

# MS *in focus*

Issue 4 • 2004

## ● Emotions and Cognition



multiple sclerosis  
international federation

## Editorial Board

### Multiple Sclerosis International Federation

Established in 1967, the Multiple Sclerosis International Federation links the work of national MS societies worldwide.

We are committed to working together and with the international research community to eliminate MS and its devastating effects. We also speak out on a global level for those affected by MS.

Our priorities are:

- Stimulating global research
- Stimulating the active exchange of information
- Providing support for the development of new and existing MS societies

All of our work is carried out with the complete involvement of people living with MS.

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## Letter from the Editor



Recently I received some letters from our readers whose experiences with both cognitive and emotional issues confirm the importance of dedicating this issue of *MS in Focus* to a comprehensive discussion of these difficult problems.

"I've noticed recently that sometimes I get tearful over things that are moving, but not THAT moving! Also, if I get upset I can't stop crying for ages. I suppose it's just one more thing that MS has changed, but is there anything I can do about it?"

"I was a lawyer working at the peak of the intellectual food chain...when an MS attack roared out of nowhere and cognitive decline forced me into permanent disability status. At the age of 52 I cannot work at all due to cognitive disability! The depression is bad. I also have seizures. But mostly I have no place in the world."

"I have been diagnosed for over three years now and I feel as if the depression and anxiety have become unbearable at times. I am on a disease-modifying therapy, which seems to help, but taking the injections and managing the depression is almost impossible."

As these accounts reveal, each person's experience with cognitive and emotional changes is very personal. For many, these types of problems are even more difficult to confront and accept than the physical symptoms of MS. Since cognitive and emotional difficulties are often misunderstood by the person who experiences them and also by others, they can create complications in relationships, in the workplace and for the self-esteem of the individual. For many people, dealing effectively with cognitive or emotional challenges will require significant life changes. The key lies in understanding that these difficulties can be part of MS, identifying them accurately and in a timely manner and seeking the support and information necessary for dealing with them effectively.

On behalf of the Editorial Board, we hope that this issue of *MS in Focus* helps readers to understand the complexities of cognitive and emotional problems.

I look forward to receiving your comments.

**Michele Messmer Uccelli**, Editor

# Contents

|   |    |
|---|----|
| From the Editor                                       | 3  |
| Introducing MS-related emotional and cognitive issues | 4  |
| Emotion-related issues of the newly diagnosed         | 7  |
| Depression and MS                                     | 10 |
| Understanding cognitive changes                       | 13 |
| Day-to-day living with cognitive problems             | 16 |
| Simple ways to compensate for memory problems         | 18 |
| Emotional issues of healthcare professionals          | 19 |
| Your questions answered                               | 20 |
| Interview: Meet Steve Cooper                          | 21 |
| Learning by doing: The Danish Way                     | 23 |
| Results of the online survey                          | 25 |
| Book reviews  | 26 |
| Subscription details                                  | 28 |

The next issue of *MS in Focus* will be on Healthy Living. Send questions and letters to [michele@aism.it](mailto:michele@aism.it) or marked for the attention of Michele Messmer Uccelli at the Italian MS Society, Vico chiuso Paggi 3, Genoa, Italy 16128.

## Editorial Statement

The content of *MS in Focus* is based on professional knowledge and experience. The editor and authors endeavour to provide relevant and up-to-date information. Information provided through *MS in Focus* is not intended to substitute for advice, prescription or recommendation from a physician or other healthcare professional. For specific, personalised information, consult your healthcare provider. MSIF does not approve, endorse or recommend specific products or services, but provides information to assist people in making their own decisions.

# Introducing MS-related emotional and cognitive issues

By Dr Nicholas LaRocca, Director, Health Care Delivery and Policy Research, National MS Society, New York, USA

Multiple sclerosis affects more than just physical abilities. It can change the way people feel about themselves and alter their cognitive functions. For many, the emotional and cognitive effects of the disease represent its greatest challenges.

## Emotional changes

In MS there is no definite set of stages leading to “adjustment”. However, there are a number of emotional responses that appear to be common as people learn to deal with the disease.

*Uncertainty and anxiety* set in when the first symptoms appear, and continue until a diagnosis is established. The disease is unpredictable, and so people with MS are often called upon to adjust to a lifetime of uncertainty.

A person with MS may find many facets of *self-image* undermined by the disease. There is often a period of *grieving* for those losses before a renewed self-image can emerge, a process that may occur many times during the course of MS. Grief is a healing and restorative process, but one accompanied by pain and sadness.

MS adds considerable disease-related *stress* to the existing pressures of modern life. Learning to

cope with stress is a major challenge. Moreover, persons with MS may worry that stress itself may make the disease worse by precipitating exacerbations. Research on the question of stress as a “trigger” for MS attacks has had mixed results. However, stress is an unavoidable part of life, and a person can create unnecessary, additional distress simply by trying to avoid the unavoidable.

There are a number of other emotional changes that may occur in MS including *clinical depression, bipolar disorder, and mood swings*. All are more common among persons with MS than in the general population.

*Major depression* is a serious and, at times, life-threatening condition. It is characterised, among other symptoms, by major depressive episodes that can be as disabling as the physical symptoms of MS. Major depression is different from the day-to-day “depression” that many people may experience for a few hours at a time. It is a severe and persistent state that may be accompanied by suicidal thoughts or actions. It requires professional attention and effective treatments including anti-depressant medication and psychotherapy. It is thought that MS may cause changes in the brain triggering major depression, however evidence for this remains limited.

*Bipolar disorder* is a rare condition characterised by alternating periods of depression and mania, or just mania. During manic periods, the affected



*'A person can create unnecessary, additional distress simply by trying to avoid the unavoidable'*

person may engage in inappropriate behaviour such as spending large sums of money. As such this disorder can be very disturbing for family members. Just as with major depression, bipolar disorder requires professional attention and is often treated with a combination of antidepressants and mood-stabilising drugs.

*Mood swings* of various types appear to be common in MS. As used in MS, the term "mood swings" refers to a number of phenomena including *emotional instability ("lability")*, *uncontrollable laughing and crying*, and *euphoria*.

*Emotional lability* refers to frequent changes in mood from happy to sad to angry, etc. These are

not much different from the mood swings experienced by most people but they appear to be more common and perhaps more severe in MS. It is believed that the causes are both the extra stress brought on by MS as well as neurological changes at work.

*Uncontrollable laughing and crying* is a disorder affecting no more than 10 per cent of people with MS. It is characterised by periods in which the person laughs or cries uncontrollably and out of keeping with the situation. This disorder is thought to be caused by MS-related changes in the brain.

*Euphoria* is a very rare symptom in MS affecting no more than five to ten per cent of people with MS. It is characterised by an unrealistic sense of optimism, which can be expressed at times of significant problems and misfortune. Euphoria may be manifest by inappropriate giggling and is

generally observed in individuals with significant cognitive impairment.

Although MS may be accompanied by a variety of emotional reactions and some serious disorders, there is no “MS personality” per se. People with MS face some very special challenges but, like everyone else, they are trying to do their best to cope with what life has sent their way. In most instances, they cope very well and often are stronger for having met these special challenges.

### **Cognitive changes**

Cognition refers to the “higher” brain functions such as memory and reasoning. Approximately half of people with MS have no apparent cognitive changes.

