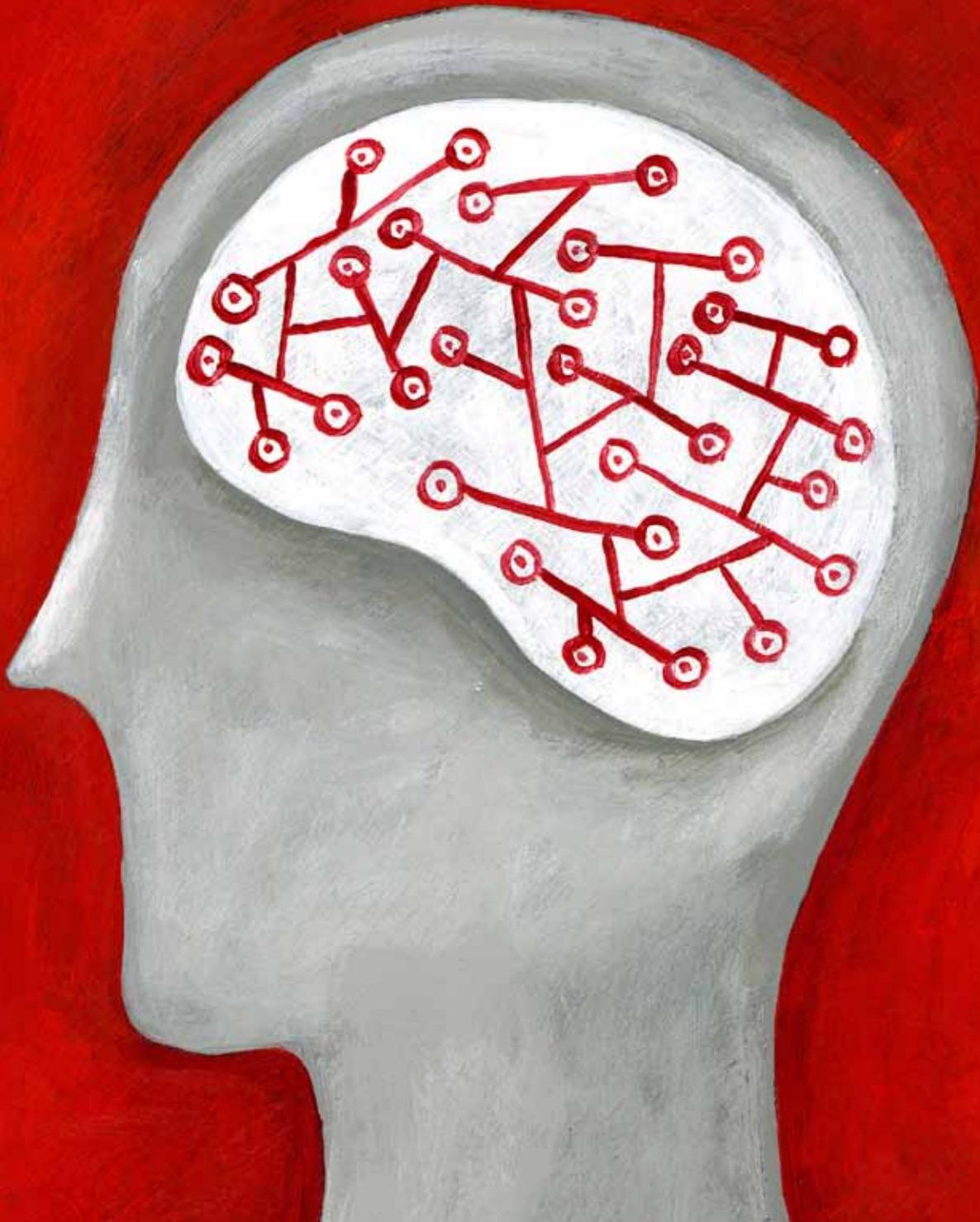


MS *in focus*

July 2013

MS and cognition



multiple sclerosis
international federation

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Multiple Sclerosis International Federation (MSIF)

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Our objectives are to:

- Stimulate and facilitate international cooperation and collaboration in research into the understanding, treatment and cure of MS
- Support the development of effective MS organisations
- Communicate knowledge, experience and information about MS
- Advocate globally for the international MS community

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ISSN1478467x

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Letter from the Editor



It was only in the 1970's that researchers began studying the neuropsychological aspects of MS using healthy control groups for comparison. Early studies demonstrated that processing and memory were affected in people with MS.

Today we know that mild cognitive impairment is quite common in MS and can be present at any stage of the disease. We know that physical disability is not always correlated with cognitive impairment. We know that MS can affect memory, attention and concentration, information processing, executive functions like planning and prioritising, visuospatial functions and verbal fluency. Equally importantly, MS experts have become skilled at distinguishing the different factors that can be mistaken for cognitive impairment, like fatigue, stress, depression or medication side effects. Health care professionals have also become more sensitive about how they discuss cognitive issues.

Health care professionals also need to be flexible and creative when providing new information or teaching new skills to a person with MS who has cognitive difficulties. It is important for any professional or para-professional (a personal assistant, for example) working directly with people with MS to understand the cognitive challenges that many people face.

For people with MS, understanding that MS-related cognitive difficulties are common but that severe impairment affects a small percentage of people is important. Experiencing memory or concentration problems can be isolating and frightening. There may be a concern about loss of employment or alienation from family or friends. In reality, once the deficits are clarified, often through testing, the individual can work with their health care team to find compensatory strategies that best fit with their lifestyle.

This issue of *MS in focus* discusses all of these aspects and more. Our hope is to provide health care professionals and people with MS with a complete picture of cognition and MS that includes physiology, diagnosis, treatment and day-to-day living with cognitive challenges.

We look forward to receiving your comments.

Michele Messmer Uccelli, Editor

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The next issue of *MS in focus* will be on Information Technology and MS. Please send questions and letters to michele@aim.it or marked for the attention of Michele Messmer Uccelli at the Italian MS Society, Via Operai 40, Genoa, Italy 16149.

Editorial statement

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Introduction to cognition and MS

Dawn Langdon, Department of Neuropsychology, Royal Holloway University of London, United Kingdom

Jean-Martin Charcot (1825-1893), pictured below, was the first neurologist to formulate clear ideas about the clinical features and pathology of MS, including cognitive symptoms: "...there is marked enfeeblement of the memory; conceptions are formed slowly; the intellectual and emotional faculties are blunted in their totality...". However, for the next hundred years there was little acknowledgement of cognitive difficulties in MS and limited attempts to assess or manage them.

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Jean-Martin Charcot

What are the cognitive difficulties associated with MS?

Since the 1950s there has been growing awareness of how reduced memory and concentration, called "cognitive difficulties",

are an important part of the MS experience for many people. These cognitive issues can affect people's lives over and above the constraints caused by physical disability. For example, people with MS with cognitive difficulties are less likely to be employed. They are likely to have reduced social and leisure activities. The quality of their relationships may be reduced. They find it harder to manage their disease, in terms of symptoms, medication and general medical decisions. There are also safety issues, with increased risks of falls and driving accidents. Overall, cognitive aspects of MS have a very real negative impact on the quality of life of some people with MS.

There is a distinctive pattern of cognitive difficulties in MS, sometimes called "the footprint of MS". Not everyone will have this same experience, but it is by far the most common. It is likely that the first – and in time the most severe – cognitive domain to be affected is information processing speed. This will be most noticeable in terms of reduced concentration or finding it hard to stay on target in a noisy or distracting environment. This is thought to be because the disease process of MS results in the myelin insulation of nerve fibres being stripped away. The electrical impulses along the nerves cannot travel as fast or reliably as before. It is as if the internal internet slows. Some experts think that this reduced information processing speed is the underlying reason for all cognitive difficulties in MS.

It is likely that the first cognitive domain to be affected is information processing speed.

Other types of mental ability may also be affected. Memory can be less reliable, particularly when remembering to do something. There can also be reduced efficiency in planning and organisation.

By working together in a collaborative and effective way, with open communication and information exchange, optimal outcomes can be achieved.

