



Living Well with MS:

Mind Matters



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The Multiple Sclerosis Society of Canada is an independent, voluntary health agency and does not approve, endorse or recommend any specific product or therapy but provides information to assist individuals in making their own decisions.

Introduction

While living with the challenges of MS, it is easy to overlook other medical problems that can develop at the same time. Among the more common conditions affecting people with MS are mood disturbances, such as depression.

Many people might say, “I have MS — so it’s normal to be depressed.” But the mood changes and other symptoms of depression that can occur in people (not just those with MS) are not normal. They are signs of an illness that needs to be treated. Fortunately, there are many treatments — such as medications and psychological therapies — that are very effective in relieving depression. No one needs to suffer from the despair and hopelessness of depression. There is hope, and help is available.

Mind Matters explains depression, why it can occur in people with MS, and how to get help. The booklet is based on information presented by healthcare professionals at the educational sessions, *Living Well with MS*, an educational series hosted by the MS Society of Canada and sponsored through an unrestricted educational grant from Teva Neuroscience.

The following information is for people living with MS and depression — to help you to understand what you’ve been struggling with and how to find the right therapy for your needs.

What is depression?

Everyone knows what it is to have “the blues”.

You feel down about yourself, your relationships, your job, your future. You feel as if you are living half-empty in a world of full cups. But then something good happens and your cup is refilled.

Clinical depression is quite different. It’s a common illness that affects about 1 in 5 people during their lifetime and causes both mental and physical symptoms (Table 1). These symptoms typically don’t go away in a day or two — they persist for weeks or months. That is because they are signs of an illness at work. So there’s no point telling yourself to “pull yourself out of it”, “think happy thoughts” or “cheer up”. Depression isn’t a sign that you lack character or willpower. It is a problem — like MS itself — that requires medical attention.

TABLE 1.

Mental Symptoms

- **Depressed mood:**
“I feel so empty and sad.”
- **Hopelessness/pessimism:**
“I don’t plan for the future.
There’s no point.”
- **Restlessness:**
“I feel jumpy and on edge.”
- **Irritability:**
“I lose my temper and say terrible things to people I care about.”
- **Difficulty concentrating:**
“I find it hard to focus my attention.
I keep ‘losing my place’.”
- **Trouble remembering:**
“I was going to do something in the kitchen — what was it?”
- **Loss of interest:** “I used to like going out with friends. Now I just can’t be bothered.”
- **Thoughts of death:** “I don’t like to talk about it — but sometimes I think about hurting myself.”

Physical Symptoms

- **Loss of energy/fatigue:**
“I feel worn out all the time.”
- **Sleep changes:** “I used to sleep 7 hours a night. Now I have trouble falling asleep or I wake up really early.”
- **Appetite changes:** “I can’t think of anything I feel like eating” or “I’m hungry all the time — and I’ve gained 6 pounds in the past couple of weeks.”

What causes depression?

Little is known about the causes of clinical depression. Some families appear to be more susceptible to depression, but genetics is only part of the story. Psychological triggers (e.g. serious loss, financial problems, stress) and environmental factors also seem to have a role in the development of depression.

Depression is twice as likely to occur in women compared to men. It is now understood that hormonal fluctuations in women can contribute to depression as well.

How common is depression among people with MS?

Clinical depression occurs more frequently in people with a variety of neurological conditions, such as Parkinson's disease and post-stroke syndromes. The same is true in MS. About 50% of people with MS will develop depressive symptoms at some point during their lifetime. So the risk of depression is much higher among people with MS than in those without the disease.

But even such high numbers may underestimate the problem. To diagnose depression, a doctor has to detect a certain number of symptoms (such as depressed mood, loss of interest and waking up early in the morning). Once a certain threshold is crossed, the person then satisfies the medical criteria for depression and the diagnosis is made.