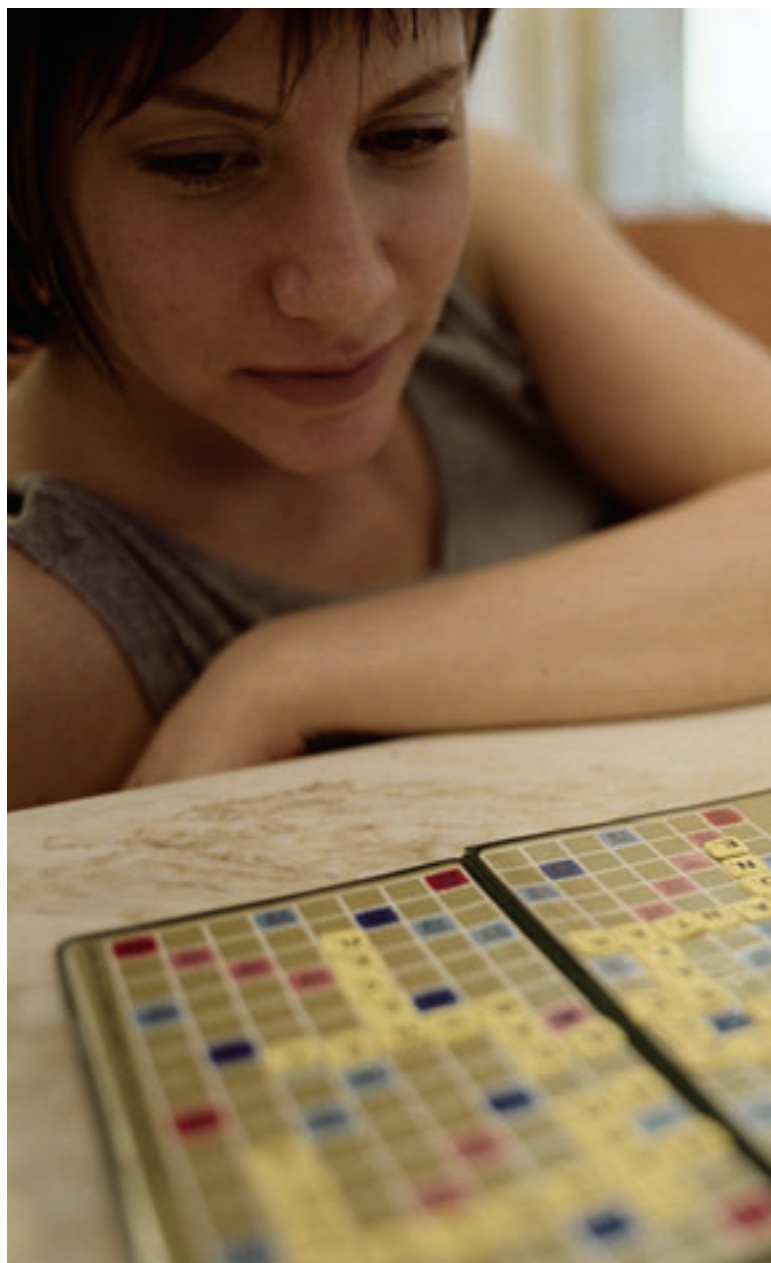
The areas of cognitive functioning that are most commonly affected in MS include the following:

- *Memory*
- *Attention and concentration*
- *Word-finding*
- *Speed of information processing*
- *Abstract reasoning and problem solving*
- *Visual spatial abilities*
- *Executive functions*

Because MS can affect any part of the brain, almost any cognitive function can be impaired. Typically, MS affects some cognitive functions but leaves others relatively intact. For this reason, MS is not likely to lead to the sort of global cognitive decline seen in Alzheimer’s disease. However, in some cases, MS-related cognitive changes can be more pervasive, rendering the individual unable to deal adequately with day-to-day responsibilities.

### **Impact of cognitive changes**

Cognitive changes can have a significant impact on one’s ability to work and fulfil family responsibilities. Family members are often unaware that MS can cause cognitive problems and this misunderstanding can result in anger



and confusion. In such cases it is wise to obtain a professional evaluation to clarify the nature and cause of the problems.

MS is a complex disease with many psychological ramifications. Adjusting successfully to MS requires understanding and addressing these changes along with the physical ones. There are many resources available for education, evaluation, and treatment. By using these resources to the fullest, the family affected by MS can succeed in living more comfortably with an unwelcome but persistent intruder.

# Emotion-related issues of the newly diagnosed

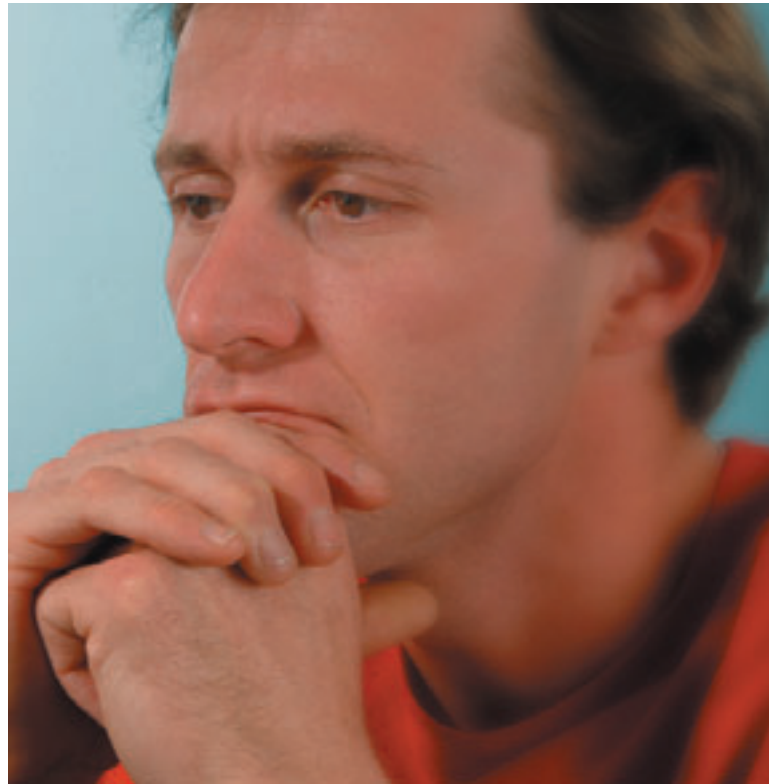
By Regine Strittmatter, Psychologist, MS Society of Switzerland

MS develops in so many different ways and has such a wide variety of symptoms that it could be called the illness with a thousand faces. From the moment the first symptoms appear, the individual faces many emotional challenges, perhaps the first one being uncertainty.

Knowledge about what causes this disease, as well as exactly what triggers a relapse, is currently incomplete. Although we know that many people will follow a relatively benign course of MS with many disability-free years, there is still no certainty, for any individual, as to the course the disease will take. Despite this basic uncertainty, hearing that they have MS provides a certain sense of relief for many. Finally they have a name for all of the different symptoms they have been experiencing. The diagnosis also confirms for the individual that all of his or her ailments have not been imagined, but stem from a verifiable, recognised disease.

However, for most of those affected, the diagnosis also comes as a great shock. Many people newly diagnosed find themselves asking "Why me?" and "What will happen to me?" With a disease like MS these questions are especially difficult to answer.

On hearing the diagnosis for the first time, many react by feeling as if they are losing control over their lives. Even if the symptoms disappear after a relapse, the unpredictability of MS can mean a life of worry and anxiety about the future. It is normal for such extreme emotions to generate anger, but also sadness and fear. It is also a normal reaction for some people with MS to try to ignore the disease's presence in their lives, while others will actively seek out information about MS from the very beginning.



## Coping and personality

People react very differently in times of crisis, but most have one thing in common: the capacity to tap into resources of strength and activate strategies for coping. Based on life experiences, people develop certain resources as part of their personality. This includes, for example, an optimistic outlook or the deeply rooted belief that one can master any crisis. For others, who have developed a generally pessimistic view of life, feelings of helplessness and powerlessness may predominate when they learn their diagnosis. Studies in a number of illnesses have shown that these fundamental beliefs have an influence on a person's quality of life, their health and on how actively they participate in the management of their disease.

Although personalities, thought patterns and attitudes are relatively consistent, professionals can help people to develop new coping skills. For example, a psychologist can help a person build confidence, motivating the individual to take a more active role in managing the disease, whilst a professionally-run workshop can teach valuable techniques for dealing with MS.

### **Living with uncertainty**

Coping means learning to live with the uncertainty that is characteristic of MS. Effective coping depends, in part, on maintaining one's self-confidence, particularly the belief that one will be able to face the daily challenges of MS.

### **The importance of being informed**

In order to regain or maintain a feeling of confidence and of having some control over one's life, it is very important that the person with MS becomes informed about the disease. Gathering information, talking to others affected and asking MS professionals questions are ways in which a person develops a great deal of knowledge about MS. People can also gain a sense of control and actively participate in making healthcare decisions by being aware of the treatments available, symptom management strategies, legal and financial rights, self-help groups and other support resources.