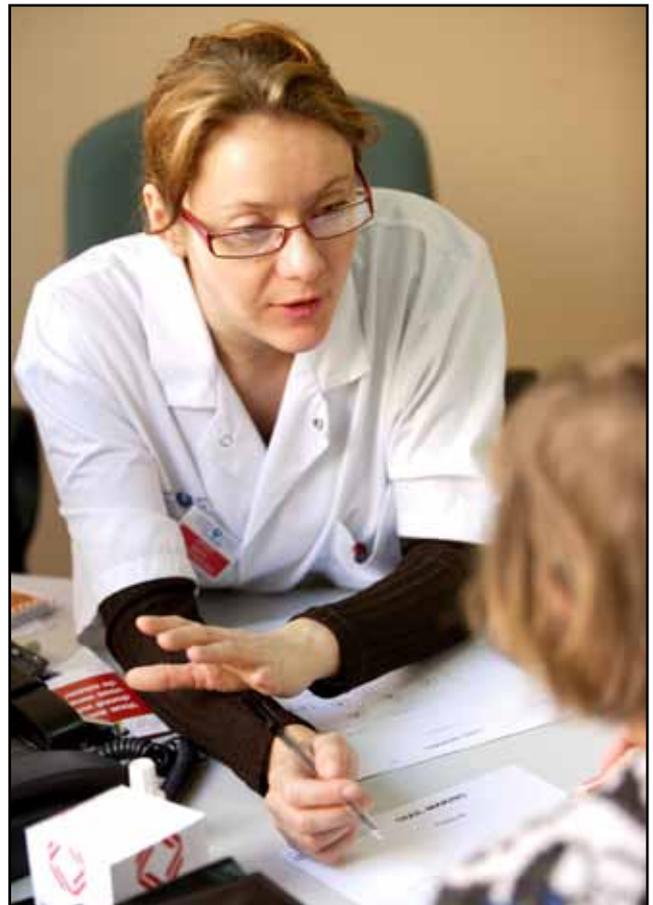
Problem solving may be more challenging, often because awareness and consideration of a range of options becomes harder to maintain. Seeing through the implications of choices and actions may also not be as clear as before, leading to decisions that are not optimal for the person, their family, their job or their health.

The good news is that language skills tend to be relatively unaffected by MS. Thankfully, communication remains an important part of maintaining relationships with family and health care professionals, and it means that support and advice can be easily obtained and provided.

Addressing cognitive difficulties

The first stage in addressing cognitive difficulties is assessment. Cognitive scales have been developed that target the aspects of cognition which are most likely to be affected by MS. They work by comparing the performance of the person with MS against the performance of healthy people. In this way, areas of weakness and strength can be identified. These test scores need to be carefully considered and integrated into the particular circumstances of the individual with MS.

Most people have a life that is a rich and unique tapestry. The experience of the person with MS, including any current difficulties, their family and employment expectations, what is important to them in terms of leisure and their identity, need to be fully explored and understood. It may be necessary to also collect information from family



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and workmates. This information must then be integrated to provide a complete picture of the current situation, as well as the challenges and goals of the individual with MS.

The next stage is to develop a plan of action, involving all interested parties. At the minimum, it should include the individual with MS, possibly their family and workmates and also health care professionals with the expertise to assist with the treatment plan. Part of this process may be giving information and support to the individual with MS and their social circle. By working together in a collaborative and effective way, with open communication and information exchange, optimal outcomes can be achieved.

Practical management

Any management plan is bound to include many aspects. As well as counselling and support, there may be specific goals to address. The cognitive aspects of MS may be implicated in managing physical symptoms. For example, a woman who works on a bank counter with continence issues may need guidance and support in developing strategies for scheduling visits to the bathroom that do not disrupt her work. Her anxiety and reduced problem solving mean that she has not been able to manage her continence optimally, but with appropriate help she can be back in control.

The cognitive aspects of MS may be implicated in managing physical symptoms.

Some challenges are more directly about cognition. For example, a person with MS who works in a busy, noisy office may find that tasks are more

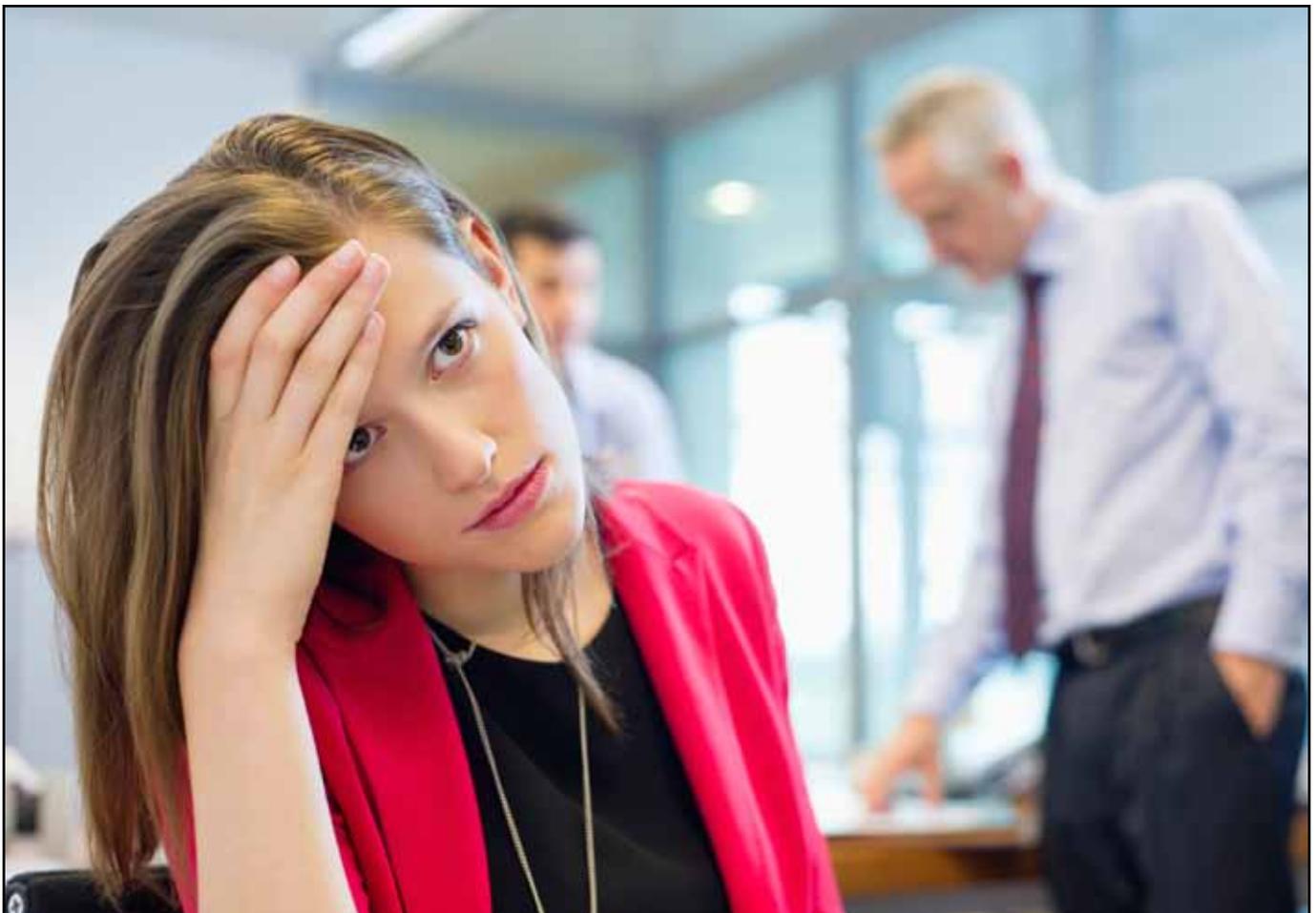
difficult to complete because of all the distractions around them which they find hard to shut out. By moving their desk to the edge of the room and a quieter corner, the distraction is reduced.

Another example might be a person with MS who works in a job with a deadline at the end of each month, for example an accountant. Maintaining concentration over extended periods to complete detailed work may become harder if the person has cognitive difficulties.

A solution might be to structure work leading up to a deadline so that all the work is not required during such a concentrated period. Setting up a pacing schedule so that rest periods alternate with periods of high concentration is helpful.

In this way, the quality of work may be maintained and the stress, anxiety and fear of failure of the person with MS is removed.

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Physiology of cognition in MS

Päivi Hämäläinen, Masku Neurological Rehabilitation Centre, Masku, Finland

What are cognitive functions?

Cognitive functions include the ability to:

- focus, maintain and divide attention
- learn and remember things
- plan, carry out and monitor activities
- think, reason and solve problems
- understand and use language
- recognise objects, assemble things together and judge distances.

