

Personality, Behaviour and Multiple Sclerosis

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This booklet has been written by a group of psychologists, neuropsychologists, counsellors and psychotherapists, members of the Psychology and Neuropsychology Special Interest Group of R.I.M.S. (Rehabilitation in Multiple Sclerosis) with the support of the MS Society, UK.

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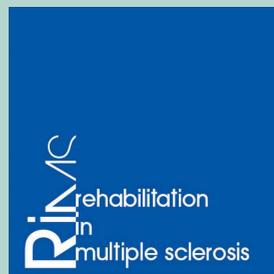
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1 | Introduction

This booklet – Personality, Behaviour and Multiple Sclerosis (MS) – is written by a group of European neuropsychologists and clinical psychologists for people with MS and those who care about them.

Changes in the ways people think, talk, feel, behave and express their emotions can affect people with MS. Some of these changes can be understood as part of the feelings of sadness, frustration or anger associated with having MS. However, changes of personality and behaviour may also be due to malfunctioning of certain brain areas and may be much more difficult to understand.

Not everyone who has MS will experience problems with their personality or behaviour. However, in these rare cases, both the person with MS and those around them may feel confused and anxious.

In this booklet we look at these changes and offer some suggestions about how best to cope with them. We hope that the information will be helpful for those people who experience the changes, as well as for anyone who lives, works or treats patients with these kinds of symptoms.

The main message is that information can promote a deeper understanding of problems and this in turn can open up new ways of coping.

2 | Personality and behavioural changes in MS

MS is a complex condition. Some people have few and slight symptoms, while others have many and severe symptoms. It is not always clear whether a symptom or experience is due to MS or to some other cause. Physical symptoms are relatively easy to recognise: most books about MS mention the difficulties with walking or balance. Some psychological symptoms are also easy to understand. For example, it makes sense that someone might be feeling depressed, anxious or uncertain about themselves because of the diagnosis or their symptoms.

There is another group of symptoms, which is seldom discussed and much more difficult to understand. These symptoms involve changes in the personality and in the ways people behave. **As with any MS symptom, these symptoms do not affect everyone, and nobody is affected by all of them!** The symptoms may come and go; they may last for a short or a long time or they may in some cases become permanent. They may be mild and scarcely detectable to anyone except the person who has them, or they may be more noticeable to others.

Behavioural and personality changes are sometimes taboo subjects. In the absence of information about these symptoms, people may draw their own conclusions, which might be more frightening than the truth.

3 | Why does MS affect personality and behaviour?

Organic changes to the central nervous system, as well as **psychological** changes, can affect people's behaviour and personality.

Psychological causes

Behavioural changes, which result from significant changes in health, employment or living arrangements, are called **psychological changes**.

Everyone reacts differently to the impact of living with MS, depending on one's personality and life history. Accepting a diagnosis of MS and coping with the changes that it creates is no small task. For many people the losses are so great that it is similar to losing a loved one or a close friend. When we lose a partner or parent, we react in different ways, but we expect to feel sad, bad tempered and less able to concentrate. The current losses may evoke memories of past losses. Some people are not aware of this process and find it difficult to understand why they feel so upset.

The impact of loss and change may cause different and unexpected psychological reactions. For example, the ability to think clearly can be affected by chaotic thoughts. Fatigue and loss of sleep are common. People who struggle with the losses may behave and do things in ways that are not at all typical. Denial is often used as a way of coping with change. Usually the symptoms gradually disappear. Over a period of about two years people usually get used to their new situation. Sometimes there is a need for professional help.

Organic causes

There is another way in which MS can affect behaviour and mood. MS causes changes in parts of the brain and spinal cord. Lesions (MS plaques and other brain changes) in the brain sometimes result in behavioural changes. The nature and severity of the changes depends on which parts of the brain are affected.

We call these changes **organic**, because the disease process causes the symptoms. Organic changes may or may not disappear as healing processes take place.