People with MS who have a desire to learn more about their disease may need guidance and suggestions about appropriate sources of information. In addition, people who are newly diagnosed may prefer to choose specific topics that are relevant to their current situation. The healthcare professional providing this type of advice should understand something about the person's lifestyle and individual needs. No two cases of MS are the same and hence people's information needs vary. Some may prefer to speak to MS specialists, while others may prefer to contact MS society help-lines or participate in mutual support groups. Others may prefer publications that allow them to absorb information in their own time, and which can be put aside for

later reference. More recently, the Internet has become an important and popular source of information. However, not all websites are equally reliable. Many MS societies have their own websites that offer up-to-date, independent information and can usually recommend other, reliable sites that can be useful for people looking for information about MS.

### **Balancing hope and realistic expectations**

Hope plays an important role in coping with any illness. It is a source from where those affected draw their strength, optimism and energy. However, it is not always easy to strike a balance between being hopeful and maintaining realistic expectations. Unrealistic expectations can lead to bitter disappointment, especially when a certain treatment or therapy does not provide the expected result.

Such unrealistic expectations can result from misinformation being provided to the individual, a lack of understanding of the therapy's capabilities, or from an especially strong desire to believe that the therapy will be able to do something that it is not actually intended to do or is capable of doing.

For these reasons, it is vitally important for the person to have appropriate education and information before beginning any treatment or therapy in order to avoid disappointment caused by unrealistic expectations. It is also worth mentioning that unrealistic expectations can cause some people to decide to interrupt a therapy regimen before its full effect can be realised.

### **Decision-making**

MS rarely forces anyone to make precipitate decisions. An acute relapse or other crisis is seldom the right time to make important or far-reaching decisions. However, it is during these difficult times that a person with MS is more prone to making life-altering changes, for example, deciding to leave the workforce while experiencing an MS relapse.



Healthcare professionals should encourage newly diagnosed people to seek support during times of crisis in order to avoid the mistake of impulsive decision-making based on anxiety and fear. The person with MS may wish to talk to those they are closest to, or those who are directly affected by their choices, to help with the decision-making process.

### Stress

Each person defines stress in his or her own way. What is known about the relationship between stress and MS is incomplete. We do know that a person's level of stress is higher during MS relapses. It appears that stress has a negative impact on well-being and poses a risk to a person's health and relationships. Receiving a diagnosis of MS is a major source of stress for anyone. The unpredictability, dealing with various symptoms, learning new information and changing roles are just some of the many other sources of stress that accompany the diagnosis.

There are ways of successfully coping with the problems of day-to-day life that will diminish feelings of being overtaxed, frustrated and angry. It is important that people with MS are not encouraged to make important changes in life based on the notion that stress worsens MS and therefore should be avoided. Rather, strategies for reducing stress, which also vary from person to person depending on one's lifestyle, should be recommended. These may include physical activity, pursuing a hobby, relaxation techniques, self-help groups, etc.

### The family's emotional experience

Partners, children and other family members experience their own emotional uncertainties and feelings of powerlessness when confronted with a diagnosis of MS. Those closest to someone with MS may have similar emotional experiences to the person who has received the diagnosis, such as the desire to ignore the presence of MS in the family, unrealistic expectations regarding therapies, daily stress related to living with the disease and challenges to effective coping. They too can

benefit from learning about MS and talking with other families who are also dealing with the disease. One of the most important resources for all involved is mutual support. Having relationships based on trust and open communication within the immediate and extended family, as well as social circles, can really help.



The emotional challenges faced by a person who is coping with a diagnosis of MS vary and do not necessarily follow a standard order. Although denial, anger, stress and anxiety are common emotional reactions, the order in which they are experienced, as well as how much time an individual requires to come to terms with each of these, depends on the person's previous coping style and the support he or she has from healthcare professionals, family and friends.

One important role of healthcare professionals is to help people recognise and effectively manage the emotional challenges that accompany the diagnosis of MS, teaching coping skills that can be useful not only early in the disease but also over time.

# Depression and MS

By Eli Silber, Consultant Neurologist, King's College Hospital, London, UK

Multiple sclerosis may affect many areas of a person's life. The physical manifestations, such as the effects on walking, hand function, speech and co-ordination, are commonly recognised because they are usually visible to others. There are other effects that remain hidden to many people, including friends and families.

This may be because they are not visible to others (such as pain and fatigue) or they may be hidden because of embarrassment, such as problems with one's bowel and bladder.

Depression is an emotional challenge that can be quite disturbing for the person who experiences it directly, as well as for those close to the individual.

## What is depression?

All of us have periods of feeling "down" or "low". Depression, in contrast, is a disorder characterised by a persistently low mood, occurring most of the time and lasting for some weeks or more. This is sufficient to cause distress or affect social or work functioning. The low mood is usually accompanied by feelings of being sad or empty.

People with depression often report a loss of interest and pleasure in daily activities and may feel worthless and guilty. In some people, particularly men, their depression is manifest as increased anger and irritability. This may be exaggerated when physical disability limits functioning.

Outward signs of depression may be visible in some people. These include tearfulness and a loss of interest in personal appearance. People may be irritable, fidgety or less active physically.



## How common is depression in people with MS?

People with MS are more prone to depression, with approximately half experiencing a period of significant depression at least once in their lives.

This is quite high when compared to the estimate of the general population, which is 15 per cent. Between 15-30 per cent of people with MS are thought to be depressed at any one time.

It is important to stress that the overall risk of suicide remains very low in the general population, including people with MS. However, recent studies have shown for the first time that the rate of suicide amongst people with MS is significantly higher than in the general population. A considerable number of people with MS have reported considering suicide at one time or another.

### **What causes depression in people with MS?**

The causes of depression are uncertain. It may be understood as a state of abnormal brain function that may be triggered by both external stresses and by underlying brain disease. In MS there are many obvious external triggers, including pain and the effects of the disease on family, housing, work and finances. There is also evidence for brain dysfunction, including increasing depression in persons with MS plaques in specific parts of the brain.

### **Overlap between depressive symptoms and MS symptoms**

People with depression commonly experience physical symptoms. These include disturbances of appetite and sleep, cognitive dysfunction, fatigue, pain and a loss of libido. These are also very common effects of MS and it is difficult to tell what may be causing the problem. If these problems are due predominantly to depression, then appropriate treatment is likely to bring about an improvement.

### **Managing depression**

Identifying depression in people with MS offers considerable hope. In contrast to many complications of the disease for which there are limited treatments, the majority of episodes of depression are not permanent. The management of depression must be tailored for

each individual patient. A vital first step is identifying depression and overcoming the stigma related to it. Treatment is built on a combination of addressing precipitating problems, anti-depressant medication and therapeutic counselling. Precipitating problems include social issues such as difficulty with housing and finances.

There may also be relationship issues that need to be addressed. MS affects both partners in a relationship. The loss of physical abilities, sexual function and work, amongst others, may affect both people. Likewise, caring for someone with MS imposes stresses on both people. In these cases, involving partners in counselling may be helpful.

The anti-depressants used include both the traditional medications, such as amitriptyline or dothiapine, and the newer agents such as fluoxetine, paroxetine or citalopram. These medications take at least four weeks to have an effect. Their availability may vary by country. As with all medicines, the anti-depressants have side effects that may limit their tolerability, including drowsiness, a dry mouth, constipation and difficulty passing urine.

They may, however, also be beneficial for treating nerve pain that commonly affects people with MS, as well as helping people with sleep difficulties or an overactive bladder. The newer agents mentioned above have fewer side effects and may also be helpful if there is associated anxiety, and in treating fatigue.

Cognitive behavioural therapy (CBT) attempts to identify and address distortions in the way that a person perceives themselves and the world. CBT involves a commitment from the person to work actively, over a fixed period, with the therapist to address their problems. CBT can be as effective as medication in people with mild to moderate depression. When the two are used in combination, there are added benefits.

## OTHER EMOTION-RELATED CHALLENGES

A part of the brain, the frontal lobe is responsible for both control of emotions and their outward expression. People with damage in this area due to MS may experience changes, usually unpredictable, that may or may not be related to the emotion being experienced.

### Mood swings

Mood swings can be described as a rapid fluctuation in mood, with alternating euphoria and depression. While many people have experienced mood swings at some time, it appears that people with MS may be more at risk of this problem. Since mood swings can create difficulty within a family or social circle, it is important that the person experiencing them discusses the problem with those around him or her, in order to help avoid misunderstanding. Some people find mood-stabilising medications or anti-depressants helpful, while others find counselling beneficial. The objective of counselling in this case is to help the person to learn effective ways of managing unpredictable changes in mood. Often a combination of these solutions can be helpful.