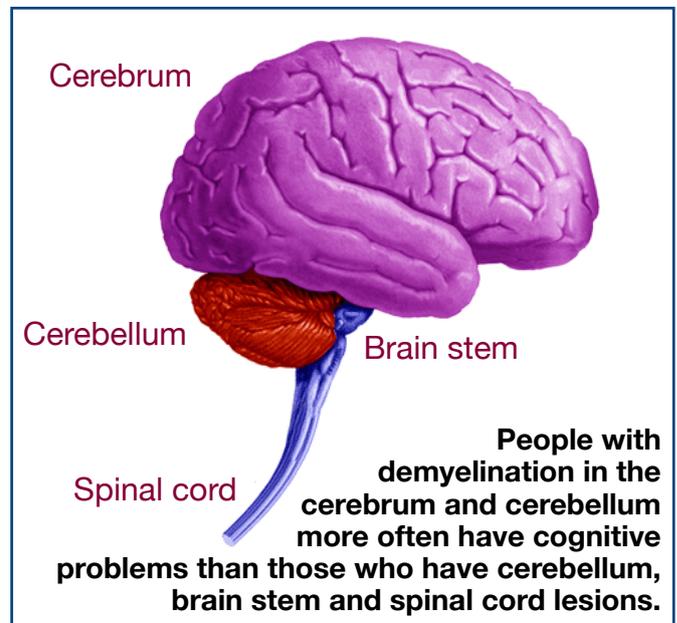
These abilities develop very individually between different people and we all have our personal cognitive strengths and weaknesses.

The physiology of healthy cognition

Cognitive performance requires that the cerebral and cerebellar neural network function efficiently. Intact cognitive functioning is a result of a complicated network of specific cognitive abilities that function together in an optimal way. Factors like depression, stress and tiredness can interfere with the functioning of the network and cause temporary cognitive difficulties. When a person is very tired, memory and concentration may not function normally. When tiredness or other factors interfering with cognition pass, cognitive performance returns to a normal level. In normal ageing, only subtle changes in cognitive performance is observed before the age of 70 years and these changes normally do not interfere with daily functioning.

What happens in MS?

In MS, lesions (or plaques) caused by demyelination appear in the central nervous system (CNS), in the spinal cord, cerebrum and/or cerebellum. Lesions in the cerebrum can particularly affect the neural network's ability to efficiently perform cognitive functions and, for example, can slow down a person's performance in cognitively demanding tasks, such as memory retrieval, the ability to concentrate on a task, or the ability to plan tasks, making these activities difficult.



Studies have shown that people with greater MS lesion burden have more cognitive problems than those individuals with less lesion burden. Measures of brain atrophy, width of the third brain ventricle, and subcortical atrophy seem to be related to cognitive impairment in MS. It seems that in people with MS, more widespread areas of the brain are activated when doing a cognitive task. This has been interpreted as a compensatory mechanism to account for the effects of cognitive impairment.

How common is cognitive impairment in MS?

Cognitive problems are relatively common in MS, with prevalence rates ranging from 40-70 per cent without any clear differences between genders. It is estimated that about 40-50 per cent of people with MS have mild to moderate disturbances, while about 10 per cent have more severe cognitive deficits.

What kind of cognitive impairment is associated with MS?

Like other symptoms of MS, cognitive problems vary greatly from person to person. Although MS is characterised by both white matter and grey matter

Cognitive impairments and their approximate frequency rates in MS

Impairment	Approximate Frequency
Memory, new learning	30-60%
Information processing	40-50%
Complex attention	25-35%
Executive functions	20-30%
Visual perception, word fluency	10-20%
Severe, widespread cognitive decline	<10%
Cognitive fatigue, neuropsychiatric symptoms	not well known
Cortical deficits (amnesia, aphasia, agnosia)	single cases

changes of the CNS, a severe decline of general cognitive functioning (dementia) is rare in MS.

The most common cognitive impairments in MS include difficulties in memory and learning, information processing, complex attention and concentration, and executive functions (problem solving, planning, performing and evaluating). Many people with MS will experience one or two of these problems, but others may function normally with no cognitive problems.

The most common type of memory problem is a difficulty in the initial learning of information. People with MS may need to hear information more than once to learn it, but once the information has been acquired, recall and recognition function normally.

Information processing efficiency refers to the ability to maintain and manipulate information in the brain for a short period (working memory) and the speed with which a person can process that information (processing speed). Reduced speed of processing is one of the most common cognitive problems in MS.

Basic attention (for example, the ability to repeat numbers) is typically unaffected in MS while problems in sustained and divided attention are more common. It may be difficult for a person to concentrate for long periods of time or to keep

track of what they were doing when interrupted. It may also be difficult to do several tasks at the same time or to carry on a conversation if there is background noise (for example, from a television).

When concentrating on something for a longer period of time, people with MS often report mental fatigue. The feelings of fatigue and deterioration of cognitive performance do not, however, go hand-in-hand, and the frequency of cognitive fatigue is not well known.

Some people experience difficulties in executive functions, especially when making plans and problem solving. People usually know what should be done but find it difficult to know where to begin or have difficulty working out the steps involved in achieving their goals. It may be especially difficult to manage changes required for completing a task if the initial plan needs to be altered or becomes too cumbersome.

People with MS may also experience word finding difficulties and often report "it is on the tip of my tongue". They know the word but cannot think of it. MS can also be related to other types of cognitive problems and occasionally to behavioural changes. However, deficits in language, simple attention, or visual perception and changes in behaviour are not as typical in MS.

Can cognitive deficits be predicted?

The appearance of cognitive impairment cannot be predicted on the basis of other symptoms of the disease. Cognitive problems do not seem to be clearly related to variables such as disease duration or the severity or type of the disease. Cognitive deficits may occur as often during the early stages of the disease as later on, in people with MS with mildly or severe disability, and in each subtype of MS.

It seems that cognitive activity may protect people with MS from cognitive problems. In a recent study, educational activity and good reading skills seemed to protect an individual from cognitive impairment. Therefore, it is important that people use their cognitive capacities by continuing to read and self-educate themselves, keeping socially active and living a healthy lifestyle that includes exercise.

Does MS-related cognitive impairment progress?

Few studies have examined the characteristics of cognitive changes in MS over time. It has been found that cognitive performance can vary during even short follow-up periods. Studies show that if people experience some cognitive problems, it is

possible that they may become worse, although the rate of progression is individual and usually slow.

Are cognitive problems always permanent?

While brain lesions can result in more permanent cognitive problems, a number of factors can temporarily interfere with or impair cognition. These factors include fatigue and tiredness, emotional stress, relapses, physical restrictions, medication and lifestyle changes.

Living with a chronic, progressive and unpredictable disease does have an effect on mood. When people are depressed or feeling low, they can suffer memory lapses or problems with concentration. These difficulties are not usually long-lasting.

Many people with MS experience cognitive problems during periods of fatigue. Recent studies show that cognitive performances may slow down or be less accurate during periods of fatigue. Temporary cognitive deficits may also occur during relapses. Like physical symptoms, cognitive problems may be restricted to the active inflammation phases of the disease.

Many factors can affect cognitive functioning



Diagnosing cognitive problems

Bruno Brochet, Service de Neurologie, CHU Pellegrin, Bordeaux Cedex, France

When cognitive problems need to be addressed

Evaluating cognitive function should be part of the regular assessment of neurological functions for people with MS. It should be done at the early stages of MS and contribute to the evaluation of the disease prognosis. Sometimes a cognitive evaluation is performed to detect cognitive problems that need intervention or support.

Typically however, cognitive testing is requested when a person with MS notices difficulties in their memory or attention. These complaints may not predict the actual cognitive functioning of

the person because they are frequently driven by mood disturbances or anxiety. The Multiple Sclerosis Neuropsychological questionnaire may help to identify cognitive problems but it is only reliable when filled in by someone who knows the person well, like a caregiver or a close family member. The emergence of difficulties at work, or in accomplishing complex tasks in daily life, often also justify a cognitive evaluation.

Which tests are commonly done to assess cognitive function?

The evaluation of cognition function requires several neuropsychological tests focused on

Neuropsychological test batteries used in MS

Batteries:	BRB-N	MACFIMS	BICAMS
Functions:			
Attention	SDMT	SDMT	SDMT
Working memory	PASAT	PASAT	
Executive functions		D-KEFS sorting test	
Verbal episodic memory	SRT	CVLT-II	CVLT-II
Visuospatial episodic memory	SPART (10/36)	BVMT-R	BVMT-R
Language	WLG	COWA	
Spatial processing		JOL	

KEY: BRB-N: Brief Repeatable Battery for Neuropsychological evaluation; MACFIMS: Minimal Assessment of Cognitive Function in MS; SDMT: Symbol Digit Modalities Test; PASAT: Paced Auditory Serial Addition Test (3- and 2-second versions); D-KEFS sorting test: Delis Kaplan Executive Function System sorting test; SRT: Selective Reminding Test; CVLT-II: California Verbal Learning Test, second version; SPART: Spatial Recall test; BVMT-R: Brief visuospatial memory test, revised version; WLG: Word list generation; COWA: Controlled Oral Word Association Test; JOL: Judgement of line orientation test.

specific cognitive domains like memory, attention and processing speed. Two specific groups (or 'batteries'), of neuropsychological tests, the Brief Repeatable Battery for Neuropsychological evaluation (BRB-N) and the Minimal Assessment of Cognitive Function in MS battery (MACFIMS), have been proposed by experts because they combine tests that evaluate the cognitive domains usually concerned in MS. They have several tests in common but the MACFIMS assesses more domains (see table, left). The MACFIMS can be administered in approximately 90 minutes and the BRB-N in about 35 minutes.

