle in vain' to remember the colours of the rainbow, or 'i before e except after c' to remember the order of letters. You could make up your own that are relevant to you.

I have trouble keeping track of what I'm supposed to do during the day

- You may find that keeping a diary – either electronic or paper – to write down everything you plan to do during the day can help. Similarly, using an organiser, calendar or alarms on a mobile phone can help.
- If you have a smartphone, there are many apps available to help you remember appointments, names and places. You could even use the camera to help remember people, places and activities.

There are probably many other apps which can help too. Remember, it is normal to need help keeping track.

- If you prefer, you could try using a Dictaphone to record notes to yourself.
- Try to establish a routine for doing things, so there's less for you to actively remember.
- A whiteboard or chalk board in your home may be a good place to jot down notes to yourself.

I sometimes forget to take my medication

- Set reminders for yourself at the time you're supposed to take your medication. You could use your mobile phone, a wristwatch with a beeper, your computer or an alarm clock.
- Putting notes or Post-its in obvious places can help. For example, if you take your tablets in the morning, a note stuck to the bathroom mirror might be enough to remind you.
- A tablet organiser may also help. Some tablet organisers have alarms to remind you when to take your medication.

I find it hard to remember what I need to buy at the supermarket

- You could try making a master shopping list of things you regularly buy and printing off multiple copies. Before going to the shops, check the list and tick off the items you've run out of.
- If you do your shopping online, most companies allow you to save 'favourites' for each time you return.

I can get lost easily, even when I'm going somewhere I've been before

- If you're driving, try using a GPS device or 'sat nav'.
- If you're on foot, many modern mobile phones have a map function.
- Visualising can also help. For example, don't just learn the directions for getting to the library – picture the route. You can use a camera to take photos of the route in case you forget it.
- If you find you forget where you park your car while out shopping, you could try attaching something to the car aerial to help you see it.

I put things down and forget where I've put them

- Have a set place for essential things – like car keys, or your glasses – and always put them there.

- If you find you're still misplacing important things, keep everything in one place – for example, in a canvas tidy over the kitchen door. Label the pockets to make it easier to know what should go where.

I find it hard to keep track of what everyone in my family is doing, and where they are

- You could try placing a large family calendar in a prominent place, such as the fridge door, where everyone in the household can write down what they're doing and when. Check things off as they are finished.
- Ask your family to remind you what they are going to do, and what they have done, especially things that matter, such as doctor's appointments.

I'm easily distracted, and sometimes forget what I'm doing in the middle of doing it

- Focus on one thing at a time. Turn off the TV or radio, and try to reduce other distractions when you're talking to someone or working on a particular task.
- Try working somewhere where you are less likely to be distracted by other people. Turn your phone off, or put it onto voicemail or answer phone, so you're not interrupted.
- Tell people that you are easily distracted, and ask them to take this into account when they speak to you.

I can't always find the words I want to say – it's like they're on the tip of my tongue

- Try using other words, or describing the word you want to use. Stressing about finding exactly the word you want to use is likely to make it harder for you to come up with it.
- Tell those close to you about your word-finding problems, and how you would like them to help. Do you want them to prompt you or not?

I find it really difficult to concentrate sometimes

- Fatigue and tiredness can both affect concentration. Plan your work so that you're doing your most demanding tasks when you're at your best.
- Pace yourself, and give yourself regular breaks.

- Focusing on one task at a time can make it easier to concentrate.
- Try to work out what else affects your concentration: room temperature? Time of day? Amount of sleep? Presence or absence of particular people? Take this into account.

Following a conversation can be hard for me

- Letting people know that you're struggling can avoid any misunderstandings. You can ask people to speak slower, or one at a time if it makes it easier for you.
- Impose a delay in the conversation and ask others to respect it. That way you have time to gather your thoughts together before expressing them.
- If you find it easier talking one to one, consider asking people to talk to you on their own.

I find it hard to think when I'm put 'on the spot'

- Ask for – or give yourself – more time to take in or retrieve new information. Tell other people that you may be slower, but that you will get there in the end.
- Try to plan ahead as much as possible, to avoid situations where you will have to respond very quickly.
- As in other situations, try to relax. Panicking is likely to make your memory and thinking problems even worse.

When I get too hot, my thinking gets muddled

- There are a number of things you can do to stay cool – such as having regular cold drinks, or sucking on an ice cube or frozen fruit, or spraying cold water on your face and wrists.
- A floor or desk fan can help to keep the temperature down and the air flowing in a room.
- Specific cooling items are available, including cool scarves, ties, wristbands, hats and vests. An ice pack wrapped in a cloth inside a hat helps some people.
- Avoid hot baths if you need to think afterwards.

The effects on other people

When someone with MS has cognitive difficulties, it can affect everyone around them. Friends and family might go through a range of reactions, including anger, frustration, worry and fear.

These reactions may come partly from misunderstanding cognitive symptoms. It can be hard to understand why someone can manage some things and not others. Someone experiencing memory loss often feels guilty about it, and people close to them often feel guilty too, because they can't be tolerant and forgiving all the time.

