

Multiple Sclerosis and Your Emotions



MULTIPLE SCLEROSIS AND YOUR EMOTIONS

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COVER ARTWORK

Mary G. Dunphy

Calm Seas, acrylic on canvas

Mary G. Dunphy is an artist from Newfoundland.

"Like most people in our society I defined myself by the career I had for many years. When MS forced me to discontinue working outside the home I searched for new avenues to provide that identity and I eventually turned to art. I find art and painting to be immensely fulfilling. Art gives me a new sense of purpose and a new way of looking at the world around me."

Calm Seas is an example of realism painting and depicts the romance and serenity of the tall ships and in particular HMS Bounty.

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People living with multiple sclerosis (MS) experience many different emotions over the course of the disease. Some of these are reactions to the stresses and challenges created by this chronic, unpredictable illness, while others seem to be symptoms of MS itself. This booklet describes the range of emotional reactions and changes that can occur and provides information for individuals with MS and their families on how to recognize, talk about, manage and learn from these feelings.

Common Emotional Reactions

No two people or families living with MS react to the disease in exactly the same way or face exactly the same challenges. Nevertheless, there are certain reactions that seem to be very common.

Initial Reactions to the Diagnosis

The diagnosis of multiple sclerosis (MS) may produce shock, disbelief, anger, fear, and denial – all of which are normal, predictable reactions to this kind of difficult news.

- ➔ **Shock:** For some people the news is so startling and puzzling that they simply cannot absorb it. It may take several days or weeks for them to be able to think about next steps for dealing with this unwelcome intrusion in their lives.
- ➔ **Fear:** For those people who know very little about MS – or those who have known someone with very progressive, disabling MS – the first reaction may be fear or even panic. They may be quick to assume the worst about their health, their life, and their future.

- ➔ **Anger:** It isn't at all unusual for people to feel angry and frustrated by their diagnosis. Certainly no one asks to get MS, and many react with resentment to the unfairness of being diagnosed. "Why me?" is the first question on many people's minds.
- ➔ **Relief:** For anyone who has had to wait months or even years for an explanation of puzzling, uncomfortable symptoms, getting the diagnosis can be a relief. Particularly for those people who were worried about having a brain tumour or some other potentially fatal disease, the diagnosis of MS can feel like welcome news. The news may also provide relief for anyone who has been told, "There's nothing wrong with you – it's all in your head."
- ➔ **Denial:** Some people react to the diagnosis by shoving it under the rug – telling themselves that it couldn't possibly be true or that the doctor has made a mistake. Denial can be a very useful and effective coping strategy during the early days of a chronic illness – allowing a person to take a brief "time out" before beginning to deal with the realities of MS. However, denial that goes on for weeks or months can also get in the way of important treatment decisions and self-care strategies.

Although physicians will generally provide their newly-diagnosed patients with information about treatment options, they recognize that some people want and need the time until their follow-up appointment to get used to the idea of starting treatment with an injectable medication – particularly if their symptoms have disappeared and they feel like themselves

again. Since most people are diagnosed with the relapsing remitting form of MS, denial is common during early periods of remission, when symptoms partially or completely disappear.

It is important to remember that any and all of these reactions are “normal.” Each person is going to react in his or her own way to the diagnosis of MS. Keep in mind, however, that there is help available if any of the feelings become unmanageable or too uncomfortable. The MS Society of Canada offers a variety of information and support services – in person, by phone, and online – to address these needs.

Longer-Term Reactions

Like people’s initial reactions to the diagnosis, their longer-term reactions will vary considerably as well. Since everyone’s MS is different, there are no predetermined stages of adjustment and no right or wrong ways to feel about it. However, there are some very common reactions that most people will experience at one time or another over the course of the disease. And they may find these feelings recycling as the disease goes through its characteristic ups and downs of relapses and remissions or causes new or worsening symptoms.

➔ **Grief:** This unique kind of sadness is a normal reaction to change and loss. Although most people associate grief with the loss of a loved one, it’s also a common, healthy reaction to any change that threatens one’s sense of self. In other words, people with MS may find themselves grieving initially over the diagnosis of a chronic illness, and then

experiencing those feelings again any time that MS causes a new symptom or interferes with their ability to do something that's important to them.

Grieving is an important first step in any person's efforts to cope with a chronic illness. As the pain of grieving gradually eases over time, the person is able to begin making positive adaptations to whatever changes have occurred. The cycle of grief and adaptation will continue to repeat itself whenever significant change or loss occurs.