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This is the same situation as is found with MS. When you first had MS symptoms, your doctor may have told you that he/she “suspected” you had the illness. But the diagnosis couldn’t be confirmed until you had another relapse. As they wait to make their diagnosis, the disease continues to progress until it becomes severe or frequent enough to meet the criteria for a diagnosis.

Similarly, you may be suffering from depressive symptoms that aren’t severe enough to be diagnosed as depression. But your suffering is still real and still needs to be treated. These depressed symptoms affect about 50% of people with MS at any given time. This means that if you were to take a picture of a group of people with MS, one-half of them would have some symptoms of depression. The problem may not be diagnosed. But it is there. And the risk is that without proper treatment, depressed symptoms may get worse.

Why does depression occur in MS?

Since MS is a chronic, frequently debilitating illness that can play havoc with career, home life and relationships, many people might think: Who wouldn’t get depressed about having MS?

In fact, this idea — that depression is simply a reaction to a diagnosis of MS — is a common misperception. Depression doesn’t set in because of a setback or disappointment. It isn’t idle complaining or moodiness.

The causes of depression in MS aren’t well understood. Genetics may be a factor. The MS disease process itself may play a direct or indirect role. The slow progression of nerve damage in the brain may cause depressed symptoms in some individuals. The inflammatory flare-ups in the brain seen during MS relapses have also been linked with the development of depression.

These physical factors undoubtedly contribute to clinical depression. But more important are psychological factors: how we cope with illness, how we perceive ourselves and how we regain a sense of control over our lives.

MS medications and depression

Many people with MS regularly take a beta-interferon (Avonex®, Betaseron®, Rebif®) or glatiramer acetate (Copaxone®) to control their disease.

In early studies, beta-interferon use was linked to depression in a small number of people, but this association is controversial. If you are diagnosed with depression, it's prudent to advise both your family doctor and your MS clinic doctor that you are taking a beta-interferon. Depression has not been linked with glatiramer acetate use.

Coping skills, MS and depression

People with MS typically have very good coping skills and know how to deal with life's inevitable disappointments. They develop new attitudes, learn new skills, and enjoy the small victories they achieve every day.

Most people learn how to manage their MS very well, scheduling activities for higher-energy times, taking a break when fatigue is overwhelming. People can learn to live with tingling and numbness. They can get practical advice from their doctor or nurse on how to deal with physical symptoms. So MS symptoms themselves do not necessarily make someone more prone to depression. What can erode a person's coping skills is uncertainty: *How will I feel tomorrow? Will I be able to do my job? Will I have the energy to take care of myself and my family?*

This sense of uncertainty is very hard. How can you make plans? It would be nice to think ahead, to imagine a picture of yourself enjoying your future. But how can you do that when you don't know if you'll be in pain, unable to function, or disabled?

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The on-again, off-again symptoms of MS also wear a person down. If you were injured in an accident, with time you would learn to accept your injuries and go from there. MS isn't like that. Even severe MS symptoms can get better, leaving you to think: *Am I okay now? Should I just go on and live my life?* But weeks, months or years later, MS symptoms return.

It is hard to know what to expect and MS is always there with its lure of false hope. It builds up expectations, then sends crushing disappointment. This continuing cycle of hope and disappointment and hope again can sap your energy and optimism. *Hope deferred maketh the heart sick* — and that sickness of heart can open the door to depression.

Angry at MS

- You feel the slow creep of symptoms.
- You can't do the things you want to do.
- Your plans are slipping away.
- You have responsibilities, pressures, demands — and you don't know if you can deal with them.
- You're not the same person anymore.
- You need help — but asking for it feels like weakness, and the help you get feels like pity.
- It makes you angry.

It is normal to think these things from time to time. It's normal to think sometimes about how life would have been without MS. People often ask, *Why me? Why did this happen to me?* It's normal to be sad and to grieve for that other person you might have been. It's not unusual to feel frustrated when you find it difficult to do something that used to be so easy to do.