These evaluations are carried out under the supervision of a trained neuropsychologist who is able to analyse the results, taking into account the clinical context and possible confounding factors, such as depression, fatigue and anxiety. The BRB-N explores attention, working memory, verbal and visual episodic memory and language fluency. In addition, the MACFIMS assesses executive functions and spatial processing.

The Symbol Digit Modalities Test (SDMT), pictured below and described on page 13, is a test that

most frequently demonstrates impairment. This test is mainly related to information processing speed (IPS), and is able to accurately identify people with MS who have IPS impairment.

Recently, the BICAMS, comprised of three tests including the SDMT, a test of episodic verbal memory (first five recalls of the California Verbal Memory Test-II) and a test of visual episodic memory (first three recalls of the Brief-Visual-Memory-Test-R), has been proposed as a brief assessment tool for practicing neurologists.

These three batteries (BRB-N, MACFIMS and BICAMS) differ mainly by the number of tests and the domains studied. The clinician determines which battery to use based on the clinical context and the objectives of the evaluation.

Cognition tests and MS treatment trials

Cognitive testing has not been performed systematically in clinical trials of disease-modifying therapies (DMT), and where it has been included, cognition was usually a secondary or a tertiary outcome measure.

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Format and example of stimuli similar to those used in the Symbol Digit Modalities Test

The effect of DMT on cognition has mainly been measured by the Paced Auditory Serial Addition Test or by neuropsychological test batteries at various time points. Since cognitive impairment has consequences for the daily lives of people with MS, a neuropsychological evaluation can be useful. In studies of new drugs acting on remyelination or neuroprotection, cognitive evaluation should be part of the protocol.

MRI and cognition

During the last 15 years, various studies have used brain MRI techniques to better understand the mechanisms of cognitive impairment in MS. These studies have applied conventional MRI (quantifying macroscopic white matter lesions and the measure of atrophy) and non-conventional techniques (assessment of the normal appearing brain tissue) in people with MS at various stages of the disease.

The majority of MRI studies performed on people with MS have suggested that all the pathological components of MS (macroscopic white matter lesions, normal appearing white matter injury and cortical and deep grey matter injury) participate in cognitive impairment. White matter injury may disturb the connectivity inside cognitive neuronal networks, resulting in impaired information processing speed, working memory and attention.

In contrast, grey matter pathology may induce memory impairment and behavioural changes. In individuals at the early stages of MS, white matter pathology (macroscopic lesions and disconnection in normal appearing white matter injury) may be the main pathological underpinnings of cognitive impairment, but the role of deep brain atrophy (cell loss) has been also shown.

Is it really a cognitive problem?

Fatigue

Fatigue is one of the most frequently reported symptoms in MS. It is usually perceived as a lack of energy and is sometimes mistaken for cognitive deficit. Subjective fatigue is usually not linked to cognitive deterioration. What is called cognitive fatigue is in fact fatigability, which is a decrease of performance during a sustained task.

Depression

Depression as a symptom is virtually ubiquitous in the lives of anyone with a disabling disease and occurs frequently in people with MS. A distinction must therefore be made between depression as a symptom and the syndrome of major depression, which is a disorder characterised by a persistently low mood, occurring most of the time and lasting for some weeks or more.

The lifetime prevalence for this syndrome in MS approaches 50 per cent and people with MS are at high risk for depression. People with MS who are clinically depressed have impairment in the executive strategies used to access working

memory, and have more difficulty planning tasks than people who are not depressed. These deficits have also been attributed to slower information processing speed in people with depression. Cognitive assessment should therefore always include mood evaluation.

Side effects from MS medications

All drugs acting on the CNS could induce some cognitive effects, such as sedation or slowness. It is more likely to occur after treatment initiation, an increase in dosing or in the case of overdosing. It mainly concerns drugs used for pain (anti-epileptic drugs, analgesics), mood (antidepressants, benzodiazepines), spasticity or bladder symptoms.



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Cognition tests: what do they involve?

Symbol Digit Modalities Test (SDMT)

Participants in this test are given a reference key that they must use to help them associate numbers to a series of geometric shapes. Responses can be verbal or written, and the entire test should be finished in 90 seconds.

Paced Auditory Serial Addition Test (3- and 2-second versions) (PASAT)

This is a measure of cognitive function that assesses auditory information processing speed and flexibility, as well as calculation ability. Single digits are presented by audio cassette tape or compact disk every three seconds and the person must add each new digit to the one immediately prior to it.

Delis Kaplan Executive Function System sorting test (D-KEFS sorting test)

This test uses sorting cards to measure concept-formation skills, modality-specific problem-solving skills (verbal/nonverbal), and the ability to explain sorting concepts abstractly.

Selective Reminding Test (SRT)

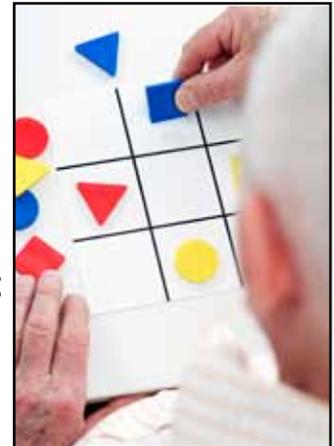
The test assesses memory by providing 12 words which are selectively rehearsed by the person taking the test until they are memorised. That is, only those words not recalled on the immediately preceding trial are presented. After a delay, the person is asked to recall the words.

California Verbal Learning Test, second version (CVLT-II)

People doing this test are read a list of words and asked to recall them across a series of trials. In addition to recall and recognition scores, CVLT-II measures encoding strategies, learning rates, error types and other process data.

Spatial Recall test (10/36)

This is a visuospatial learning and memory test in which participants are given a 6x6 checkerboard with 10 counters placed in specific locations. After 10 seconds, the person tries to replicate the pattern on a blank checkerboard. The test is repeated three times, followed by a 20-25 minute interval, after which they try to recall and replicate the pattern again.



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Brief visuospatial memory test, revised version (BVM-T-R)

In this test, which measures visuospatial memory, participants view a page of geometric figures for 10 seconds and then have to draw as many of the figures as possible in their correct location.

Word list generation (WLG)

This test, sometimes referred to as verbal fluency, tests language dysfunction. Commonly, people are asked to name as many animals as possible, or words beginning with a particular letter, in one minute.

Controlled Oral Word Association Test (COWA)

This verbal fluency test measures a person's ability to make verbal associations to specified letters. Participants have to say as many words as possible in a given time that start with a particular letter.

Judgement of line orientation test (JOL)

This test is used to measure visuospatial awareness and is based on judgements about a pair of angled lines. Participants are asked to indicate which two lines from a selection are in exactly the same position and point in the same direction as two lines on the previous page.

Treating cognitive issues in MS

Maria Pia Amato and Benedetta Goretti, Department of NEUROFARBA, Section Neurosciences, University of Florence, Italy

Currently there are no definitive affective pharmacological or non-pharmacological treatments for cognitive deficits in MS.

The disease-modifying treatments (DMT) that are approved for the treatment of MS in many countries (interferon b-1a and b-1b, glatiramer acetate, mitoxantrone, natalizumab, teriflunomide and fingolimod) can reduce the relapse rate and, in some cases, the progression of disability, and may improve MRI parameters. These drugs could also have a positive impact on the long-term cognitive outcome of the person with MS by containing inflammation in the brain, lesion burden and the progression of brain atrophy. Some of them, moreover, may also exert direct neuroprotective effects through different mechanisms.

However, most of the pivotal clinical trials on DMT have not included cognitive endpoints, or included them as secondary or even tertiary end-points, so the effects of these drugs on cognition are not definitively established. The current weight of evidence suggests that DMT may have beneficial effects on cognitive performance and that, in particular, early treatment may help to maintain cognitive function or delay cognitive dysfunction.