- ➔ **Anxiety:** Feelings of anxiety are very common in MS. Whether people are concerned about getting to the bathroom on time, holding on to their job, keeping up with their kids, or becoming severely disabled, they tend to feel anxious when they can't be sure what's going to happen next. Learning how to live with the unpredictable ups and downs of MS is a significant challenge for anyone affected by this disease.
- ➔ **Anger:** As the disease runs its course, people may find themselves feeling very angry about all the changes it brings to their lives. Although anger is a common and normal response to changes and losses that feel unfair, many people find it difficult to know what to do with it – how to handle and express their anger in ways that are productive and don't spill over onto family members, friends, and colleagues. The goal is to find ways to put that energy to good use – to channel it into effective planning and problem-solving. Healthy anger can fuel a lot of productive creativity.

➔ **Guilt:** If and when the disease begins to interfere with activities at home or at work, people may begin to feel that they are letting others down. They may worry that their loved ones or colleagues are having to take on extra responsibilities. They may worry about not contributing to the family income or that their children aren't getting as much attention as they used to. If the disease progresses in spite of their best efforts to manage it, they may feel guilty about that, as if the disease is their fault or that they could have made a difference by trying harder.

While each of these reactions is a natural response to the upheavals caused by MS, they can, themselves, begin to feel unmanageable. Grief can feel so overwhelming that it becomes difficult to distinguish it from depression (see page 12 for information about the diagnosis and treatment of clinical depression). People can become so anxious about the future that they can't deal with how things are at the moment. Anger can begin to drain a person's energy and interfere with important relationships. And the guilt can rob a person of the confidence and self-esteem he or she needs to deal with the challenges of the disease.

Whenever these common feelings start to feel unmanageable or overwhelming, it's important to know that help and support are available. For most people, the opportunity to talk about them in a supportive setting – in a self-help group, or with a knowledgeable counsellor – can help relieve the feelings and channel them into productive problem-solving.

Family Members Have Feelings Too

As if all these feelings weren't challenging enough for one person, it's important to keep in mind that family members are experiencing a similar set of emotions. Everyone who loves someone with MS, and whose life is affected in one way or another by the presence of MS in the family, needs to figure out how to respond to it. Since no two people handle feelings in exactly the same way, the result is a household full of strong emotions that are being expressed in different ways at different times. It's a lot like a symphony orchestra without a conductor – everyone is playing his or her own tune, not necessarily in synch with anyone else. All these feelings pose some significant challenges for families:

- It's important for family members to acknowledge that they are all affected in one way or another by MS. Like a pebble thrown into the water, the disease creates its own ripple effect on the whole family's everyday life.
- Family members also need to acknowledge and respect each other's coping styles and strategies. People tend to react to stress, express feelings, and problem-solve in very different ways – and one person's style isn't necessarily any better or more effective than another person's style. While acknowledging these differences, family members will benefit from learning how to communicate comfortably and respectfully in spite of them. Talking comes more easily to some people than others; the challenge lies in making sure that everyone's feelings are recognized.

- ➔ Parents with MS are often reluctant to talk about the disease with their children because they don't want the children to be frightened or upset. However, children (even very young ones) are very sensitive to their parents' moods. They know when mom and dad are upset or not feeling well – even when the MS symptoms are mostly invisible. And they worry about what might be wrong. It's important to give children age-appropriate information about MS so that they have the opportunity to ask questions and express their own feelings about whatever is going on.
- ➔ Teamwork makes everything easier. By making MS the “common enemy,” family members can direct their frustrations at the disease rather than each other, and work together to figure how best to handle the changes in their lives.

Common Emotional Changes

The previous section talked about common reactions people have to the challenges of living with MS. This section describes emotional changes that are thought to result, at least in part, from the damage to the nervous system caused by MS. In other words, these changes are considered by MS experts to be part of the disease process itself rather than just a reaction to the challenges it poses.

Mood Swings

People with MS report feeling more sensitive and moody, and family members may find their loved ones to be cranky at times, quick on the emotional trigger, irritable, and unpredictable in

their emotional responses to things. Knowing that these mood swings can be part of the disease as well as a reaction to it, can make it easier for everyone to understand and tolerate them. But mood swings aren't comfortable for anyone, so it's important to let the health-care team know about them. A mental health professional with expertise in MS can teach strategies for managing uncomfortable mood swings. For people whose mood swings are more extreme, medications are available to help control them.