The most common behavioural changes in MS, which can arise from organic reasons are:

- Depression
- “Hidden” depression (depression “hidden” behind a seemingly happy surface)
- Euphoria (appearing unrealistically happy and undisturbed by anything distressing)
- Emotional lability (when emotions swing from one moment to another)
- Blunted emotions (emotional flatness)
- Uncontrolled laughter or crying (sudden laughing or crying without a reason)
- Lack of insight (being unaware of the symptoms or their consequences)
- Disinhibited behaviour (lack of judgement, lack of empathy / failure to perceive other people’s emotions)
- Lack of initiative (apathy)

Medication

Some drugs given for MS symptoms may cause temporary behaviour or mood changes. We recommend that you ask your doctor or MS specialist about the possible side effects of any medication.

On the other hand, drugs can help some psychological symptoms associated with MS. Antidepressants, for example, may be helpful at times, both for people who are depressed and for those who have difficulties controlling their emotions.

4 | How does MS affect behaviour and personality, and what can be done about it?

In this section we describe the most frequent forms of behavioural problems and provide some suggestions about ways to cope.

Depression

It has been shown that MS lesions in specific parts of the brain may result in depression. Depression occurs more frequently in people with MS compared to people who have other serious diseases. Depression may also be a reaction to the changes of one's life situation due to a progressive disease.

People who are depressed may be worried, angry and miserable; they may lose their love of life. They may blame themselves, feel guilty and have suicidal thoughts. Depression may also be expressed by angry outbursts. Depressed people often do not sleep well. They are likely to suffer from fatigue and lack of interest in things and people around them.

■ ■ ■ *Colleen has had MS for 12 years. Recently her symptoms began to get worse. Indoors she can manage independently but outside she needs help, which she finds very difficult to accept. Colleen is convinced that her husband and son cannot love her as she is now. Her husband tells her that he still loves her, but Colleen does not believe him. Colleen only talks about the things she could do if she were better. Psychological counselling, together with antidepressant medication, has helped Colleen to recognize not only her weaknesses but also her strengths, and has enabled her to find a way of living with the new symptoms.*

Suggestions:

- Antidepressant medication may help depression, whatever its cause.
- Counselling and psychotherapy often reduce depression, partly by addressing thoughts and ideas connected with the effects of MS.
- A combination of medication and counselling has shown to be the most useful in helping people to overcome these feelings.

“Hidden” depression

Some people appear cheerful but will, if asked, admit they are covering up more depressed states of mind. People around them can usually, but not always, tell that sadness and despair is hidden behind the cheerful surface, making the depression difficult to detect.

Suggestions: The same suggestions as mentioned in relation with depression.

Euphoria

Euphoria is a mental condition in which an overly cheerful and inappropriately optimistic mood prevails. Often the person is unrealistic about what he or she can do for him or herself. Euphoria is typically associated with a lack of insight. Cognitive problems (disturbed memory, attention, thinking etc.) usually underlie euphoria. Some people see the euphoria as a “merciful symptom” preventing people from being sad and unhappy. However, relatives and professionals may witness serious problems arising from this euphoric state of mind, particularly if, like Olivia, the person is a single parent.

■■■ *Olivia talked about her life in a bright and cheerful way saying that she was fine and had no problems. She reported that she lived with her son and that he looked after her. She went on to say that he helped with the shopping and cooking, while she did the housework. In fact, the boy was only six years old, and Olivia was unable to get out of her wheelchair without assistance. It was therefore worrying when she said that she did not need any help from anyone else; that she and her son were “enough” for each other. Olivia and her son were referred to a child guidance clinic where they were offered support and therapy. This helped Olivia realise the need for assistance.*

Suggestions:

- It is difficult to help people with euphoria, because often they do not acknowledge the existence of their problems.
- Relatives, particularly children of people with euphoria, often need professional support, counselling or advice.