There is increasing consensus that future trials should include more systematic cognitive assessment in order to better clarify the impact of DMT on cognition and underlying pathophysiological mechanisms.

Symptomatic treatments

Studies of symptomatic treatments, including treatments for fatigue (such as amantadine, potassium channel blockers and modafinil), Alzheimer's medications (for example donepezil, memantine and rivastigmine) and psycho-stimulants

(such as amphetamine and methylphenidate) have mainly provided negative or inconsistent findings for treating cognitive deficits in MS. However, there is renewed interest in the field and larger studies on symptomatic drugs and their uses are underway.

Cognitive rehabilitation

Cognitive rehabilitation is a non-pharmacological approach to cognitive retraining to improve impaired cognitive function through practice, exercise, compensatory and coping strategies, and adaptations to maximise the use of residual cognitive function. In contrast to pharmacological interventions, cognitive rehabilitation has the advantage of being free from side effects.



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Cognitive rehabilitation can bring considerable benefits to people with MS, although research in the field is still too limited to draw any firm conclusions about optimal strategies and approaches. Currently, there is some evidence to support the use of strategies borrowed from cognitive psychology to improve learning and memory and, to a lesser extent, targeted training programmes for attention and executive functions.

Preliminary evidence also suggests that aerobic exercise, such as jogging or swimming, may have a positive impact on cognitive performance and behavioural control, as well as an improvement in physical performance. Combining cognitive rehabilitation with physical rehabilitation and pharmacological therapy is an interesting approach that is certainly worthy of further investigation.

Other MS symptoms that can influence cognition

As discussed on page 12, depression and fatigue can be confused with or can worsen cognitive difficulties. Successful management (pharmacological or other) of depression or fatigue can help resolve cognitive problems.



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Beyond pharmacological strategies, cognitive behavioural therapy (see below) is an effective treatment that is recommended for depressive disorder and fatigue in adults of all ages and, in particular, for people who cannot tolerate medication or are reluctant to take it.

Cognitive behavioural therapy (CBT)

CBT is a talking therapy that aims to help a person manage their problems by changing the way they think and behave. CBT cannot remove the problems, but it can help a person manage those problems in a more positive way. Talking and changing a person's behaviour can change how they think (cognitive) and what they do (behaviour), which can make a person feel better about life. CBT looks for practical ways to improve the state of mind on a daily basis.

CBT has been shown to be particularly helpful at tackling problems such as anxiety, depression, post-traumatic stress disorder, eating disorders and drug misuse, but has also been used to treat people with long-term health conditions. CBT

cannot cure the physical symptoms of a health condition like MS, but it can help people cope better with it.

CBT works by helping a person make sense of overwhelming problems by breaking them down into smaller parts. Thoughts, feelings, physical sensations and actions are interconnected, often trapping an individual in a negative spiral. CBT tries to stop this negative cycle by breaking down factors that are making a person feel bad, anxious or scared, so that they are more manageable and therefore improve the way a person feels.

CBT is usually carried out with a therapist on a one-to-one basis, but it can also take the form of group therapy, a self-help book, or a computer program known as computerised CBT.

Day-to-day living with MS-related cognitive problems

Nancy D Chiaravalloti, Neuropsychology & Neuroscience Research, Kessler Foundation, West Orange, USA

Cognitive impairment is common in MS, and people with the disease frequently report difficulties, such as following along in complex conversations, recalling information and forgetfulness. These cognitive challenges can impact the successful completion of everyday tasks.

Impact on quality of life

Research has shown that people with MS who are cognitively impaired participate in fewer social and vocational activities, and have greater difficulties carrying out routine household tasks compared to people who have a purely physical disability. People with MS themselves report a reduced quality of life with a decrease in cognitive functioning, making cognitive difficulties a potentially significant detriment to productivity.

Additionally, the onset of MS typically occurs between 20 and 40 years of age, when individuals are most active in their professional lives, resulting in considerable disruption to employment status and yearly earnings. Many individuals with MS experience problems with processing speed, learning and memory, which can contribute to problems maintaining employment, and in some situations, the loss of gainful employment altogether.

Cognitive impairment can have a resulting detrimental effect on personal, occupational and social functioning, leading to a reduced overall quality of life. Although physical disability can impact the performance of everyday activities, it does not account for the extent of additional challenges encountered by those with significant cognitive difficulties.

Techniques to improve cognitive function

Given the significant impact cognitive problems can have on daily life, there is a need for improved techniques that enable people with MS to better manage cognitive difficulties. While research on cognitive rehabilitation efficacy in MS remains sparse, there is some evidence that it can be effective. Short-term memory is commonly impaired in MS and recent research has demonstrated that the source of this memory dysfunction is in the area of initial learning. Targeted approaches to improve learning would therefore be expected to result in improved memory in people with MS. Several studies now support this notion.

Self-generation

Self-generation is a method that has been found to be effective in increasing a person's ability to learn and remember new information, in both the general population and those with MS. The concept of self-generated learning states that recall and recognition of information is significantly better when a person generates their own correct responses to a problem, compared to when the correct answers are provided to them.

The application of self-generation to daily life requires knowledge of the concept on the part of both the person with MS and a partner or family member, as well as an understanding of how to restructure the learning situation so that the individual can better remember new information. This can be taught fairly simply and several ongoing studies are examining ways of teaching self-generation to people with MS and their families in the hope that this will improve everyday memory.

©TIPS



Spaced learning

This technique has also been found to be beneficial for people with MS. Spaced learning involves repeating a learning activity with a delay between each learning session. People struggling with memory impairment can be taught to space out repetitions of information that they have to remember in an effort to maximise learning. This approach appears to result in significantly better memory performance than consecutive learning trials, in which a person undertakes a block of continuous learning with no delay.

Spaced learning requires restructuring of the learning environment, but this can be accomplished by the individual themselves. Support or help from a partner or family member would be expected to maximise outcome.

Retrieval practice

Retrieval practice is yet another technique shown to improve learning for people with MS. This is a well known phenomenon by which testing memory for

previously learned information (such as quizzing) improves subsequent recall more than restudying material. Once again, a restructuring of the learning environment is necessary to apply the technique, which can be accomplished by an individual alone or with assistance from a significant other.

Future techniques

There is growing evidence demonstrating that each of these techniques improves learning and memory performance in MS, supporting the idea that a known deficit in these areas can be effectively treated through cognitive rehabilitation. The next step in this line of work is the development of treatment protocols or methods designed to teach an individual how to apply these techniques in their everyday life. Such development is underway.

In addition to evidence supporting the use of these specific techniques to improve learning, evidence is also building in support of structured treatment protocols. For example, the modified story memory technique, which consists of training in context and imagery, improves learning and memory in MS and results in changes in brain function on neuro-imaging.

By far, learning and memory has received the most attention in cognitive rehabilitation research in MS. However, limited work has been conducted in other areas, including attention and executive functioning (for example, problem solving or mental flexibility). Such studies have shown mixed results. Multiple groups have noted that treatment methods designed to improve attention and executive functions show some benefit in people with MS.

An important cognitive domain that has received relatively little attention in the MS cognitive rehabilitation research literature is processing speed. Processing speed can be a strong predictor of long-term cognitive decline and such deficits are typically observed alongside the other cognitive deficits commonly seen in MS. Focusing treatment on a basic cognitive skill such as processing speed is likely to lead to widespread cognitive improvement in other realms of cognition. Research is necessary to begin to develop effective methods to improve the

processing speed problems experienced by many people with MS.

In summary, while cognitive difficulties in MS exert a significant impact on daily life, researchers and clinicians are now developing and testing techniques to help treat these problems, in the hope of improving overall quality of life.

Importance of support at home

It is important that the partner and/or family of a person with MS understands that cognitive problems can be a part of their MS and what some common problems might be. This understanding will

allow the family to support the individual with MS by helping them apply techniques in their daily life. This will reduce the impact of the cognitive problems on a person's quality of life.

Offering support in a social situation can be important too, as cognitive problems are some of the "hidden" symptoms of MS. Support may include reminders of people's names or scheduled social activities and helping the person to prepare for situations and challenges in advance.

Additionally, simple reminders, such as a phone call or a sticky note can be very helpful.

Tips for common cognitive problems

Taken from www.stayingsmart.org.uk (run by the UK MS Trust), reviewed on page 27.