Depression

While everyone has occasional days of feeling blue or down-in-the-dumps, major depressive episodes (also known as clinical depression) are more common in MS than in the general population or in other chronic illnesses. In fact, more than half of people with MS will experience a major depressive episode at some point over the course of the disease. MS experts believe that depression is a symptom of MS as well as a response to it. This is supported by the fact that depressive episodes can occur early or late in the disease, regardless of a person's other symptoms or level of disability. It's important to know, however, that people who are in the midst of an exacerbation (also called a relapse or attack), or who have a personal or family history of depression, are at greater risk for a depressive episode.

Depression is not a sign of weakness – it is a medical condition that can and should be treated because it interferes with a person's comfort and ability to function. And living with MS can be challenging enough without the added burden of a depressed mood.

Depression continues to be under-diagnosed and under-treated in people with MS. There are three primary reasons why this is so:

1. Several of the symptoms listed on the next page (marked with an asterisk) overlap with common symptoms of MS. Therefore, it may take a psychiatrist or psychologist with expertise in MS to sort out the various symptoms and confirm the diagnosis.
2. Many people are too embarrassed or ashamed to admit these kinds of feelings to their doctors, as if they were something to be ashamed of.
3. People mistakenly believe that anyone with a chronic, unpredictable illness like MS would or should be depressed – and this is definitely not the case. Everyone with MS needs to grieve over whatever losses the MS may cause, and everyone has days of feeling down or discouraged, but not everyone experiences five or more of the symptoms on the list (next page) for days for weeks at a time.

For those who do, the good news is that depression is a treatable problem. Most experts agree that a combination of psychotherapy and antidepressant medication is the most effective treatment strategy. For more detailed information about depression and its management, see the brochure entitled *Living Well with MS: Mind Matters* .

Diagnosing Depression

The diagnosis of depression can be made if a person experiences five or more of the following symptoms most or all of every day for at least two weeks:

- Ongoing feelings of sadness or emptiness, irritability, or tearfulness
- Loss of interest or pleasure in most activities
- Significant weight loss or gain or a decrease or increase in appetite
- Sleeping too much or inability to sleep
- Physical restlessness or slowed movement observed by others*
- Ongoing fatigue or loss of energy*
- Feelings of personal worthlessness or guilty without appropriate cause*
- Diminished ability to concentrate or make decisions*
- Recurrent thoughts of death or suicide, or planning suicide.

At least one of the first two symptoms must be present for the diagnosis of a major depressive episode to be made.

Uncontrollable Laughing and Crying

Episodes of uncontrollable laughing or crying – also called pseudobulbar affect – are another symptom that can be caused by MS. These episodes occur independently of how the person is feeling emotionally, and they start and stop unpredictably. In other words, a person may find him- or

herself laughing inappropriately at a funeral, while actually feeling sadness and loss or they may be unable to stop crying uncontrollably while watching a comedy. Individuals with MS and their family members understandably find these episodes frustrating and embarrassing, and employers may find them unacceptable. Fortunately, uncontrollable laughing and crying can often be managed with medication, so it's important to bring this problem to the attention of the health-care team.

A Word about MS Medications and Mood

The medications that people take to manage MS or its symptoms can also affect mood.

- ➔ **Steroids and mood swings:** The corticosteroids that are sometimes prescribed to treat MS exacerbations cause some people to experience fairly significant mood swings – from bubbly, energetic “highs” while on the medication to irritable, depressing “lows” as it is being tapered or stopped. While not everyone experiences these mood changes with corticosteroids, and not everyone has the same experience each time they are prescribed, the mood changes can be very uncomfortable. For those people who experience significant discomfort, the physician can prescribe a short course of a mood-stabilizing medication.
- ➔ **Interferons and depression:** All three of the beta interferon medications (Avonex[®], Betaseron[®], and Rebit[®]) that are used to treat MS carry a warning about depression. Although studies have failed to show a clear connection between these medications and depression in people with MS, there have been reports of people experiencing significant

depressive episodes. Therefore, anyone who has a history of depression should discuss it with their doctor before starting one of these medications. And any person who experiences a significant mood change while taking an interferon should alert the doctor immediately. Glatiramer acetate and Tysabri, other disease-modifying medications used to treat MS, have not been reported to affect mood.

The Role of Stress

What We Know – and Don't Know – about Stress and MS

A common question on people's minds is whether stress – or the emotions that accompany it – can cause MS or make it worse. We still don't know what causes MS, but there is no evidence to suggest that life stresses are the primary culprit. MS experts believe that the disease occurs in those individuals who are genetically predisposed to respond to some environmental trigger, such as a virus or bacterium, which alters the functioning of the immune system.