### Disinhibition

MS-related disinhibition, or a loss of control over impulses causing inappropriate behaviour, is a difficult problem to manage and can be very upsetting, especially for the family. Aggressive or sexually inappropriate language or behaviour may be controlled with mood-stabilising drugs, although hospitalisation, in order to follow a more intense medication regimen, may be required in rare cases.

### Pathological laughing and crying

Pathological laughing and crying is a symptom in which the person experiences episodes of laughing and crying that occur independently from any emotion. In other words, the manifestation of sobbing or seemingly



*Pathological laughing and crying can be easily misunderstood and relatively disruptive.*

exaggerated laughter is not the result of what the person is feeling, but an uncontrollable, unpredictable demonstration resulting, apparently, from demyelination in the emotion-centre of the brain. Both the individual and those close to him or her should receive information about this problem since it can be easily misunderstood and very disruptive. Currently there is no definitive treatment for this rare symptom, although clinical trials of dextromethorphan (combined with an agent to sustain therapeutic levels) are underway for people with uncontrollable laughing and/or crying from a variety of neurologic conditions.

### Conclusion

Emotional changes are common in MS, and can be as distressing as many physical symptoms. However, help is available and most emotional symptoms can be treated successfully in the majority of people. This may or may not involve the use of drugs. It is important for those affected by MS, either personally or professionally, to remain aware of the potential emotional changes that can arise, so they may ensure that appropriate help is sought and provided.

# Understanding cognitive changes

By Päivi Hämäläinen, Chief Psychologist,  
Masku Neurological Rehabilitation Centre, Masku, Finland

Cognitive functions include the abilities to:

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

These abilities develop very individually. We all have our personal cognitive strengths and weaknesses.

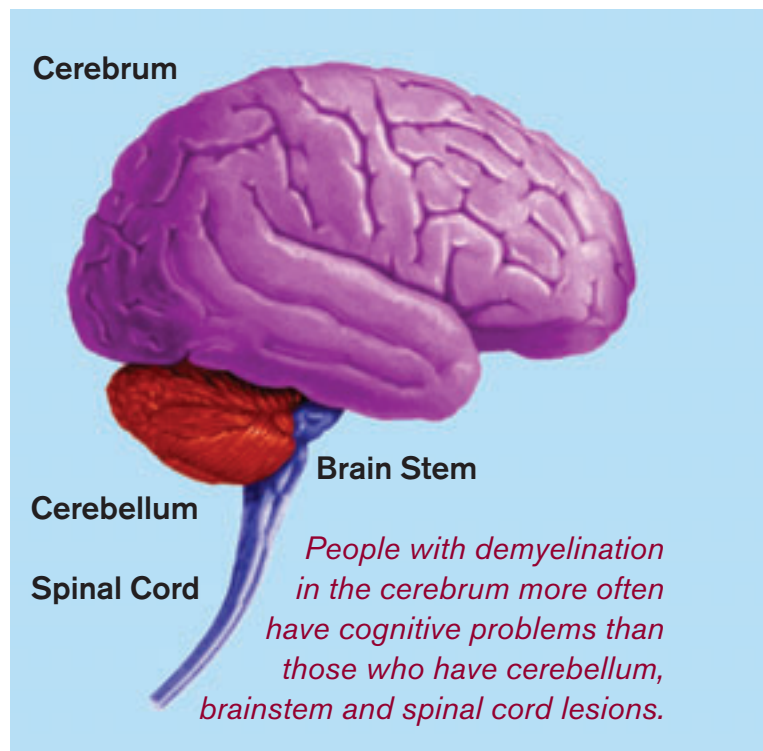
## How typical is cognitive impairment in MS?

Cognitive deficits are not the most typical symptoms of MS. In fact, severe cognitive impairment that makes everyday coping difficult is reported in 10 per cent of people with MS, whereas an estimated 40-50 per cent experience mild to moderate disturbances. This means that about half of those diagnosed with MS never experience cognitive impairment.

Even mild impairment may require changes in a person's routine and habits. For example, coping at work may require extra effort and the use of aids or compensatory techniques. If cognitive deficits are not identified properly, they may be a cause for stress and misunderstanding at work and at home. They should, therefore, be recognised as early as possible, so that steps can be taken to ease the situation.

## What kind of cognitive impairment is associated with MS?

The most common types of *memory* problems are difficulties in remembering recent events and remembering planned or necessary tasks. Some people with MS also report that it takes more time



and effort to find misplaced items and to remember new information.

Some people find it difficult to *concentrate* for long periods of time or have trouble keeping track of what they are doing or saying when distracted or interrupted, for example, carrying on a conversation while the TV or radio is on. Moreover, many people describe feeling as though they cannot function as quickly as they could before MS.

Some people experience difficulties when *planning* and *problem solving*. People with these types of problems usually know what should be done but find it difficult to know where to begin or to work out the steps involved to achieve their goal.

People with MS may also experience difficulties in *word-finding*, reporting that a word or name is “on the tip of my tongue”. The person knows the word but is unable to retrieve it.

MS can lead to other types of cognitive problems. One well-known study reported that visuospatial abilities are affected in up to 19% of people with MS. However, deficits in language are less frequent. Furthermore, severe cognitive decline or dementia, such as that commonly seen in Alzheimer’s disease, is rare in MS.

### Are cognitive deficits predictable and do they progress?

It is not possible to predict from other symptoms of MS whether someone is likely to suffer from

## CURRENT UNDERSTANDING OF MS AND COGNITIVE CHANGES

Much of our understanding of cognitive changes related to MS has come from scientific research. Here are some general statements we can make based on current knowledge in this area:

- There is little or no relationship between duration of the disease, or severity of physical symptoms, and cognitive changes.
- People with a progressive form of the disease are at a slightly greater risk of cognitive changes, although those with relapsing-remitting MS can have difficulties.
- Cognitive problems can worsen during an exacerbation and lessen with remission, although the changes in these symptoms appear to be less dramatic than those seen with physical symptoms such as walking and vision.
- Cognitive changes can and do progress like other symptoms, but the worsening appears to be slow in most cases.

Source: *Multiple Sclerosis: A Guide for Families*, Rosalind Kalb, Ph.D., Demos Vermande, 1998 p.24

cognitive impairment or not. Cognitive problems do not seem to be related clearly to such disease variables as duration, severity or disease course. Cognitive deficits may be present during the early stages of the disease, as well as later on, in mildly or severely physically disabled patients. Cognitive impairments have no known link to any single physical symptom of MS. However, sometimes dysarthria (poorly articulated speech), ataxia (problems with co-ordination) or nystagmus (rapid involuntary eye movements) may be falsely interpreted as a sign of cognitive impairment.

It has been found that cognitive deficits are more common in people who have changes in the cerebrum than people who have changes in the cerebellum, brainstem and spinal cord alone.

Unfortunately, little information exists about the progression of cognitive impairment in MS. It has been found that cognitive performance can vary during even short follow-up periods. Recent studies show that if a person experiences some cognitive problems, worsening is possible, although the rate of progression is usually slow.

### Are cognitive problems permanent?

Whereas brain lesions can result in more permanent cognitive problems, a number of factors can interfere with or impair cognition temporarily. These factors include fatigue and tiredness, emotional changes, MS relapses, physical difficulties that may require extra effort and concentration (such as unstable walking), medications and lifestyle changes, such as having to leave employment and therefore having less mental stimulation.

Living with a chronic, progressive and unpredictable disease inevitably affects a person’s mood. When people are depressed or feeling low, they may experience memory lapses or problems concentrating. Usually these difficulties are not long-lasting. Many people with MS report cognitive problems during periods of fatigue, and recent studies have shown that cognitive performance may be slowed or be less accurate when the person is experiencing fatigue. Temporary cognitive difficulties may also occur during relapses. Just as

## MANY FACTORS CAN AFFECT COGNITIVE FUNCTIONING



with physical symptoms, cognitive problems may be restricted to the active inflammation phases of the disease. Cognitive functioning can be affected by several factors, so it is not usually appropriate to evaluate cognition if the person is experiencing depression, a relapse or excessive stress.

### Evaluating cognitive problems

Even mild cognitive impairments can cause feelings of uncertainty and fear. It is important to know that these symptoms, just as with bladder problems, or difficulty walking, are part of the disease and that there are ways to live with them.

