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Emotional reactions and MS

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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).

internet: www.rims.be

email: ms-mels@rims.be

Core group: Päivi Hämäläinen (Finland)
Agnete Jønsson (Denmark)
Roberta Litta (Italy)
Patricia Maguet (Spain)
Bente Østerberg (Denmark)
Michelle Pirard (Belgium)
Julia Segal (UK)
Liina Sema-Vahter (Estonia)
Peter Thomson (UK)
Wim Van de Vis (NL)
Luc Vleugels (Belgium)

Layout: Päivi Vänttinen (Finland)

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1 | Introduction

This booklet, written by a group of clinical psychologists, neuropsychologists and counsellors, is for people with multiple sclerosis (MS) as well as to family, friends, colleagues and healthcare professionals.

The aim is to describe some of the most common emotional responses to MS and to suggest ways of dealing with them.

2 | Working through the process of loss

Emotional impact

MS is an unexpected "guest" that arrives in peoples' lives and is there to stay. It can bring a series of losses for the people with MS and their families. Previous ways of thinking, feeling and behaving are replaced by new ones.

The normal reaction to any loss requires a grieving process, which involves a range of emotions and a need to "work through" the consequences. People with MS may experience losses in their self-image and their expectations. They may also experience changes in their social life, their role in the family as well as their ability to work. It is important that all these losses are mourned, and that expectations about oneself, others, life and the future are modified.

The process of mourning these losses may include feelings such as frustration, upset, anger, sadness, shock and guilt. These feelings may be a normal part of a grieving process, especially during the first months. Sometimes the process continues for longer. It takes time to assimilate the unexpected changes. However, grieving is generally time-limited and counselling, support groups, an understanding and supportive environment may all be helpful.

The grief and mourning process

On receiving the MS diagnosis some people are left in a state of shock, and their first reaction may be, “This can’t be true” or “This must be a mistake” or “Why me?”

Other people may have been expecting the diagnosis and feel relieved that the waiting period is over.

Shock may be followed by denial. This is especially true if some of the symptoms of MS disappear, making it easier to “forget” that one has the illness. The length of this stage varies from one person to another, but at some point, especially if new symptoms appear, the diagnosis of MS can no longer be denied and the grieving process begins.

Once the diagnosis of MS becomes a reality, emotional reactions such as panic, sadness or anger may emerge. These are normal reactions, which can be either turned inward as a feeling of guilt, or acted out on family members, friends or professionals. The thoughts and feelings are often chaotic. Facing the unpredictability of the disease course, not knowing what may happen in the future, is perhaps the most difficult and frightening challenge.

Little by little all these chaotic thoughts and feelings are sorted out and the process of recovery and acceptance begins. People start to deal with realities instead of feeling powerless and overwhelmed. Even if the recovery process is moving in the right direction, it is important to remember that it is perfectly all right to feel bad from time to time.

Grieving the losses, and redefining expectations for the future, is part of the process of acceptance. This also includes introducing lifestyle changes, and involves both the person with MS and the family. Examples include changing roles in the family, modifications at work, and perhaps different leisure activities.

Once people find new ways of living with themselves and others, they feel more in control and are better able to enjoy their lives.

Because MS is a progressive and unpredictable disease, the adaptation process is continuous. Most people with MS experience long periods with a stable disease course, and grieving and adaptation is not needed until new symptoms emerge.

What affects the way people go through this?

How people cope depends on factors such as personality, past experiences, social support, their economic situation as well as the MS course. These factors are likely to influence, facilitate or complicate the mourning process.

Pre-existing relationships will be of importance. People with MS, and their families, have to redefine their roles and their way of functioning. It is risky to react in an extreme way, for example by overcompensating. Sometimes the spouse may take over too many of the everyday tasks, and will tend to become the "caring partner" leaving the person with MS feeling even more helpless. Or the spouse may be overprotective which could lead to dependency and passivity of the person with MS. It could also restrict his or her integrity while overloading the other members of the family, so it is important to maintain mutual respect and equal status.

In short, some things have to change, while other things can remain the way they were before.

Communication is also important. Open communication, where one is allowed to express one's thoughts and feelings, facilitates closeness between partners, and promotes the adaptation process. Because many symptoms of MS are not visible (pain, fatigue, sensory disturbances etc.), there is a danger that the person with MS may try to hide these problems. This may be an attempt to spare the partner from painful feelings, but risks creating distance and uncertainty instead. Mutual fear about the future is often not shared between the partners due to so-called "misunderstood concern".