Research has shown that stress interacts in complex ways with the body's immune system, but the relationship between stress and disease activity or disease progression is unclear. The difficulty in sorting this out seems to come from the fact that not all stress is the same. For example, studies have shown that an acute, traumatic stress may have no effect on the disease course, or may even be associated with reduced risk of exacerbation, while chronic stress/distress may be associated

with an increased risk of exacerbation. Whatever the relationship turns out to be between stressful life events and the course of MS, it is also likely to differ from one individual to another. There is ample evidence to suggest that coping strategies differ markedly from one person to another, and that some people are more resilient to life stresses than others.

This means that trying to manage or control MS by reducing the stresses in one's life is not the best strategy – for several reasons:

- ➔ The impact of stress on the course of MS is unclear.
- ➔ Everyday life is filled with stressful events, most of which are out of an individual's control. Trying to eliminate them can only lead to feelings of frustration and failure. And then people may feel guilty or inadequate if their MS progresses in spite of their best efforts to reduce their stress levels.
- ➔ The stressful events of everyday life are both negative and positive. Work, for example, involves the stresses of deadlines and year-end evaluations, as well as the pressures of a promotion or a new, exciting job. Family life may be stressful because of arguments or illness, but also because of the arrival of a new baby or an upcoming holiday celebration. Eliminating all stress from everyday life would rob it of everything that makes life exciting, challenging, and worthwhile.
- ➔ While there is little or no evidence to suggest that controlling stress can reduce disease activity, there is ample evidence to show that the available disease-modifying medications can. Regular use can reduce both the risk of relapses and the development of new lesions as shown on magnetic resonance imaging.

Strategies for Managing Stress

Everyone – with or without MS – feels and functions less well under stress. The best way to deal with the stresses of everyday life is to learn how to manage them more effectively – by eliminating those that aren't essential and finding more comfortable ways to deal with those that are. A good place to start is by carefully tracking one's activities for a week or two to see how much time and energy are being taken up by things that don't really matter. By figuring out what's most important and meaningful, it becomes easier to establish clear priorities and decide what to keep doing and what to let go. A tidy house or a perfectly tended lawn, for example, may just not be as important as quality time with the kids.

The next step is to find a stress management technique that fits one's tastes and lifestyle. For one person it may be exercise or meditation; for another it may be listening to music or getting together with a friend. The point is to find whatever healthful strategy provides relief from the pressures of everyday life – and then make time for it on a regular basis. For a detailed discussion of stress management strategies, see the brochure entitled *Taming Stress in Multiple Sclerosis*.

Some Helpful Tips

MS is a complex, unpredictable disease that can pose significant emotional challenges for even the strongest, most resilient people. It will probably take time to find the coping strategies that work best for you. In the meantime, here are some suggestions:

➔ **Be an active partner in your own health care**

Seek out good information about MS and its management – the more you know, the more prepared you'll feel to make the treatment and lifestyle choices that work for you. And find a physician with whom you are comfortable. Any doctor can prescribe medication and provide periodic examinations. Having a physician who can discuss personal matters and explain complex issues is another matter. It is legitimate to shop for a doctor who is knowledgeable about MS and able to spend time listening and educating patients. Multi-disciplinary MS clinics have much to offer both families and individuals.

➔ **Appraise your MS with realism and flexibility**

Allow yourself to grieve over whatever changes or losses the MS brings your way. In time this will free you to take steps to create new options for yourself. Some people stubbornly try to do all the things they did before – in exactly the same way – regardless of their symptoms. A realistic approach means letting go of some activities (or learning how to do them differently) and/or taking on new ones that are more feasible – and thus more enjoyable and rewarding.

➔ **Maintain strong bonds with family and friends**

Strong connections with others are an important ingredient in a fulfilling life whether one has MS or not. Most of us need to know we are loved and cared for, and we also need to love and care for others who are important to us. Although MS may alter some of the things you're able to

do with and for other people, it's important to maintain meaningful relationships in which you're on both the giving and receiving end.

➔ **Keep a sense of purpose by setting goals**

Personal goals help point you in the direction you want to go and provide a feeling of accomplishment and pride when you get there. An unpredictable disease that saps your energy and alters your ability to get things done can make progress towards your goals more difficult. It may even make it necessary for you to re-think previous goals and develop new goals over time. Whatever course your MS takes, it's important to set your sights on things that are important to you. And working toward your personal goals – whatever they may be – will help you maintain your self-confidence and self-esteem, and feel more in control.