- Have a set place for everything (your glasses, your car keys) and always put these essential items in their set place.
- If a word is on the tip of your tongue, don't tense up or panic. Stress will make it harder to get it out. Instead, either use another word or words to say what you need to, if possible. If it is a specific name or place where another word won't do, just say "I'll come back to that".
- If you find it hard to stay on task, you can manage distractions by finding a quiet environment and letting others know when you can and can't be disturbed.
- If you have trouble remembering appointments, paper diaries and electronic organisers are unobtrusive and very useful. You may find that you need to use them more often and more scrupulously than previously, but they work.
- Most people with MS are able to remember information from a small prompt or cue. For example, a post-it note saying "dry cleaning" on your car dashboard will probably be enough to remind you to stop to pick up the cleaning.
- Try to schedule important discussions at a time when you won't be fatigued, or arrange to have a rest beforehand.
- If your attention wanders during conversation, you can always repeat or summarise what the other person had just said before making your comment. For example, you could say "I hear that you enjoyed your holiday in France, because the weather was so good. Have you ever been to France when it rained?". It might feel a bit strange at first, but it will soon feel natural. You will find that your friends will feel flattered that you are paying so much attention to what they are saying.
- Routinely check routes on maps in advance and if you need to, make a photocopy or brief route notes for reference. This will help in two ways. By thinking about the route in advance and preparing the route notes, you will have reminded yourself of the way. You will also have the notes for guidance when travelling.

Your cognition questions answered

Q. I'm recently diagnosed with MS and am worried about the impact it might have on my job in the future, especially the cognitive aspects. How likely is it that I'll have to give up my job?

A. The likelihood of giving up your job in the future is not something that can be predicted. It depends on whether or not you will ever even experience cognitive difficulties. Remember that many people with MS will never experience this problem.

While it is true that people with MS with cognitive difficulties are less likely to be employed, the majority who experience these types of difficulties are likely to have mild to moderate impairment. In the case that cognitive problems do become an issue, maintaining employment will depend on the type and severity of the difficulty, as well as on what type of work you do. Importantly, maintaining employment also depends on the support a person has in finding compensatory strategies and other ways of confronting and managing cognitive impairment at work. With the right type of support, people with MS experiencing cognitive difficulties can find solutions that enable them to stay in the workforce.

Q. How do I know if my cognitive problems are related to MS or are just changes due to normal ageing?

A. In normal ageing, subtle cognitive changes are common before a person reaches their 70's, but these are changes that generally do not impact on daily life. Normal age-related changes in cognitive abilities can occur in individuals who do or do not experience MS-related cognitive impairment. Understanding the underlying cause of a specific cognitive difficulty (whether it is age, MS or another factor) can be complicated. A

health care professional with knowledge about MS and cognition, with the help of specific neuropsychological tests, is the best resource for helping you to better understand the cognitive difficulties you are experiencing.

Q. I've started getting muddled with my words sometimes, especially when I am speaking to a group of people at a party or at work. It is starting to make me nervous and unsociable. Do you have any advice on how to address this problem?



©Stockphoto.com/Rich Legg

A. It is common for a person with difficulty finding the right word or a problem with verbal fluency to feel anxious in a social situation, particularly with people you are meeting for the first time. When you find yourself among people who know you have MS, it might help to ease your anxiety if you try to explain the difficulty you experience. In this way, they know that this is part of your MS, just like a mobility or other type of MS-related problem.

When speaking to a group of people in a work situation, some of whom are not likely to know that you have MS, the situation is a bit more complicated. If you are speaking more formally, prepare for your presentation by writing it out on note cards or on an electronic tablet. In both types of situations, eliminating distractions of any kind can further help you to focus your attention on the discussion.

Interview with Jeffrey Gingold: author and MS cognition awareness-raiser

Jeffrey, can you please give us a brief biography?

I live in Milwaukee, Wisconsin, USA, near the shores of Lake Michigan with my wife, Terri, and our two girls, Lauren and Meredith. I was a partner in a law firm practicing as a litigation attorney when I retired in 2001 at the age of only 41, due to the cognitive impediments of my MS.

How long have you had MS?

I was diagnosed with MS in January 1996 after I began to lose vision in one eye, due to optic-neuritis. This was the first of numerous physical symptoms: left-sided body numbness from my scalp through to my toes and equilibrium loss, then a wealth of cognitive battles.

How did you know that the cognitive challenges you were experiencing could be MS-related?

At first, I didn't know that there was any connection between cognition and MS. In fact, a neurologist told me that there was no "mental" part of MS. She not only missed the boat on the MS cognitive research, she didn't even know where it was docked. It was time for a second opinion. Clinical research had established that 50-65 per cent of the MS population, to a greater or lesser extent, would experience cognitive challenges. Simply stated, that is the majority of the MS population!

There is no excuse to ignore, misdiagnose or mistreat those people with MS who are enduring a loss of their mental connections and memory functions. There is no reason to hold back acknowledgement of these real and damaging losses slammed behind a closet door of fear and misinformation.

The MS-patient discussion was void of any first-person discussion from inside the MS cognitive mental twister. I reviewed hundreds of books and clinical articles all confirming the direct connection, but there was nothing for the person living with the cognitive symptoms, nor any clear tactics for



copied with them. Nothing. It was difficult to receive a proper MS cognitive assessment when the bulk of the medical community seemed unaware of how the symptoms were silently lurking in their patients.

Fortunately, the studies and books have caught up with the MS medical and lay communities, and are now readily available, and can be read and incorporated into every patients' care. Cognition is part and parcel with the physical symptoms of MS.

In your book *Facing The Cognitive Challenges of Multiple Sclerosis*, you wrote about the process of coming to terms with having MS. What helped you to develop a positive attitude about living with MS?

For me, it was vital to get the cognitive "moments" on the discussion table with my family and treating medical professionals. You can't have a successful driving trip if everyone in the car has a different map and destination. I may be a bit irreverent toward my MS, but I take its effects on me and others very seriously. Once I realised that I would not be alone and chose to be surrounded by an informed and trusted care team, then it was time to "do something" and stay in my challenged game of life – despite MS. For my wife and children, as well as others similarly enduring invisible MS symptoms, I was not going to leave the cognitive landmines for others to blindly hit.

Did your cognitive symptoms make writing more challenging for you? How did you overcome the challenges?

Oh yes. I needed much more time to organise myself, but with patience and persistence, and a bit of passion to share with the silent majority of “us,” I was focused to get it written and made accessible (book, i-Tablet, brail, audio and in libraries) for others to help them find the words for themselves.

I am not finished. When I was diagnosed with MS, I was not told to go home with a crate of MS research and therapy options, and then figure it out for myself. I needed to learn from others who acknowledged and understood the MS cognitive challenges and that the impediments were an aggressive part of my MS which would lead to my permanent disability. I needed to take action for myself and share with countless others.

How are you involved with MS organisations?

I am fortunate that I have been able to volunteer on a MS-macro and micro level. Whether as an on-line mentor of others with MS or accepting opportunities to advocate and achieve legislation providing funding for improved home access, there is no shortage of means to engage and face MS challenges and improve life. Find your skill set and volunteer.

While I have enjoyed working with MS organisations across the US and Canada, I have especially welcomed experiences with international MS organisations to evolve their MS cognitive discussion in a way that is meaningful and informative for their professionals and people living with MS and their carers, for examples in videos and articles for the UK MS Trust website www.stayingsmart.org.uk (see page 26 for a review).

Do you think medical professionals are now more aware that MS can affect cognition?

Yes, but being “aware” is not an end-point for the cognitive discussion. Dr Eric Maas noted in his chapter of my second book, *Mental Sharpening Stones: Manage the Cognitive Challenges of Multiple Sclerosis*, that care of cognitive difficulties should involve ongoing assessment. Tossing the cognitive issues into a drawer, then saying it was noted, ignores the person’s ongoing care and leaves it incomplete.

What were your goals when you started writing about the cognitive challenges of MS?

When I introduced my initial encounters with cognitive pitfalls online – and how I struggled to understand why I was losing mental grip of previously taken-for-granted information, familiar faces, locations, directions and details – I needed answers, but found none. The overwhelming, honest reaction from the MS community was “You too?!”. They embraced the discussion of disconnected fog-like thoughts and were frankly scared of the answer they might be facing. They had been hiding in shadowed fears of having their memories and life pulled away. Perhaps a discussion would bring better acknowledgement, better information and coping techniques for the majority of the MS population.

Do you feel you have achieved your goals?

With the kind assistance of many, it is a work in process. This is a clarion call for the MS community that the cognitive discussion is accessible and needs to be on-going. Informed MS cognitive discussion and treatment is paramount validation for those who are grasping with mental fingernails at their drifting thoughts.