Personality type will also influence the grieving process. There is no personality type or style that is MS-prone. However, some personality traits and behaviours may be exacerbated or become less prominent due to the impact of MS. For example, shyness and passivity may lead to withdrawal and social isolation. Dependency may lead to helplessness or extreme attention seeking behaviour, and independency to an "I don't need any help, I will face the problems by myself" type of attitude.

These attitudes, if extreme, may lead to behaviour which complicates the process of adjustment to MS.

Our beliefs about health and healthy living are important. We all have beliefs about how to stay healthy. For example "If I eat wholesome food and exercise, I will stay healthy". Some people believe that they will become ill no matter what they do. These beliefs affect the way we think and how we cope with grief. Recognising our beliefs about illness and disability, and about what is really important in life, may be helpful when it comes to adjusting to MS.

The manner in which the diagnosis was given may also influence the grieving process. Empathy and understanding from the health professionals can facilitate the grieving process.

The MS course and degree of disability may have an influence. The grieving process does not run proportionate to the MS course. Typically a person with MS who fully recovers after the first symptoms will not be aware of the possible changes that MS may require. There may not be any noticeable emotional reactions at that time. On the other hand, someone who experiences a serious relapse, followed immediately by another, may experience feelings of chaos and anxiety. The constant changing of symptoms makes it difficult for the person with MS to cope with the disease, and this may complicate the grieving process. Each symptom may have to be grieved for separately. However, people do get used to their symptoms and their situation and they can learn to live well with it.

The presence of cognitive and/or behavioural problems may also influence the mourning process. The capacity to experience certain feelings (such as strong affection) can also sometimes be affected by the disease process. This too can affect the mourning process. It can also mean that others think the person with MS does not care. It can help if relatives and the person with MS themselves know that MS can affect people in these ways.

Coping with the consequences of MS can be hard enough in any circumstances. Having sufficient financial means, a decent place to live and satisfying daily activities can make life a little easier. Worry and uncertainty can limit the mental resources needed for sorting things out.

3 | Reactions to MS

Knowing about some of the most common emotional reactions to MS can help you.

Anger and frustration

Anger and frustration are intense feelings that can arise at any time. They may be normal reactions to any situation in which a person is prevented from doing something they expect to be able to do. Anger can be a sign that a change is being resisted and fought. When the change is finally accepted, the anger usually disappears.

You can feel angry about many aspects of your illness. You may resent being ill or feel you have been badly treated. You may feel angry with yourself, fate or the doctor. You may also be angry with people who do not help, or do not understand. This may be due to what is actually happening or it may have more to do with feelings of powerless and despair. Some people "take out" their anger on other people. Others turn it inward, giving rise to self-blame.

Being angry all the time can be hard and exhausting. It can also be difficult for family and friends, particularly when their attempts to help are rejected. This could be because offers of help remind people with MS that they need help, and this makes them angry.

Fear

Feeling frightened when faced with danger is both healthy and normal. Fear helps us to sense that something is wrong and that we need to take action. Sometimes it can lead to panic and "freezing". Uncertainty about the future is frightening for most people. Some react by feeling the fear and taking evasive action. Others react by ignoring their fear and perhaps living more dangerously than they did before.

Sometimes you may get frightened of things that have nothing to do with MS. You might be afraid that your fears will be "catching", or will overwhelm others, and this may stop you talking about your experiences. You can also be afraid that talking about fears will make them come true. In fact, talking to someone about fears can often reduce them, and may also be able to 'unfreeze' other emotions.

Anxiety and worry

The diagnosis or the symptoms of MS can create a generalised feeling of anxiety. You can be anxious about the present or about the long-term future, about the effects of MS on your relationships and plans. MS can affect your feelings about yourself and others. Anxiety often decreases when specific worries are looked at more closely and are understood and acknowledged; even when solutions cannot be found for all of the difficulties.

MS may increase any pre-existing anxiety. People often worry about whether they will be a burden on others, or whether they will continue to be able to look after those they care for. You may also worry about your children getting MS or whether your family members still love you.

Denial

When a problem seems too big, people may deny that it exists at all. With MS you may feel so fearful of the changes in your body and mind that you deny being ill. This is a way of defending yourself from being overwhelmed. Even emotionally 'strong' people use denial as a way of allowing problems to be taken on board a little at a time. Used in this way denial can be a form of "first aid", and may do no harm. However, it can get in the way of problems being resolved, and important ideas or actions may be missed.

Talking about the symptoms and the changes can make them feel more real, but in order to do this you need to be mentally ready.

Feelings of unreality

Some people react to the diagnosis or onset of new symptoms by cutting themselves off in such a way that they feel unreal. It might feel as if you are walking on clouds, or in a dream, or watching a play. You may know that you are saying or doing things, but still feel that it has nothing to do with you. This defence against overwhelming and painful feelings usually fades away after a relatively short period of time.