Since realistic information can help a person to cope with a new situation, it is important that each person diagnosed with MS receives information about cognitive impairment. Cognitive problems are evaluated with a neuropsychological assessment, which includes testing and a detailed interview. The goal of neuropsychological assessment is to individually evaluate the severity and characteristics of cognitive impairment. Furthermore, an individual's cognitive strengths can be identified and strategies to alleviate the effects of impairment can be suggested.

Not everyone necessarily requires a neuropsychological assessment. Many people can identify for themselves the individual areas that are causing problems and work out ways to deal with them. Neuropsychological assessment is important when evaluating ability to work, possibilities for re-education or driving ability. An assessment should also be performed if cognitive impairment continuously interferes with a person's daily activities and/or social interactions.

### The role of neuropsychological testing in research

Neuropsychological assessment has been employed for study purposes in evaluating the frequency, the characteristics and natural history of cognitive impairment, as well as its relationship to other disease variables. Studies on cognitive functioning in MS have been able to show the effects of cognitive impairment on employment, driving skills, personal independence, etc. Many recent studies have evaluated the effectiveness of medications and different rehabilitation methods on MS-related cognitive deficits. These kinds of studies have made it possible to develop methods to alleviate the effects of cognitive problems.

# Day-to-day living with cognitive problems

By Dawn Langdon, Senior Lecturer, Royal Holloway, University of London, UK



The cognitive impact of MS on everyday living is often overlooked, because cognitive difficulties are so much less visible than physical symptoms. Cognitive factors can have their own separate effect on people's lives, above and beyond the physical restrictions imposed by MS. A person with cognitive difficulties is less likely to be employed and more likely to cease employment in the years ahead. Similarly, the number of social contacts is likely to be less and to reduce in the years ahead. Cognitive problems can mean that a person is able to do less well in physical rehabilitation. Because of these and other impacts, people whose experience of MS includes cognitive dysfunction need information and support.

If a person with MS feels that memory and concentration are not as good as they used to be, the person may find it hard to admit that this is happening as part of the MS. This is entirely understandable, because we tend to think of our

mind as a perfect whole. For some people, it reflects their spirit or soul. Any changes or lapses, such as forgetting a word we want to say or missing an appointment, can seem to cast doubt on the whole mind or the whole person. Cognitive problems do not mean that a person's spirit or soul is lessened or involved in any way. Instead, cognitive difficulties occur when MS affects the areas of the brain that control memory and concentration.

Cognitive symptoms are very much like physical symptoms. Just as a person with stiffness in the legs may have difficulty walking, but still be able to walk to the nearby shop, so a person with cognitive difficulties may need to take longer to read a book, but can still enjoy doing so. Similarly, as walking may vary during the day or over periods and be influenced by fatigue, so too can cognitive skills fluctuate at different times and be blunted by fatigue.



For most people with MS who have cognitive symptoms, some types of thinking are affected, but not all and not uniformly. Everyone, whether they are healthy or ill, experiences difficulties such as unintentionally substituting one word for another or suffering a memory lapse, but because these difficulties occur more often for some people with MS, they start to impact on daily life.

Cognitive problems may be noticed by family. Sometimes family members can find it hard to talk about cognitive difficulties, because of embarrassment or fear. However, in a trusting, positive relationship, talking about cognitive problems is often the first step to constructive help. It may be that the family observes the effects of cognitive problems in MS, but mistake them for something else. For example, a person with MS who always forgets to feed the cat whilst their spouse is at work might mistakenly be thought by their spouse to be deliberately unhelpful with household chores and unappreciative of the load that the spouse is carrying to support the person with MS in the home. In fact, the real reason for not feeding the cat is simply that the task slips the mind of the person with MS, and it slips their mind nearly every day, as a result of their MS. In this situation, a small reminder such as an alarm, a note stuck on a door, or a phone call, might be enough to help the person with MS feed the cat routinely and possibly complete other tasks as well.

Colleagues at work may also be aware that things are not going well. Again, being able to talk with the person with MS about their particular difficulties can lead to solutions. For example, a person with MS who is working as a gardener may not be completing her daily planting tasks, despite being given clear instructions for the day by her boss. Mistakenly, the boss thinks that the failure to finish all of the planting is due to laziness on the part of the person with MS. In fact, by talking about the problem, it becomes clear that the first few plantings are always done expertly and quickly. It is the later tasks that are not completed, because by the afternoon, the gardener with MS is finding it hard to remember the instructions. This could be solved by either taking notes of the instructions

each morning, or possibly placing all the plants where they are to be planted, before any planting starts, to act as “prompts”. This helps the gardener with MS remember the morning’s instructions.

Talking about cognitive difficulties will usually be a source of relief to the person with MS and their family and may lead to easy solutions, but sometimes more expert help is needed. This may be because there are several factors involved, such as fatigue, anxiety or depression. Or perhaps the cognitive difficulties are interacting with the management of physical symptoms, such as bladder function or self-administered medication.

The simplest strategies for dealing with cognitive problems involve some physical aids, such as diaries or electronic journals. Others involve ways of thinking and organising facts so that they can be retrieved more reliably on demand. For people whose memory problems are more severe, it is helpful for them to learn to perform tasks without mistakes. Trial and error is difficult for them, because they find it hard to forget the wrong way of doing things and hard to substitute the new, right way. Small, early studies of this approach, known as “errorless learning”, have been promising.

Understanding and acceptance are vital for living well with cognitive problems in MS. The first step to constructive change is talking, to share one’s experiences of cognitive problems and solutions in MS. A positive, confident approach is likely to lead to good coping.

#### **MEDICATIONS THAT MAY AFFECT CONCENTRATION\***

| <b>Chemical name</b> | <b>Use in MS</b>          |
|----------------------|---------------------------|
| Amantadine           | fatigue                   |
| Clonazepam           | tremor, pain, spasticity  |
| Diazepam             | muscle spasms, spasticity |
| Fluoxetine           | depression, MS fatigue    |
| Gabapentin           | pain                      |

*\*It is important to keep an updated list of current medications and never to adjust or discontinue a medication without consulting the prescribing physician.*

# Simple ways to compensate for memory problems

- Keep a daily diary or notebook. Write down all appointments, reminders, and lists of things to do in one place. Tick things off once they are done. Get into the habit of referring to this diary routinely, perhaps at the same time each morning and again in the evening for tomorrow's schedule.
- When you make or receive a phone call, note the date, time, whom you spoke with and a short reminder about what was said.
- Post a large family calendar in a prominent place, maybe the refrigerator door, where



*"What you're trying to do is replace memory with organisation."  
Dr Nicholas LaRocca*

everyone in the household writes down their activities and schedules. Tick things off as they are completed.

- Use a wristwatch with an alarm, and set it to remind you of events. People who must take medication at certain intervals find this especially useful.
- Electronic gadgets like personal digital organisers are effective for lists, agendas, important phone numbers, and addresses. Or try other organisational tools such as index cards, or a portable computer.
- Place reminder notes in useful locations around the house or work place.
- Keep important things in a designated place. Keep your daily diary on your night table or next to the phone, your keys in a particular drawer or on a hook near the door. Consistency and routine make it easier to remember where things are.
- Design a master shopping list, with all the items you normally need, and make multiple copies. Before going out to shop, review the list and check off the items you've run out of.

Try to stay calm when memory fails. "It's normal to tense up or feel frustrated if you are forgetting or losing something, but when you do, you switch out of the problem-solving mode and into the angst mode," notes Dr LaRocca.

\* Adapted from *MS and the Mind - Memory and Problem Solving*, by Martha Jablow, National MS Society, USA.  
[www.nationalmssociety.org](http://www.nationalmssociety.org)

# Emotional issues of healthcare professionals

By Kaye Hooper, MS Nurse Consultant, USA/Australia

Healthcare professionals are committed to providing care, education, support, treatment, counsel and advocacy for patients with MS. During this time, personal and meaningful relationships are formed between the healthcare professionals and the person with MS and family members. There are times of sadness for the person with MS and family members, when the diagnosis is given and then during the changes and challenges that MS brings into their lives. This can be an emotional, stressful and challenging time for the healthcare professionals too. Healthcare professionals need to develop coping strategies in order to keep well themselves so that they can continue to support, care for and inspire hope in people with MS.