People who have MS cognition moments can now openly receive the informed answers to two silent questions: 1) Am I losing my mind? No; and 2) Is there anything that you can do to slow down the disconnection of thoughts? Yes. Ask for help so you can benefit from the cognitive tactics of others and treating professionals. If necessary, get a second opinion from a professional who has “cognitively” been there and done that for other people with MS. Personally, my interest is in no honorarium outreach and all royalties from my MS cognition books are directly donated to MS research and education. This sustains me to engage and move cognitive awareness forward.

Is there anything you would like to say to people with MS who have cognitive symptoms?

While these symptoms vary for each person, there are successful treatments and strategies available to cope with the invisible challenges. Ask questions and demand answers. It begins with an informed discussion, bolstered by a support team that “gets it”. Open the cognitive tools for your MS community, engage their passion to help themselves and appreciate those who are by your side. Extra hugs are great too!

Results of the online survey about cognition and MS

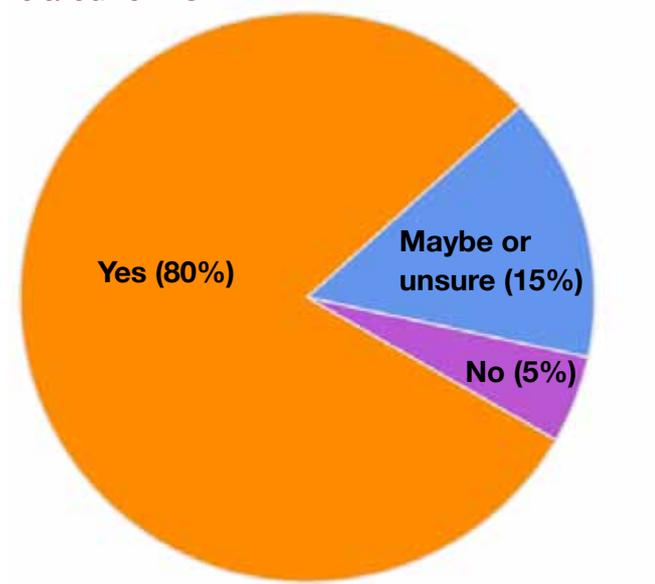
A total of 4,639 people from 88 countries took part in our online survey about cognition and MS during March and April 2013.

The majority of respondents were female (79.1%) and from a wide range of ages. The most common type of MS was relapsing-remitting (66.1%), followed by 13.5% who had secondary progressive MS. 6.8% had primary progressive MS and 4.2% had progressive-relapsing. The remainder (9.4%) were not sure what type they had.

A large proportion of respondents (80%) had experienced cognitive challenges related to MS (as shown below), demonstrating the prominence of this symptom for the majority of people with MS who took the survey.

When asked about the impact of cognitive challenges in areas of life, where 0 is no impact and 5 is very high impact, the impact on work/employment was rated 5 by the majority of respondents. This correlates with published

Have you experienced cognitive challenges related to MS?



findings that the biggest impact of cognitive issues in MS is the impact it has on people's jobs.

“In about two years, I went from working a 10-hour day and multi-tasking in a school system for 28 years to not being able to follow a simple recipe”

Other areas of life, including everyday living, family functioning, social functioning, recreational activities and financial management, were given a medium rating by the majority of people who took the survey. This shows how the cognitive challenges of MS can impact in a meaningful way on all the main areas of life, not just work.

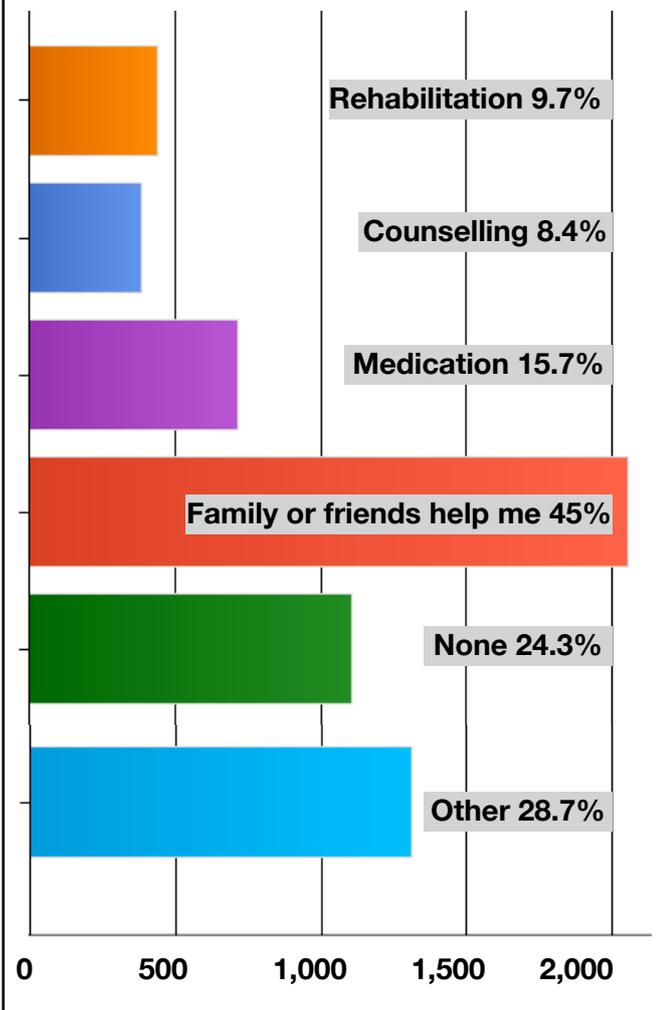
Respondents were asked which cognitive difficulties have the most impact on their life. The one that the majority of respondents selected (73.7%) was difficulty expressing yourself clearly, which highlights some of the difficult ‘hidden’ symptoms of MS in social or work situations.

“Your family is the best support system but even they look at you funny when you put the cereal box in the fridge.”

Difficulty concentrating and difficulty remembering were also selected by a large proportion of respondents (70.7% and 63.9%).

When asked which strategies respondents used to help address their cognitive challenges, the majority said that family or friends help them (see right), indicating the importance of support and understanding from loved ones, but also the

What strategies most help you address the cognitive challenges you experience?



potential impact of cognitive problems on those relationships.

“I think cognitive issues are the hardest part of my MS for my family members to accept.”

Also of note was that almost a quarter said that they used no strategies to help them address their cognitive difficulties, emphasising the impact this symptom – and its limited treatment options – can have on the quality of life of people with MS.

A large number of people who took the survey also used “other” strategies to address their cognitive challenges. These included rest, making time to

do tasks carefully, writing lists and using a smart phone for reminders of important tasks or dates, sitting close to people during conversation to ‘block out’ background noises, reducing multi-tasking and focusing on one task, keeping the mind busy with crosswords or number games, using audio versions of books, exercising and keeping a sense of humour about it.

“Expressing myself spontaneously is hard sometimes, not every time or all the time. I just make the best of it, which can create a lot of laughing.”

Respondents were asked whether people they are close to understand that cognition can be affected by MS – half said “sometimes”, 31.2% said “no”, and 18.7% said “yes” indicating that work is needed to raise awareness of this symptom of MS.

“It’s hard for friends and family to grasp that it is a permanent issue because some days are significantly worse than others.”

When asked if they had ever been tested for cognitive difficulties, the majority (54%) said “no”, 34.4% said “yes”, and 11.6% were “unsure”.

Of those that had been tested, most gave the reason as being for their own interest, followed by the test being part of an evaluation to receive a disability benefit, or as part of a research study.

In conclusion, the survey highlights the need to raise awareness of the cognitive difficulties that can be part of MS to family members, friends, employers and the general public.

There could also be increased awareness among people with MS and health care professionals about the strategies that can be used to help minimise the impact that cognition difficulties have on day-to-day life.

A workshop for people in India with MS-related cognition problems

Sheela Chitnis, National Vice President, MS Society of India

About the MS Society of India (MSSI)

The MSSI, established in 1985, is the only organisation in India working for people with MS. Initially, it was thought that MS was rare in India but now neurologists believe there are 90,000-100,000 people with MS in India. We have eight chapters in Mumbai, Delhi, Bangalore, Chennai, Hyderabad, Indore, Kolkata and Pune and a support group in Pondicherry. Since 1996 we have introduced free or highly subsidised home physiotherapy and occupational therapy for people with MS, which is necessary to maintain the physical as well as mental abilities.

Background to the programme

Over the past two decades, cognitive impairment in MS has received increased interest worldwide. While it is now recognised as being common in MS, this issue was rarely discussed in the past with our members. This meant it was not included in the clinical assessment, and therefore, cognitive impairment increased the impact of the disease on the daily lives of people with MS and further delayed its therapeutic management.