➔ **Talk about your concerns and feelings**

It's important for people with MS to have at least one trusted individual to talk with about how MS is affecting their life. While this may be a relative or friend, many people find it helpful to have someone – perhaps a counsellor or spiritual advisor – who is less personally involved and therefore more objective. The MS Society of Canada, a doctor, nurse, social worker, or other professional can provide referrals. Most people find that talking with someone from time-to-time lets off steam and helps them develop perspective.

Most people also talk to themselves in ways that can affect their feelings in a positive or negative way. For example, a

shift from saying to oneself that “This situation is impossible” to saying “I think I can handle this” is a major step toward a healthier, more satisfying life.

➔ **Find an exercise regimen that’s right for you**

A regular exercise program is a key strategy for maintaining emotional health. Many studies have shown a positive link between exercise and improved moods. And the long-term benefits of exercise on the heart, lungs, bones, nerves, and muscles apply to people with MS just as much as they do to the general population.

Studies of aerobic exercise (geared to a person’s level of ability) have shown that training improves fitness and muscle strength, and reduces depression and fatigue in people with MS. Participants in exercise programs not only enjoy an improved sense of well-being, but experience improvements in bowel and bladder function as well. Talk with your doctor about what kinds of exercise would be best for you.

➔ **Build relaxation into your schedule**

Together with aerobic exercise, programs to enhance physical and mental relaxation – such as yoga, Tai chi, or meditation, can be extremely helpful. Other techniques, such as massage, progressive relaxation, and using a mantra (“slow down” is a good one), help establish a sense of well-being. All of these are proven tools for reducing daily tensions.

➔ **Avoid the negative cycle**

Fatigue and depression can prompt people to stop doing things they once enjoyed and reduce their contacts with friends and colleagues. What begins as feeling tired and blue easily becomes a negative cycle, in which reduced activity reduces physical well-being, which in turn leads to less energy for activity and more fatigue and depression. Medication to relieve fatigue or depression may be needed to break the cycle once it is established. But awareness of the cycle is the first step toward dealing with it.

➔ **Don't underestimate the value of your spiritual beliefs**

Faith is a very important part of many people's lives. Studies of people with chronic illnesses have found that those who have a strong religious or philosophical belief system do better than those without such a source of support. Even the simple act of regular attendance at spiritual gatherings appears to improve coping, perhaps because it gives those individuals a feeling of belonging and a sense of group support. And for those who choose not to attend meetings of this kind, support groups and other social networks may meet the same need.

➔ **Plan on having some fun**

Recreation is often the first thing people eliminate when they need to cut back on regular activities because of fatigue or a too-busy schedule. Putting responsibilities at the top of the priority list is understandable but playing and taking part in social activities can reduce stress, refresh spirits, and contribute to overall health and well-being. The

people who are able to laugh and enjoy humour generally feel better about themselves and manage their lives more effectively. Humour goes a long way toward taking the sting out of some of the more challenging aspects of life with MS.

Resources

Books

300 Tips for Making Life with Multiple Sclerosis Easier, (2nd Ed.) by Shelley Peterman Schwarz. New York. Demos Press, 2006. 128 pp.

MS and Your Feelings: Handling the Ups and Downs of MS, Allison Shadday, LCSW. Hunter House, 2006. 256 pp.

Multiple Sclerosis: A Guide for Families, (3rd Ed.), Rosalind Kalb, PhD, ed. Demos Medical Publishing, 2006. 256 pp.

Multiple Sclerosis for Dummies, by Rosalind Kalb, PhD; Nancy Holland, EdD, RN, MSCN; and Barbara Giesser, MD. Wiley Publishing, Inc., 2007. 362 pp.

Chat

- ➔ The Manitoba Division of the MS Society of Canada offers websites which have scheduled chat room times for kids of parents with MS, teens of parents with MS, and parents with MS:

www.msforkids.com

www.msforteens.com

www.msforparents.com

- ➔ My World of MS
An international online community through the Multiple Sclerosis International Federation

<http://www.msif.org>

- ➔ In collaboration with MS World Inc., MS World is the official chat and message board site for the National MS Society (USA).

<http://www.msworld.org/html/chat.htm>

- ➔ Teens with MS and their parents may be interested in the email group support offered through the Children and Teens with MS: A Network for Families. Contact the MS Society of Canada for more information.

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How to reach the MS Society of Canada

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Our Mission

To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.