Confusion

MS may cause changes, which can lead to feelings of confusion. Your whole life has suddenly changed and yet everything around you goes on as if nothing has happened. This may be hard to grasp, and you may feel confused about how to handle things. Will life ever be the same? Will I have my life back? For many people these moments are experienced as insurmountable. Feelings of optimism and hope may alternate with feelings of despair and hopelessness.

People often report periods of confusion during which they forget things easily and wonder if they are going mad. Usually these feelings pass.

Depression

"Depression" is an everyday term used to describe low mood. Clinical depression is something more severe and undermines normal functioning. Sometimes it is hard to distinguish it from grief and sadness. People who are clinically depressed feel sad, melancholic or tense in such a way that they feel locked up with no ability to see a way out. People who are clinically depressed may also appear angry and irritable to those around them. This type of depression is closely tied to feelings of lost identity and low self-esteem. As MS often causes feelings of lost identity as well as loss of function it follows that many people also feel clinically depressed as well.

It is important that you allow yourself to grieve your losses, and at the same time to build up a new identity by realising what has not been lost.

Depression may be a reaction to the initial diagnosis or to a sudden worsening of symptoms, or it may be a reaction to long-time stress. However, disease processes in certain areas of the brain can also cause depression (ref. booklet on Personality, Behaviour and MS).

Guilt

MS can make you feel guilty. You can feel guilty about being ill or about your belief that you are no longer "good enough" for yourself or others. In everyday life, most people strike a balance between others' expectations on the one hand, and their personal abilities and resources on the other. However, if this balance is disturbed, feelings of guilt may take over. When someone has to cancel work or social arrangements, guilt about letting people down is understandable but not helpful.

People may feel guilty about being irritable and short-tempered. Some people feel that it is their fault that they have MS.

Shame

MS can make you feel ashamed about your symptoms. The degree of shame people experience depends on their basic self-esteem and how they feel about themselves. In some cases children feel ashamed of their parents having MS. The way in which children react to a parent having MS usually depends on a number of factors such as the parents' own attitudes towards the disease, the attitudes of other family members and the response of the children's friends.

Hope

Hope is vitally important in order to keep life meaningful. It can be hard to keep up hopes when you are forced to live with MS. People with MS may find sources of hope in many places and in many ways. Some of these are realistic: the hope of a cure for MS in our children's lifetime, the hope of living a good life in spite of MS. Some hopes take on an unrealistic and magical character: for example, the hope that MS can be kept in check by thinking the "right" thoughts, or by doing the "right" things.

Letting go of unrealistic hopes can be so painful that people may cling to them despite the knowledge that they are unrealistic. Finding sources of realistic hope makes coping easier.

4 | Stress and MS

Stress is well known to many people with MS. In small doses pressure may help you produce good work. However, if the challenge is too big, or if it lasts a long time, pressure can turn into stress and become a problem. The fact that MS cannot be either predicted or controlled can be very stressful. The losses that MS can cause (practical, physical, psychological and social) may lead to stress. Not only negative events, but also positive ones, such as getting married, having a baby or moving to a new place, may be experienced as an excessive demand on your resources and feel stressful.

Many people fear that stress worsens the course of MS and provokes disease progression. The topic is very complex, and research has shown different results. Some people do not seem to be affected by stress, whilst others seem to be vulnerable to the effects of stress at some times, but not at other times. However, it seems that social support is helpful and that talking with others has a positive effect on the perceived stress, not least because it is often very reassuring to learn that others are experiencing similar problems. It is known that people with MS who report being well supported, tend to function better psychologically.

Unfortunately we cannot decrease stress by thinking happy or positive thoughts or by "good behaviour" of any kind.

However, to limit the impact of the disease on daily activities, it is important for the person with MS to have access to as much detailed and practical information as possible. This includes symptomatic treatments as well as compensatory strategies and devices. If the person with MS can look at the disease as a series of smaller problems, each of which can be adequately managed, he or she will have a stronger feeling of control, which will lower the perceived level of stress.

Relaxation techniques may be helpful. They can reduce tension and decrease the severity of the experienced symptoms.

Of course, every individual has his or her own favourite coping style with respect to MS and stress. Some people may benefit from special relaxation and coping sessions, while other people find psychological counselling helpful.

5 | Emotional reactions of others

How do relatives feel about MS?

MS affects the whole family, children and friends. If you are close to a person with MS it is difficult not to identify with his or her feelings. Adjustments have to be made to accommodate the changes MS may bring. Roles within the family may have to change. A loving husband or wife may have to do more around the house, or even take on the role of a "carer". Children may feel scared or confused by what is happening to their Mum or Dad, though they may not show their anxieties.