We recognised the need to reduce the burden of the disease on people in India with MS and their caregivers by timely assessment of the various factors associated with a reduction in quality of life. As cognitive impairments have a direct impact on quality of life and on being able to work, determining the characteristics of these difficulties was required to improve the overall management of the disease in the Indian population.

Objectives of the programme

The primary objectives were:

- To make people with MS and caregivers aware of the cognitive problems related to MS

- To underline the importance of cognitive rehabilitation among our neurologists, physiotherapists, occupational therapists and speech therapists

The secondary objectives include:

- Assess the cognitive deficits in each person and subsequently impart rehabilitation measures
- Reduce the communication gap between the therapist and the person regarding their cognitive problems
- Implement a uniform system of evaluation and treatment among all the people with MS registered with the organisation

Programme development

In 2011, one of the physiotherapists associated with the Mumbai chapter, Dr Darshpreet Kaur, received a prestigious Du Pré Grant from MSIF to undertake advanced training in cognitive rehabilitation in France. This encouraged us to take up cognitive rehabilitation more actively with people with MS throughout India.

The first step was taken in August 2011, when a one-day workshop was organised by the Mumbai Chapter for people with MS, their caregivers, physiotherapists, occupational therapists and speech therapists, conducted by Dr Kaur. Attendees were made aware of cognitive impairments in MS and of various cognitive rehabilitation techniques in exercise sessions. The success of this workshop motivated other chapters around India to follow the lead.

Since then there have been further workshops in Mumbai, Delhi, Chennai, Indore and Pondicherry. At each of these events, individuals were assessed



Dr Darshpreet Kaur working with one of the workshop participants.

by Dr Kaur and advised on appropriate cognitive rehabilitation techniques or ways to manage cognitive problems day-to-day.

Outcomes and results

Our inspiration comes from none other than people with MS – their overwhelming response to the workshops has been a great driving force. We keep in contact with workshop participants via e-mail, including advice and do's and don'ts while doing any exercise, as well as links to therapy videos on YouTube. Exercise charts, designed by Dr Kaur, are also sent to them with full instructions. We try to find as many ways as possible to stimulate the cognitive capabilities of people with MS in India.

Marketing the programme

To ensure that a maximum number of people can benefit from the programme, before any workshop or seminars, the respective chapters make sure to use all possible means of communication to reach out. People with MS are informed well in advance through telephone, e-mail and letters. The therapists are contacted and the programme schedule is highlighted on social networking sites.

Expenses to consider

Cost is a key limiting factor which affects any comprehensive rehabilitation programme to be undertaken in India. India is a low-middle income country and it is not surprising that India's expenditure on health care is also quite low. A

We try to find as many ways as possible to stimulate the cognitive capabilities of people with MS in India.

widespread lack of health insurance compounds the health care challenges that Indian people with MS face.

To bridge this gap, and to ensure that each individual is given a chance to take advantage of all the possible therapies available, each chapter of MSSI has found suitable solutions. For example, the Mumbai Chapter provides 12 rehabilitation sessions per month for free and if any additional session is required they are provided at subsidised rates. The other chapters are providing therapy sessions at very subsidised rates and efforts are being made to make a few of them totally free. During these sessions, we request that therapists concentrate on both physical and mental rehabilitation techniques.

Limitations and suggestions for future programmes

The main limitation that we face is finding a sufficient number of therapists with expert knowledge about cognitive impairments in MS and its management. Also if participants have visual problems, it makes therapy sessions more challenging.

In our future programmes we are looking forward to forming a team of rehabilitation experts who are well versed with coupling physical and cognitive rehabilitation techniques. We aim to have at least two such therapists at each chapter of MSSI. Apart from therapy sessions, we also plan to send therapy video CDs to those people who have limited access to the internet.

For more information about the programme please contact:

Dr Darshpreet Kaur at
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Mrs Sheela Chitnis, National Vice
President, Chairperson Mumbai Chapter,
sheelachitnis26@gmail.com

Reviews

www.stayingSMART.org.uk
UK MS Trust



Reviewed by Nasheem Mehmood, MSIF People with MS Advisory Committee member, India

This website is very informative and answers many questions that a person with MS has. I think it can definitely help people overcome the cognition aspects of the disease. The home page makes it simple to find help with tabs for specific cognitive difficulties, for example “I forget where I put things” which guides the user straight to a page on this topic, including practical tips. Viewers can also add their tips.

I really like the videos that have been posted of people with MS – they are very informative and are a great way to give guidance to other people

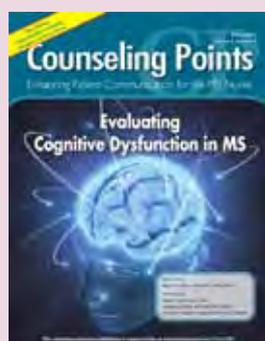
with MS. It would be nice if there was an option for viewers to post their testimonials for other people or doctors to comment on.

The site covers the major aspects of living with cognitive issues in day-to-day life and how to overcome them, as well as frequently answered questions related to cognition and MS.

There are size and contrast options for viewing the page, however I would have liked to have the option of black text. I would also have liked to be able to see all six sections from the home page instead of clicking on “more”, as it took me a while to figure it out, but once in a section, the tabs to the other sections appeared in the top panel, aiding navigation through the site.

The layout is attractive, particularly where there are pictures relating to the subject – it would be good if there were images used on every page.

An option of a blog on the site in the future would help individuals who wanted to discuss the various topics and their own experiences with cognition and MS.



Counseling Points™ – Evaluating Cognitive Dysfunction in MS
www.nxtbook.com/nxtbooks/dmg/MSCP_2012-04

Reviewed by Francesco Pastore, MS Nurse, Madonna delle Grazie Hospital, Matera, Italy

Evaluating Cognitive Dysfunction in MS is an on-line continuing education tool developed for nurses

working with people with MS. The purpose of the tool is to provide nurses with the knowledge necessary to recognise early signs and symptoms of cognitive dysfunction, to evaluate the entity and to develop appropriate strategies for treatment decisions.

The tool presents scientific evidence that describes the impact of cognitive dysfunction on the quality of life of people with MS, the limited role of magnetic resonance imaging in detecting cognitive change, the impact of therapy and the contribution of brain training techniques.

Facing the cognitive challenges of multiple sclerosis

By Jeffrey Gingold
Second edition,
2011, Demos Health

Reviewed by
Colomba Polit, Italy



This book is an autobiography of a man who started his journey with MS as a “spectator” and then ended up being the “main character”. This experience has given the author, Jeffrey Gingold, a full vision on how MS can change people's lives. He has focussed mainly on how cognitive functions can be compromised by MS and on how they are often undiagnosed, creating a deep chasm of unseen disability.

This is a book for people with MS who want to learn more on how MS can affect their different cognitive abilities such as thinking and remembering. In addition it offers a patient's perspective and a professional explanation to family members, as well

It also provides practical information on counselling people who experience cognitive deficits, stressing the need for sensitive communication and practical advice.

This educational tool uses clear and concise language and comprehensively describes progress achieved in the diagnosis and treatment of cognitive dysfunction in MS. The text is structured in a logical format and the content is complete.

The tool can be consulted on-line, downloaded and printed, thus making it accessible to users with varying needs. The Ntxbook format provides

to MS professionals who are trying to understand the cognitive distortion that can be part of MS.

The author has used an anecdotal style to share his MS-related thinking difficulties to help others with MS to recognise similar changes within themselves. In addition he has provided strategies and tactical suggestions for living each day fully.

Reading this book you can feel Gingold's energy, commitment and also his courage in sharing his personal experience of cognitive difficulties in MS. It provides a source of information, comfort and inspiration to people with MS who want to learn more about how cognitive difficulties can change their lives, stressing that everybody's experience will be different.

Cognitive issues can significantly affect the lives of people with MS and their families, while remaining largely invisible to most of us. Using his personal experience and struggles with MS, Gingold looked for solutions for himself and then shared them with others.

I find this book informative, and at the same time highly personal, and I recommend it to people with MS and those who want to know more about MS.

excellent legibility and the reader can adjust the text and page size for ease of reading. The tool also provides a brief multiple-choice quiz at the end so that nurses can test their understanding of the content. The only criticism is that unfortunately Counseling Points™ is currently only available in English.

This educational tool can contribute to improving the quality of nursing care for people with MS by promoting a better understanding of cognitive deficits which can be misunderstood as well as underestimated, in an accessible format.

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With many thanks

MSIF would like to thank Merck Serono for their generous unrestricted grant, which makes the production of **MS in focus** possible.