It is easy to feel angry at MS. Anger is part of a person's coping mechanism. Anger can help us fight the difficulties we face. But it will become destructive if it just keeps boiling away. If anger starts to define us, it doesn't overcome barriers anymore — it creates them.

It's important to make peace with your situation. Everyone — not just people with MS — has to come to terms with his or her limitations. We are born rich or poor, we have different talents and abilities. We become injured or sick. We get old. There are many unfairnesses along the way. We don't always have the power to change the way life is. But we do have the power of deciding how we are going to react to things.

If you give up anger, it doesn't mean you have given up the fight. Anger has to pass before the real struggle can begin: exploring your unique abilities, making the most of the loved ones surrounding you, and celebrating the gifts that life has given you.

How do I know if I'm depressed?

Detecting depression can be a challenge for healthcare professionals and it is frequently overlooked. Clinical depression is a collection of symptoms (see Table 1) that may be quite unique to that individual. Some people may appear sad and tired, others may appear jittery and on edge.

Recognizing depression can be doubly difficult in a person with MS. This is because MS symptoms and depressed symptoms are very similar. When you feel fatigued and dispirited, is it because you're having a bad day with your MS? Or are you clinically depressed? If you often feel uncertain and frightened about what the future holds, are these feelings "normal" to a person with MS? Or are they really depression?

A Simple Test

Two questions can provide some insight as to whether you have depression.

Over the past few weeks:

- 1.** Have you felt down, depressed or hopeless?
- 2.** Have you lost your interest or pleasure in doing those things that you normally enjoy?

If you answered Yes to these questions, it's important to talk to your doctor about depression.

Other symptoms of depression are listed in Table 1. If you have one or more of these symptoms, talk to your doctor. Remember: it's worthwhile talking to your doctor even if you have only a few depressed symptoms. Treatments can be very helpful to relieve chronic, low-level depression.

Suicide

Depression isn't a benign illness. It causes great pain and suffering and can drive people to thoughts of suicide.

Have you ever thought:

- *"My life is hopeless. There's nothing to look forward to."*
- *"My family would be better off without me."*
- *"Things would be much easier if I just died."*
- *"I've figured out a quick, painless way to end it all."*

If you have had these or similar thoughts, contact a healthcare professional **immediately** — your doctor, a hospital emergency room, a clinic or crisis centre. Don't hesitate to seek help.

Suicidal thoughts are part of the syndrome of depression. Like other depressed symptoms, they will ease once you receive proper treatment. Do not suffer in the silence of your thoughts and think about harming yourself. Help is available.

What can I do if I'm depressed?

There are many therapies available that can help to alleviate depression.

The first and most important step is to seek help. It's important to keep in mind that depression is an illness that requires treatment. If it's left untreated, depressed symptoms may get worse or can persist for weeks or months.

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See your doctor

If you suspect that you are suffering from depression — see your family doctor. He/she can discuss your symptoms and will identify if you need treatment.

Don't suffer in silence. It's important to get prompt treatment before your symptoms get any worse. Depression can be treated!

Drug therapies

There are many drug therapies that are very helpful in relieving depression. These medications — called *antidepressants* — are taken as a pill (usually once a day). Table 2 lists some of the more common medications.

The choice of the most appropriate medication is made in consultation with your family doctor. Antidepressants typically require 4-6 weeks of daily dosing before there is a significant relief of depressed symptoms. Don't get discouraged — it is important to continue taking the medication until it has had time to work.

Most medications, including antidepressants, have the potential to cause unwelcome side effects. These may include stomach upset (nausea, diarrhea), headache, fatigue or dry mouth. These side effects often go away within a few weeks. However, if your side effects are severe or you are troubled by any of your medication's effects, talk to your doctor. He/she can adjust your dose or select another medication that may be easier to take.

If you aren't satisfied with the medication, DO NOT stop taking the drug. Talk to your doctor first. Some medications need to be slowly discontinued to avoid withdrawal effects. Abruptly stopping an antidepressant may also worsen your depressed symptoms.