Emotional lability / emotional fluctuation

When someone's mood becomes "labile," it means that the person may easily burst into tears, both at happy and at sad events; or might suddenly become very angry over something, in a way that seems exaggerated or out of proportion. These outbursts, whether they involve crying, anger, laughter or anything else, are typically prompted by a specific event. This is different from pathological crying and/or laughter. Like any other MS symptoms, emotional lability may vary in severity – from very slight to more severe.

■ ■ ■ *James, a 45-year old man who went back to college when he lost his job, was unable to contain himself when someone else started talking. He would jump up and interrupt, often saying something quite irrelevant. James was very annoyed that he could not "stop" himself. He was given a small dose of antidepressant medication, which helped him to listen, think and consider before he spoke.*

Suggestions:

- For most people it is easier to cope with emotional lability if they acknowledge and understand their symptoms.
- Family members and close friends should be informed about the symptoms, as information increases understanding and tolerance.
- Slight and moderate emotional lability can often be successfully treated with antidepressant medication.
- It is useful to find out if there are specific situations that provoke emotional outbursts, and then try to avoid or minimize these situations.

- Sometimes the person with MS and the spouse can agree about how to handle “unreasonable” emotional outbursts, for example by leaving the room.
- People who are emotionally labile are often aware that they have reacted in an unreasonable way. However, the same person may also be appropriately angry or sad, and it is important that this is acknowledged.
- Emotional lability may cause more severe problems if the person, due to lack of insight, is not aware of the problem – not even when it is explained. In this case close relatives may need information and psychological counselling.

Blunted or “weak” emotions

Emotions can also become blunted. When this happens the emotions become “weak” or almost neutral and the swings between happiness and sadness disappear. It is no longer possible to feel real happiness, sadness or anger. To other people this may look as if the person does not care any more. These changes are very difficult to understand, especially for a partner. When a person no longer reacts in the usual way their partner may misinterpret what has happened and believe that there is an underlying relationship problem. In some cases people with MS experience the blunted feelings in a painful way, while in other cases the person does not realise what has happened.

■ ■ ■ *Susan told: “It is strange, but I never feel really happy, really sad or really excited anymore; and if my husband leaves me, I would not really care, even though I still love him.”*

Suggestions:

- Unfortunately there does not seem to be any treatment for this problem; we can only help people to recognise and understand it as part of the illness
- In a marriage or a close relationship, both people involved may need counselling.
- It is also important to remember that it is perfectly appropriate for the partner to seek advice and counselling on his or her own.

Uncontrolled laughing and crying

Uncontrolled or pathological laughing and crying means that someone involuntarily starts crying or laughing, completely independently of their state of mind at the time. It seems to be caused by partial or total destruction of the system in the brain that inhibits emotional expression. In spite of acute embarrassment, the person cannot control his or her behaviour.

■ ■ ■ *William went to a funeral, and it was really very sad, but suddenly he started laughing loudly and just could not stop. People turned around and stared, the priest stopped his sermon, and William felt awfully embarrassed.*

■ ■ ■ *Michael was sitting in the living room when his seven year-old son, Bobby returned from school and proudly reported that the teacher had praised his schoolwork. Michael burst into tears, and Bobby ran to his room. When Bobby's mother later that day asked him about his experiences at school the answer was "nothing". It took quite some time before the family realised why Bobby no longer told his parents about his experiences. When the symptoms of sudden crying or laughing were explained to Bobby, and also that his father's reac-*

tions had nothing to do with him, he gradually got used to his father's "new" ways of reacting and became talkative again.

Suggestions:

- It is important to know that uncontrolled crying and/or laughter may be a symptom of MS. Close relatives, friends and children should be given information in order to avoid misunderstandings.
- In some cases the laughing or crying can be prevented either by thinking of something else or by doing something to distract one's attention. One person looked at his watch whenever he felt himself beginning to cry. Another person raised his toes.
- Using voluntary facial muscles can sometimes stop involuntary movements; so, for example, when involuntary crying or laughing is about to start, raising the eyebrows and opening the eyes wide may be helpful.
- Attempts to calm or sympathise with someone who is crying or laughing can sometimes make things worse. Ignoring the symptom may sometimes be the best course of action. Children, as well as other people, need to know that this is a MS symptom and not a reaction to something they have done.
- Antidepressant medication can sometimes be helpful.