Family members and other people close to them need to recognise that cognitive problems are not under the person's control. You wouldn't blame someone for having problems walking because of their MS, so don't blame them for forgetfulness. Discussing things openly can help people to accept changes and work out how to manage them together. Some people find counselling or psychotherapy for the whole family can address behavioural changes and emotional responses, and help to develop realistic expectations.

See the MS Society booklet *Living with the effects of MS* for more information.

Below are some common issues and suggestions for tackling them. Other people with MS might also have their own suggestions of things that work for them. The discussion forums on the MS Society website can be a good way to find out from other people what works for them.

- Someone who knows you well may 'fill in' for you when you forget something or don't answer a question right away. You may be comfortable with this, or you may not be. It is important to tell other people how you would like them to react.
- Other people may get frustrated when you don't answer a question as quickly as you did before, or if you give a confusing answer.
- If you are having problems during discussions, it is a good idea to tell family members and friends about these rather than trying to cover them up.
- Other people may think you are awkward when you just can't think straight or can't remember something – particularly if there are times when you don't experience problems like this. You might need to explain to people about MS symptoms coming and going – and to remind them that MS can cause 'invisible' symptoms, such as cognitive problems, as well as more obvious difficulties.

- Other people may think you don't care about them if you forget to ask about something important.
- If you are angry about what is happening to you, you may take your anger out on others without realising you're doing it.
- It is a good idea to talk about your feelings to those who are close to you.
- As well as talking to them, you might want to share this booklet or the MS Society booklet *Living with the effects of MS*.
- Other people may become angry, depressed or anxious about your cognitive problems and be afraid of losing you. This may make them irritable or withdrawn.
- The person you are closest to may feel muddled and confused themselves, as if they have 'caught' some of your difficulties with thinking clearly.
- They may feel better and be able to think more clearly if they have someone to talk things over with.

An MS nurse, counsellor, psychologist, occupational therapist or other professional might be helpful in this.

Further information

Read more

Our free booklets help explain MS, look at its practical and emotional effects, and help you find your own ways to manage life with MS. Titles are available in large print, audio format and a number of languages. For copies, email shop@mssociety.org.uk or call 020 8438 0999.

We can help you find and borrow other books, research articles and DVDs about living with MS. Search online or call the librarian on 020 8438 0900.

Find out more online

Get the latest on research, campaigns, and MS news. Chat online with our message boards and Facebook. Follow us on Twitter, see the MS community at Flickr and watch us on YouTube.

Join us

Just by being a member you strengthen the voice of all people affected by MS. For just £5 a year you will receive our national magazines – *MS Matters* and *Research Matters* – local newsletters and details of local events, as well as being able to vote on how we are run. Help us continue our vital work and join online at www.mssociety.org.uk/joinus or by calling 020 8438 0759.

Get in touch

The Freephone MS Helpline offers confidential emotional support and information for anyone affected by MS, including family, friends and carers. Information is available in over 150 languages through an interpreter service. 0808 800 8000 (weekdays 9am-9pm) or helpline@mssociety.org.uk

Near you

Our volunteers run over 300 local branches and support groups. They provide information about MS and local services, and a chance to meet others affected by MS and take part in a range of activities.

In many parts of the country, you can pick up our booklets at MS Society Info Points. Larger information centres – including ones in our national offices in London, Belfast, Cardiff and Edinburgh (Newbridge) – can help you with information about MS and services in your area.

Or come along to our local and national events and learn more about MS from expert care professionals, researchers and other people with the condition. Find out more online or call your national office.

Other organisations

Websites

www.stayingsmart.org.uk

An online project from the MS Trust and Royal Holloway, University of London. Learn more about cognitive challenges in MS, and build confidence in managing them.

www.meetinglifeschallenges.com

Website set up by Shelley Peterman Schwarz, author of Memory tips for making life easier, to offer practical information to people with chronic illness. Includes a radio interview with Jeffrey N. Gingold, author of Mental sharpening stones (search 'Jeffrey Gingold').

www.msql.org.uk

Set up by Dr Anita Rose, Clinical Psychologist, Walton Centre of Neurology and Neurosurgery, Liverpool to help people understand the cognitive problems that may happen because of MS.

References

A list of references is available on request, and all cited articles are available to borrow from the MS Society library (there may be a small charge). Contact the librarian on 020 8438 0900, by email on librarian@mssociety.org.uk, or visit www.mssociety.org.uk/library

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Suggestions for improvement in future editions are welcomed. Please send them to infoteam@mssociety.org.uk

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The MS Society provides this information free of charge but if you would like to help cover the cost, which will help towards our essential work, please call 0800 100 133 or visit the fundraising section of our website to make a donation. Anything you can give will be greatly appreciated.

MS Society

100,000 people live with multiple sclerosis in the UK. Every one of them shares the uncertainty of life with MS.

The MS Society is the UK charity fighting to improve treatment and care to help people with MS take control of their lives.

We're a world-leading funder of MS research. We've already made important breakthroughs, and we're now at the start of a generation of MS research that holds incredible promise.

With your support, we will beat MS.

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