## Some signs of stress and emotional burnout

- Exhaustion and sleep disturbance
- Headaches and increased susceptibility to illness
- Distancing from colleagues and patients
- Negative self image
- Depression, anger
- Impaired ability to make decisions and care for patients

## Stress factors which may lead to burnout

- Work overload in your practice, and/or staff shortages
- Working in an isolated situation without the support of other team members
- Unrealistic expectations of oneself or the treatments given
- Watching patients progress in disability – despite all interventions
- No time for self reflection and assessment
- Poor relationships and poor communication with other colleagues

- No recognition for your achievements and skills
- Lack of supervision and mentoring
- No division between home and the workplace – taking work home with you
- An inadequate knowledge base and lack of experience in MS

## Coping strategies for self care

- Develop a peer support network
- Attend regular team meetings and schedule times with colleagues
- Recognise the importance of supervision – have a qualified supervisor to offer supportive and educational oversight
- Guard your daily schedule – be available but not to constant interruptions
- Continue your education – increase your competency and knowledge of MS
- Keep your sense of humour and cultivate creative thinking
- Take regular exercise and maintain a balanced diet
- Separate home and work – “switch off” when you leave work
- Take holidays/vacations at regular intervals
- Allow time for yourself and your family
- Keep a diary of feelings and experiences
- Take one day at a time
- Take time out to discuss emotionally difficult situations when clinical cases are reviewed
- Time management – plan ahead and stick to it
- Decline extra commitments – learn to say “no”

**Burnout is a risk for all health care professionals – prevent it by caring for yourself.**

# Your questions answered

Readers of *MS in Focus* put questions to the Editor, Michele Messmer Uccelli. With many thanks to our experts for their advice.

**Q. Are there medications that help to improve cognitive problems in MS? Thanks, Daniel**

A. No medications have yet demonstrated long-term success in large clinical trials in reducing cognitive problems. During recent years, there have been studies of ways to stabilise or improve cognitive dysfunction. Some have focused on whether MS disease-modifying drugs, which have all been shown to reduce the accumulation of new demyelinating lesions, can also slow the progression of cognitive problems. In theory, this should be the case, although results, thus far, have been varied.

**Q. Why do I frequently use words that are inappropriate? For example, the other day I said “gloves” in a sentence when I meant to say “pockets”. Regards, Barbara**

A. Studies show that difficulty in naming objects is a fairly common problem in MS. Some researchers believe that this difficulty is related to myelin damage in the brain preventing people from retrieving language information stored in the brain. Unfortunately neither cognitive rehabilitation nor compensatory strategies seem to help in managing this type of problem. What can help is for you to inform others around you (family, friends, work colleagues) that you occasionally experience this difficulty and encourage them to communicate their concerns in order to avoid misunderstandings.

**Q. I am concerned about the control of emotions. I find that I can become tearful at the strangest and most inappropriate times, and in any situation. It has started to become a concern and very embarrassing! Is this a common thing for people with MS? Is it part of the condition? Do you have any tips on dealing with this? Thank you, Gerry**

A. These emotional changes that you describe sound like a term referred to as “emotional instability” (also called “emotional lability” or “emotional release”). It seems that about 10 per cent of people with MS have similar experiences as a result of demyelination in the part of the brain that controls emotions. If you feel that this tearfulness is disrupting your life in some way now or may cause problems (for instance with family life, work or social interactions), you should talk to your neurologist or psychologist. Some MS centres have specialised nurses who are skilled in helping to manage these types of problems. There are even some self-management strategies that you can learn from a healthcare professional to apply in everyday life. It's really worth discussing this problem in order to manage it better.

**Q. Is it possible that MS has influenced my terrible mood swings? I'm a teacher and children's worker. One time I think I can take activities with kids and another time it drives me to despair to even think of the responsibility. One day I'm all gung-ho and another day I couldn't even think of it – or even the next hour. It can literally change by the hour. Please help me manage this if possible. Linda**

A. It is important that the people around you are aware that you are having this difficulty. This serves mostly to avoid misunderstandings. Some people are prescribed mood-stabilising medication or anti-depressants, which do help in some cases. For others, counselling is an excellent solution, giving the person the chance to explore her feelings with a professional and learn ways to manage unpredictable mood changes better. In all of these cases, the first step is to talk to your healthcare provider – neurologist, MS nurse or psychologist.

# Interview: meet Steve Cooper

Steve Cooper from Philadelphia, Pennsylvania, USA, talks to Chloe Neild about his successful management of MS-related cognitive difficulties and other experiences of living with MS.



*Steve Cooper at work*

## **How long have you had MS?**

I was diagnosed in April 1982. In retrospect, I believe the first signs of MS appeared in January 1980.

## **When did you first have MS-related cognitive symptoms?**

In 1980, I was working and also completing part-time graduate studies in New York City. As I lived approximately 160 miles from the university, I had to travel for eight hours a day on top of work and lectures.

The travelling, lack of rest and the 19-hour day did not become a factor until January 1980, when I was in the last year of the course and shortly to graduate. It was then that I began experiencing pronounced fatigue and an inability to study and absorb the content of the material read.

*'I have learned the need to exercise the mind. In my case, I find it important to read extensively. I enjoy writing on varied topics, both factual and fictional'*

## **When they began, were you aware that cognitive problems were part of MS?**

For a long time, I didn't suspect that these problems were even related to MS. I thought it was just a case of getting older.

Much later in 1999, when I was working at the MS Society, a client had asked whether treatment for his cognitive symptoms would be covered under his health insurance policy. Whilst researching the answer, I realised these symptoms were certainly MS-related and that I too could be suffering from MS-related cognitive dysfunction. I now have no doubt this is the case.

### **Can you describe the cognitive difficulties you experience?**

In addition to memory loss, I have difficulty in paying attention to complex lectures and concentrating on work requiring professional skill. I also find it problematic to remember names, appointments, errands to be completed and that appropriate word needed to finish a sentence.

### **Have your cognitive difficulties changed over time?**

I had the good fortune to be seen by a psychologist who specialises in treating MS-related cognitive impairment. Our sessions included, among other exercises: the need and way to take proper notes; the correct method for reading material to establish its central theme; and directing my thoughts on a single task, not multiple ones.

### **How do your cognitive difficulties impact on your lifestyle?**

Before I became aware that my symptoms were related to cognitive dysfunction and there were techniques to manage them, I thought, at times, my conversations with people made little sense. I was also convinced that my IQ had dropped dramatically and that my ability to understand complex ideas was questionable. I now know that: this condition is treatable; my IQ is unchanged; my worry about not clearly conveying my thoughts during a conversation was wrong; and that I was much too critical of my abilities. Yes, I have a problem, but I have learned how to live with it.

### **Did healthcare professionals provide support to help you learn techniques to manage your cognitive difficulties?**

The treatment by the therapist taught me ways to overcome problems related to this impairment. I realise now not to rely on my memory, regardless of the simplicity of the task. I understand the necessity of taking good notes, resting when it's needed, and not being too critical of my abilities.

### **What advice do you have for others who may be experiencing cognitive difficulties?**

In addition to the above techniques, I have learned the need to exercise the mind. In my case, I find it important to read extensively. I enjoy writing on varied topics, both factual and fictional. Since I have a passionate interest in history and politics, I relish a good debate in both areas. I have a close friend whose politics are a bit to the right of Attila the Hun. I enjoy our discussions when I have the opportunity to challenge his opinion, whether it relates to health care in the United States or his thoughts on this year's political races.

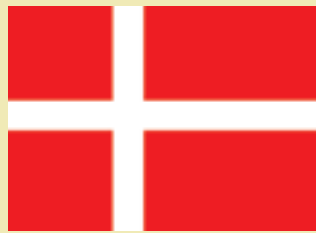
*'My IQ is unchanged; my worry about not clearly conveying my thoughts during a conversation was wrong; and I was much too critical of my abilities.'*

I also find it useful to search the Internet, regardless of the subject, and to play as much Scrabble as humanly possible. These are simply methods of exercising the brain and strengthening the thought process.

It is equally essential to limit one's distraction as much as possible. At work this includes not sharing my work space, confining myself to a small cubicle of an office and closing the office door when necessary.

# Learning by doing – the Danish way

By Marianne Nabe-Nielsen and  
Bente Østerberg, Senior  
Psychologists, The Danish Multiple  
Sclerosis Society



## Rationale

Over the last decade it has become increasingly clear that MS can cause permanent cognitive problems and, along with this, that most people with MS have concerns and fears regarding their cognitive abilities.