Lack of insight

Sometimes people lack insight about their situation and this can cause problems. Reasoned argument, unfortunately, usually does not work because the person with MS cannot understand. Serious conflicts can arise. For example, it may be obvious to everyone ex-

cept the person with MS that it is not safe to drive or use a motorised wheelchair. Other problems that can arise from lack of insight include carelessness with cigarettes, cookers, kettles or coffee machines.

Lack of insight can cause problems in day-care or rehabilitation settings too. For example, the person with MS who persists in trying to regain the ability to walk when it is obvious to everyone else that he or she will never walk again. Conflicts may arise if family or caregivers do not know whether to encourage or discourage unrealistic hopes.

■ ■ ■ *Sean said he was safe driving the car; his wife disagreed. She reminded him about his dangerous driving and the damage to the car. However, it seemed impossible to convince him that he was unsafe on the road and he continued to blame his wife for preventing him from driving. However, after he was referred for neuropsychological evaluation and given feedback about his cognitive functioning, he eventually understood that he should no longer be driving a car.*

Suggestions:

- Unfortunately, if insight is lost (through an organic cause) there is no way to bring it back.
- If insight is only partly lost it might be possible - by repeated and concrete reminders – to learn new routines.
- Information and counselling for family and carers may help them to tolerate and find ways of getting round some of the problems involved.
- Gently reminding the person of their limitations and focussing on their abilities can sometimes help. We suggest that family and carers refrain from supporting unrealistic expectations.

- Getting support and advice from a third party, such as a counsellor, may help when the conflict is between the partners.
- When a topic is especially sensitive, for example driving, it can be helpful to request an independent medical assessment.

Disinhibited behaviour

Sometimes people start behaving in unusual ways. They seem to lose their sense of social rules. Normal consideration for others, awareness of others' feelings and the usual sense of decency may disappear. For example, someone may make hurtful or totally inappropriate remarks in a way they would never have done before; or they may interrupt a private conversation, or do something they previously would have considered outrageous. In all of these situations the person appears to be totally unaware of the inappropriateness of their own behaviour or the likely consequences.

■■■ *Rebecca is 35 years old. She has relapsing remitting MS and minimal physical symptoms. She works in a very responsible managerial job. During a relapse, she experienced a period of two to three weeks where she felt she was losing her inhibitions. She wanted to say things to people that she knew were not acceptable. She wanted to touch people. She had to fight very hard to stop herself from doing certain things, to the point where she had to withdraw from situations because she could not trust herself. She found herself wanting to touch a colleague's backside. She described this time as awful, as she wanted to do things that she would never even have dreamt of earlier; that were alien to her way of thinking and upbringing. Fortunately for Rebecca, this behavioural change was temporary and*

disappeared as she recovered from the relapse. Rebecca now looks back with a great deal of embarrassment and fear that it will happen again.

■ ■ ■ *Jonathan was no longer behaving in his usual way at the dinner table. He helped himself to food from the table without any considerations for others' needs.*

Some people have lack of insight as well as disinhibition; others are aware but cannot use their insight at the time and are unable to stop themselves.

Suggestions:

- Family members and friends should be informed about the symptom.
- It is helpful to remember that it is a symptom and not a conscious act. Therefore, the person cannot just be told to stop the disinhibited behaviour.
- Pointing out the inappropriateness of the behaviour at the time may be of help.
- It is inappropriate to scold the person.
- Discussing the situation may help to put it into context and make it easier not to take offence. It may also open up acceptable ways of coping.
- Family members may need professional help in order to cope with the situation.

Lack of initiative

Normally people plan and carry out different kinds of activities – for example, they take the initiative to dress themselves, to get things done around the house, to take part in social or leisure activities. Starting things, initiating actions or activities, is different from carrying on doing them, and is controlled by a different part of the brain. Someone with a lack of initiative may be able to carry on doing something once they have begun, but be unable to take the first step. This can be frustrating for family members, particularly if they do not understand the problem and think the person “can’t be bothered”, or is lazy, or is “always expecting someone else to do something”.