Each family member may have a different way of coping with the changes related to MS. They will react differently, and their needs and priorities may vary. In some cases the worries about the person with MS may lead to excessive protection, in other cases the fear and pain may be so hard that ignoring or neglecting the illness may be the only way to cope.

The spouse or the whole family of the person with MS might be reluctant to share their feelings because they want to avoid increasing the suffering of the person affected. This may be unhelpful. Sharing feelings typically makes them easier to handle; in the same way that sharing good experiences makes them even better.

Our clinical experience suggests that it is possible for families to overcome the crisis, readjust to the new circumstances and even strengthen their relationships.

How do the children feel?

It is understandable that parents want to protect their children. Many try to hide their worries about MS in order to protect the children from the associated pain and uncertainty. Nevertheless, children are very sensitive, and are usually aware of the changes that have taken place. If they are not offered a reassuring explanation about the situation, they may feel confused and guilty. They may even lose their confidence in adults and imagine that the parent with MS will die.

Usually, children are not that fragile, and are able to accept painful and difficult situations better than we imagine.

MS raises a lot of questions that do not have simple answers, and this may be very frustrating for the family. A confident and relaxed climate at home allows the children to raise their doubts and concerns about MS, and the parents to give age-appropriate information.

Sometimes children may feel responsible for everything that happens to their parents and this can lead to feelings of guilt about the disease. This in turn can make them very anxious to please, or uncharacteristically helpful. It may even make them feel frightened of doing wrong. Parents can help their children recognise these fears, which in turn makes them feel understood.

The reactions of colleagues and employers

Getting back to work, or applying for a new job, after having had the diagnosis of MS, may raise a lot of questions: "When should I disclose that I have MS?" "What will my colleagues think?" "Will I get the job if I talk about having MS?"

The reaction of colleagues and employers plays an important role in the way the person with MS feels about the work situation. At the workplace many people may not know what MS is, and they will be uncertain how to react towards the person with MS. Should they take special precautions, ask about the disease, or simply pretend that nothing has happened?

Because some of the symptoms of MS are invisible, it can be very difficult for colleagues to understand exactly how you are affected. This may result in misunderstandings. At the same time colleagues may be afraid of aggravating the situation and refrain from asking relevant questions. Instead, they may concentrate on their work and expect you to take the lead as far as handling the situation is concerned. This passive response often reflects the wish to do the right thing, but could easily be experienced by the person with MS as a lack of concern.

Many people with MS function completely normally at work. However, it may be necessary to re-evaluate the work situation from time to time to match the available resources with the tasks. Often, this is an ongoing process in order to create the optimal situation for both you and the workplace.

6 | Sources of support and treatment

You, and the people around you, have to adapt to the situation and it is important that you feel supported. One or several of the different ways outlined below may be helpful to you.

Psychological counselling and support

Talking to a professional who knows about MS and the “normal” emotional reactions associated with MS may support you in coping with the new circumstances. Psychological counselling may also be beneficial for the spouse and members of the family.

Counselling may help you to sort out chaotic thoughts and feelings and bring them into the open. Counselling sometimes uncovers and examines hidden fears, making them less frightening. This may help you to cope and adjust in a more realistic and positive way.

Solving one or a few problems at a time, and leaving other problems for later, may help you to keep an overview and prevent you from feeling overwhelmed.

Learning appropriate anxiety management strategies may help you to regain control over your life again.

Moving the focus from disabilities to abilities may give you the feeling of strength and being in control.

Recognising and acknowledging losses is important before you can move on. People often need others to recognise and acknowledge their losses too, before they can move on.

Social support

There are several sources of social support; for example, family and friends, colleagues at work, leisure activities. These may help to strengthen your self-image and improve your self-assurance and self-esteem.

Maintaining different social contacts, which are not focused on MS, may help you feel like a friend, a colleague, a brother-in-law etc. rather than a person with MS.

Self-help groups

Sharing emotions with other people who are likely to have had similar experiences may be helpful. Furthermore, in groups it is possible to express difficult feelings that one may not want to share with one's family. Self-help groups often provide information and advice about coping strategies as well as practical issues such as technical aids, civil rights and so on.

Medication

Depression is frequently treated with antidepressant drugs. Research has shown that the most effective treatment is a combination of antidepressants and psychological counselling.

Further reading

- MS, memory and thinking. In MS Essentials published by the Multiple Sclerosis Society, UK 2002.
- Personality, Behaviour and Multiple Sclerosis. RIMS publications 1, 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
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