Therefore the Danish MS Society has developed courses for people with MS who experience cognitive problems that influence their daily life and social activities.

## Objectives

The objective of the course is to improve the cognitive and psychological coping of people with MS.

## Background

Research shows that the majority of people with MS who have cognitive problems experience mild or moderate degrees of impairment. These symptoms may negatively affect a person's self-esteem and cause embarrassment, the consequences of which may lead to social isolation. Research also shows that people with MS can learn to compensate for some of these impairments and that this is of crucial importance for their quality of life and social well-being.

Experience shows that basic knowledge of potential cognitive difficulties helps those affected to cope. For the individual with MS, it is important that they are psychologically aware and open about any "invisible" and potentially socially disabling cognitive symptoms, as this will help them to adjust and cope. Participating in a group with others in a similar situation provides the opportunity to exchange experience and knowledge. This may help the person expand his or her own coping resources, and reduce anxiety and the feeling of being stigmatised.



*Don't forget...*

### Marketing the programme

The course is advertised in the MS Society magazine and through brochures distributed locally. More recently the MS Society website has been used to advertise MS Society courses.

### Programme Structure

Each course has between eight and 12 participants with mild or moderate cognitive problems. The programme consists of lectures, discussion and activities aimed to help the individual:

- learn how the brain functions
- learn about what types of cognitive problems are related to MS
- increase awareness of one's own cognitive approach and thought patterns
- increase awareness of one's cognitive weaknesses and strengths in order to find suitable ways of compensation
- explore strategies for compensating for cognitive problems

In order to meet the needs of each and every participant, it is important that sufficient time is incorporated to absorb key points. Participants are asked to use a variety of techniques in the process of memorising, and time is allowed for them to reflect and comprehend, repeat and recall, and to take notes.

An important teaching strategy used throughout the courses is based on the principle of learning by doing. Participants are given the opportunity to practice newly learned strategies in the group setting, and are encouraged to talk about which strategies can be useful in daily life and where further special attention may be required.

The combination of lectures, discussion and exercises challenges the participants' ability to find the strategies to aid memory and problem-solving. The participants work individually, in pairs and in small groups. The duration of each course is from three to four hours and is held locally. The course is led by a psychologist from the MS

Society with relevant knowledge and experience in group psychology and neuropsychology.

### Outcome/results

There is a great demand for the course. Due to the number of accessible locations available for hosting courses, limited expenses and minimal practical preparations, it has been possible for the MS Society to meet the demand in most regions of Denmark. To date approximately 20 courses have been held.

### Expenses

Include the following:

- venue\*
- psychologist's salary (planning and carrying out the course)
- audio/visual equipment
- lunch for participants
- brochures

\*Facilities that can be used at no charge, such as MS Society branch office, libraries, community centres and schools, are convenient.

### Limitations

It is obvious that with the limited time and range of the course, it cannot be considered a complete training programme on cognition. Neither is it an individual-focused programme, so a person with particular needs may require additional one-on-one consultation with the psychologist. Also, it is a type of programme that cannot meet the needs of people with serious cognitive impairment. Finally, participant recruitment does not involve a thorough neuropsychological assessment.

### Suggestions:

- Offer follow-up courses, so that participants can provide feedback on what they were able to apply to daily life and refresh their recently learned skills.
- Apply the same general format to courses that involve the partner and/or the family members.

*For further information contact the authors  
info@scleroseforeningen.dk*



# Results of the online survey

Responses to a brief online survey on the MSIF website ([www.msif.org](http://www.msif.org)) have revealed how many of our online readers are dealing with emotional and cognitive issues, and what kinds of strategies are most often used.

## Here is what we learned:

Two hundred and seventy people with MS completed the survey. The graphs shown here summarise the frequency with which respondents reported experiencing emotional and cognitive problems.

The results show quite a high frequency of problems, but most people attempt to manage these using a variety of means. The percentage of those who are trying to manage their specific problem in some active way ranges from 93 per cent to 100 per cent.

Anxiety and difficulty concentrating are being managed by 100 per cent of the people who reported experiencing these problems. Although care must be taken when interpreting survey results, especially when there is no demographic

or clinical information on the respondents, this result is very encouraging.

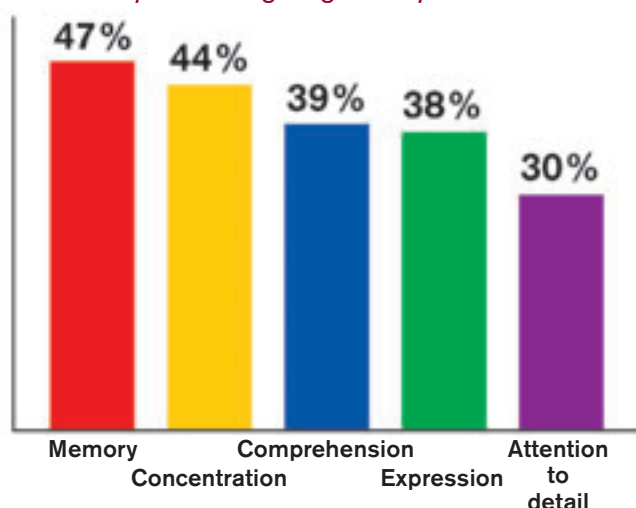
The methods most reported for managing emotional and cognitive problems include medication, compensatory strategies and counselling.

In this group of survey respondents, emotional problems are managed more frequently with medication, followed by compensatory strategies and counselling.

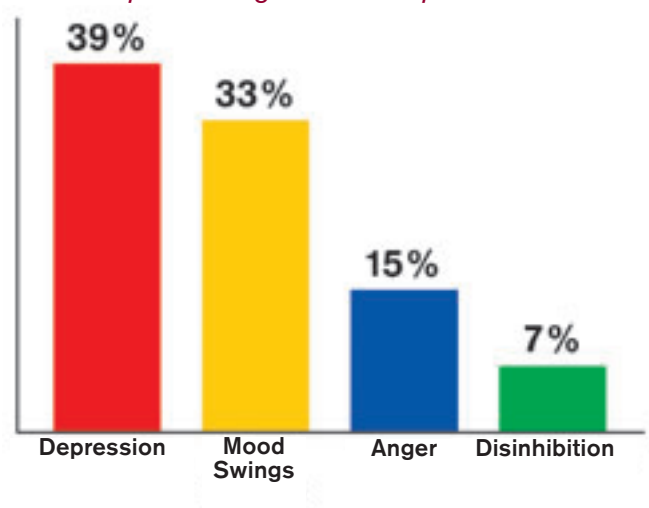
Cognitive problems, on the other hand, are managed more frequently by utilising compensatory strategies, followed by medication and counselling.

The results of this survey confirm what research and experience tell us about the frequency of emotional and cognitive problems in MS. They also reinforce the belief that many people living with MS are active in attempting to manage problems that can have a negative impact on their lives.

*Percentages of survey responders experiencing cognitive problems*



*Percentages of survey responders experiencing emotional problems*



# Reviews

## Love, Honor & Value.

### A family caregiver speaks out about the choices and challenges of caregiving

By Suzanne Geffen Mintz

President/Co-founder,

National Family Caregivers Association (NFCA)

Review by Mary Crowley

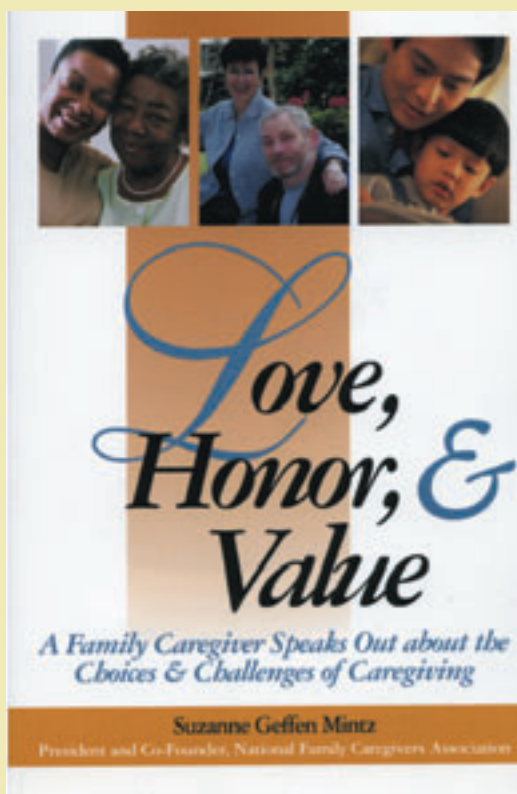
caregiver, MS Ireland

Suzanne Geffen Mintz has written an inspiring, compelling and emotional account of her life as a caregiver to her husband, Steven, who has MS. In a story that all carers will be able to relate to, she highlights the tremendous contribution that the caregiver provides, not only to their individual loved one but also to society as a whole. Some do this at huge physical, emotional and financial cost to themselves.