■ ■ ■ *Michael walks with a stick and has taken early retirement due to his MS. He now spends most of his time at home, and is quite content with the situation. He is happy to help with any household tasks that his wife Mary asks him to do. However, Mary feels infuriated with him, because she has noticed that he will not do anything unless she asks, and then she needs to tell him exactly what to do. Mary feels as if she has to think for him now. If they run out of milk or coffee he would not go to the shops to buy more, unless she told him to. He would never think to switch on the oven, or begin to prepare a meal if she is out, unless she calls or leaves instructions beforehand. He has stopped telephoning friends or arranging to see people, yet he is happy to socialise if someone else makes the arrangements. Mary feels as if she has lost an important part of her husband.*

■ ■ ■ *Psychological counselling helped Mary and Michael to see the changes in a new way. Mary could see that Michael’s behaviour had nothing to do with laziness or tiredness, nor was it a reaction to her and her behaviour. Mary is now able to accept her husband’s behaviour and gets less irritable with him, even though she is still sad and aware of their loss.*

Suggestions:

- Information and knowledge about the fact that lack of initiative may be a symptom increases understanding, tolerance and acceptance.
- It can be useful to think of these problems as a loss of an internal “drive” and that external cues may be needed instead. Partners or other family members may learn to provide these cues.
- Practical help comes in the form of alarms that remind people to take their pills. Diaries or “to do” lists are often helpful.
- Discussing and clarifying the situation with a professional who understands can help people to work out their own ways of dealing with it. Family members or professionals may be able to take on the task of reminding the person what they have to do.
- The healthy partner may need professional support and counselling.

5 | Where to get help

- Psychological therapy and counselling of various kinds are carried out by specialists such as clinical psychologists, neuropsychologists, psychiatrists, psychiatric nurses, social workers and trained counsellors.
- An MS rehabilitation team (neurologist, nurse, neuropsychologist, social worker, occupational therapist, physiotherapist etc) should be available to anyone with MS. Any member of the team may be able to offer some kind of support and counselling, and should also be able to refer to other professionals when needed.
- In some settings help is offered to relatives or carers as well as the person with MS; often it is not, and they may need to seek counselling separately.
- Diagnosis of emotional or behavioural problems may be made by a doctor, psychiatrist, psychologist or neuropsychologist. A doctor may offer medication or referral to psychotherapy or counselling.
- If cognitive problems interfere with therapy of any kind, or if the person with MS complains about cognitive deficits, then a neuropsychologist can make an assessment. (See booklet on MS, Memory and Thinking).
- Informal help may also be available at day centres or in self-help groups or from friends or relatives who are prepared to listen and help with thinking and understanding.

Further reading

- MS, memory and thinking. In MS Essentials published by the Multiple Sclerosis Society, UK 2002.
- Emotional reactions and MS. RIMS publications 2, 2006.
- Anthony Feinstein: The clinical neuropsychiatry of multiple sclerosis. Cambridge University Press 1999.

Rehabilitation in Multiple Sclerosis (RIMS),
the network of MS Centres in Europe
was created in 1991, in Milan, Italy to enhance collaboration
by the foremost MS Centres in Europe.
Today the Organisation has 40 member centres
throughout Europe.

The aim of RIMS is to link the European MS Centres in order to
encourage professionals interested in Multiple Sclerosis
to exchange their knowledge of clinical, scientific, social,
economical and educational matters about the disease and
to establish individual and scientific contacts between persons.
In addition, individual membership for those
who have a special interest in MS is welcomed.

RIMS has established a number of Special Interest Groups (SIG).
The groups aim to promote research and improve
the management of Persons with MS and their caregivers.

RIMS newsletter Network is published twice a year.

Find more information: www.rims.be

This booklet has been written by the members of
SIG on Psychology and Neuropsychology