She brings us through the early stages of her husband's illness, when he first experienced a tingling sensation in both legs; the anxious time when Steven was in hospital and when the doctor finally informed her that he had MS, a degenerative and incurable neurological disease; the depression and despair that followed for her and her family; and how she picked herself up and coped.

Suzanne explains a SWOT analysis. SWOT stands for Strengths, Weaknesses, Opportunities and Threats. This enables the carer to begin to take charge, to find ways to cope with their fears, to decide what choices they have, maybe to seek assistance from family, friends or from their community, and to realise that they are not alone.

She highlights the isolation that comes from having to focus so much on day-to-day living while family and friends turn away. She shares with us the experiences and sacrifices of other



carers: some may have a father, mother, child or other family member in their care; some may have to give up their employment health insurance or pension rights.

In conclusion, she highlights the frustration, sadness, grief, love, kindness, compassion, anger, pride and guilt in a very sympathetic way. It is fascinating and reassuring to read about the experiences of so many different people and how they coped. It conveys the important message to carers that there are others out there having the same experiences.

It should be noted that Suzanne is American. While she has written about her life as a long-term female caregiver in the US, the book manages to retain a universal appeal. I would recommend it to carers of both sexes and all nationalities.

*Publisher: Capital Books, 2002, ISBN 1892123568, Price US\$14.95*

## Me and My Shadow – Learning to live with Multiple Sclerosis

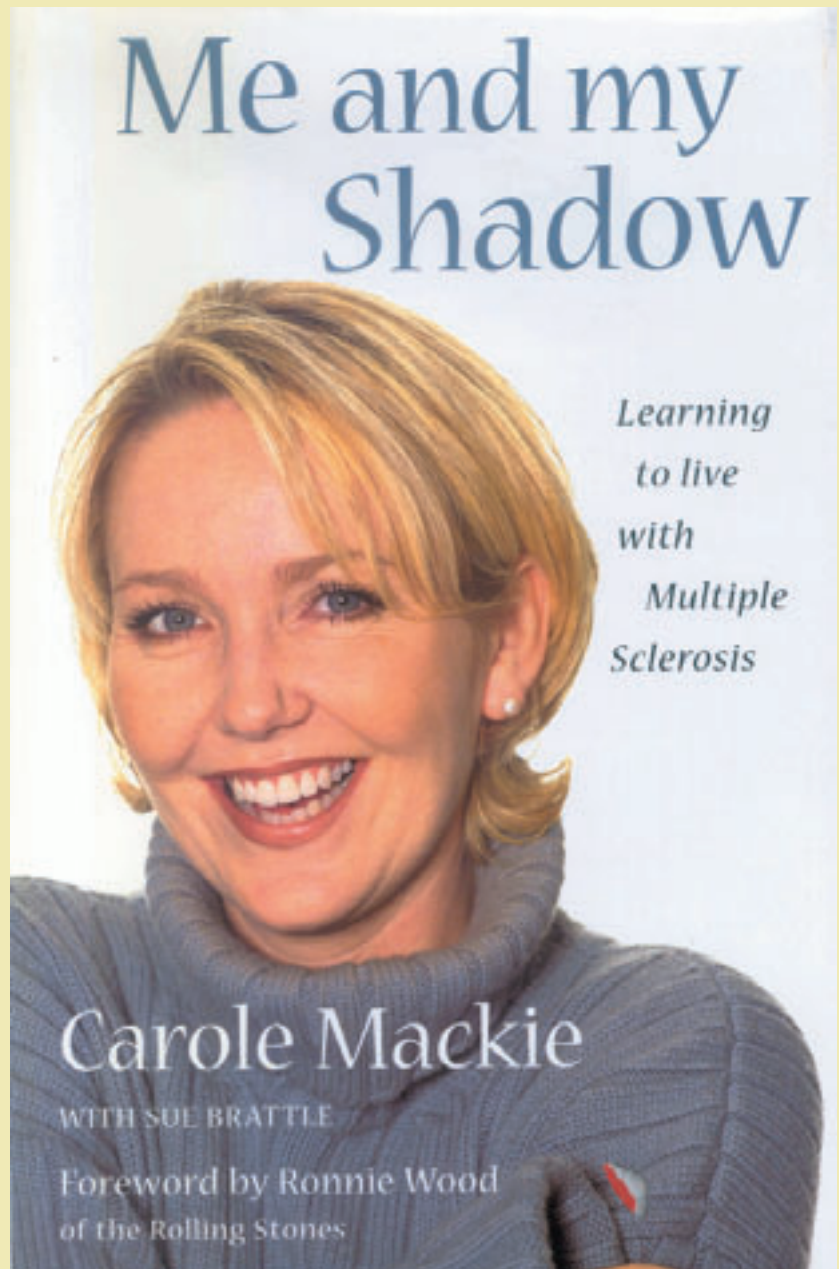
By Carole Mackie  
with Sue Brattle

*Review by Jackie Weight  
cattle farmer, England.*

This is an autobiography of a young woman who is enjoying life to the full in her dream job as a British Airways stewardess, when suddenly, on a break between flights in Rio (her dream destination), she is taken ill and hospitalised. So starts her journey to discovering that she has MS.

Like many of us who have been through it, the journey can be a long and emotionally painful one. Carole's story is told from the heart. It's an open, honest and positive account of the struggle faced when trying to get answers that sometimes don't exist. In the book, Carole's parents, ex-boyfriend and employer take the opportunity to describe Carole's illness from their viewpoint – this helps us understand their different reactions. The book also tells us of Carole's amazing fundraising events in aid of MS research.

This book may worry some people who have recently been diagnosed with MS and don't know what to expect. Carole was unfortunate enough to experience quite quickly many of the symptoms involved with the condition. However, from the moment I started reading the book, I couldn't put it down; partly, I suppose, because I saw myself in Carole too many times and felt myself agreeing with her, both from a symptomatic and a personal



point of view. I was surprised to learn that two such different women could be so alike.

Overall, a very positive book and a really good read which I would recommend not only to people with MS, but also to their family, friends and anyone who really wants to understand how it feels to have MS.

*Publisher: Aurum Press Ltd, 1999, ISBN  
1854106279, Price US\$24.95*

# MS *in focus*



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MSIF is a non-profit charitable organization 501(c)(3) IRC chartered in the State of Delaware, USA, in 1967

## Subscriptions

The Multiple Sclerosis International Federation produces **MS *in focus*** twice a year. With an international cross-cultural board, easily accessible language and free subscription, **MS *in focus*** is available to all those affected by MS worldwide. To subscribe, log on to [www.msif.org](http://www.msif.org)

## With many thanks

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## International MS Nurse Care Plan

The new International MS Nurse Care Plan encourages the standardisation of MS nursing worldwide and promotes the MS nurse as a specialist in the field.

Based on previous work of the Canadian MS Nurse Network, European Nurse Network, UK MS Specialist Nursing Group, the plan was developed during an international meeting of nurses in September 2003 where, in the words of Coleen Harris (University of Calgary), "the most universal and significant theme was the significant role of the nurse in ongoing care of individuals affected by MS".

With multiple applications, the International MS Nurse Care Plan provides a comprehensive and practical guide to

MS nursing which may be used as a:

1. complete teaching and learning tool for MS nurse training;
2. professional development instrument for recognising MS nurse qualifications; and an
3. every day reference for practicing MS nurses.

National experts are now encouraged to adapt the care plan to ensure effective implementation in individual countries.

The Care Plan was developed according to accredited continuing medical education regulations (CME). Content is free from commercial bias.

### Maria Grazia Cali

President, Serono Symposia International  
[www.seronosymposia.org](http://www.seronosymposia.org)