DO NOT take any prescription or nonprescription antidepressants or any product containing St. John's Wort (an herbal product) if you are taking a prescription antidepressant. Talk to your doctor before taking a migraine medication. Tell your doctor and pharmacist about all medications you are taking, including prescription, nonprescription or alternative remedies.

TABLE 2. Medications commonly used to treat depression.

BRAND NAME	CHEMICAL NAME	NOTES*
Prozac®	Fluoxetine	May cause or worsen sexual side effects (e.g. difficulty achieving orgasm). May worsen suicidal thoughts. May cause withdrawal effects if stopped abruptly.
Zoloft®	Sertraline	
Paxil®	Paroxetine	
Luvox®	Fluvoxamine	
Celexa®	Citalopram	
Remeron®	Mirtazapine	Fewer sexual side effects than above. May cause sedation and worsen MS fatigue. Avoid driving or other activities requiring mental alertness.
Effexor®	Venlafaxine	May increase blood pressure in some people. May cause insomnia, anxiety and nervousness.
Norpramin®	Desipramine	May cause side effects such as dry mouth and difficulty urinating.
Manerix®	Moclobemide	May cause stomach upset.

** Most antidepressants have not been studied specifically in people with MS. The antidepressants listed have been shown to be generally effective in clinical depression in adults. Consult your doctor before starting, stopping or changing the dose of any medication.*

Drug and alcohol use

When taking an antidepressant medication, it is important to tell your doctor about any other drugs you are taking.

Antidepressants should not be mixed with alcohol or any illicit drugs. If you abuse any substances (alcohol, cocaine, amphetamines, etc.), it's important to know that this can cause or contribute to depression. Talk to your doctor if you abuse alcohol or illicit drugs and discuss any problems you are having. There are many resources in your community that can help you overcome a dependence on alcohol or drugs. Depressed symptoms often improve once alcohol/drug abuse is under control.

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Marijuana use is becoming more common among people with MS as a way of relieving MS symptoms, such as spasticity, pain and tremor. However, marijuana can adversely affect mood and frequent marijuana use may contribute to depressive symptoms in some people. Marijuana use is not recommended in people with depressed symptoms or mood swings.

Psychotherapy

Depression can also be treated with psychotherapy, such as cognitive-behavioural therapy (CBT). Simply stated, CBT tries to identify negative thoughts and behaviours that are causing distress and teaches simple techniques to reorient these thoughts/behaviours to a more healthy approach. This can be very helpful in addressing issues such as self-esteem, body image, sexuality, anger and negative beliefs.

Interpersonal psychotherapy has also been shown to be effective for depression. This technique focuses on personal relationships and how they may be contributing to depression.

A short-term course of psychotherapy may be completed in 10-20 weeks. There are two main drawbacks to nondrug therapy. There are few qualified therapists so the waiting time may be lengthy; it may be difficult to find a therapist in some communities. Secondly, therapy can be expensive, so it is best to confirm if psychotherapy is covered by your provincial health plan or private insurer.

Other counselling and support

MS can be very challenging for family members as well. Relationship counselling may be helpful to address family issues, sexuality and how to live with MS. Your spouse or partner is an important source of love and reassurance and helps you guard against feelings of social isolation. Your partner is your ally — you can get through the toughest times if you work together. Communication is the key to maintain a loving, supportive environment.

The MS Society of Canada, MS support groups, MS clinic nurses and community groups can also provide support and encouragement. Many communities offer services, such as housecleaning and hot meals, that can be invaluable. Books by and about people with MS can help to reassure you that you're not going through this alone. Local religious groups can help you get in touch with your spirituality and provide many useful services.

The key is to find the information and resources that suit your needs and circumstances.

Community resources

Family doctor: _____

Telephone: _____

MS clinic: _____

MS Society of Canada

1-800-268-7582

www.mssociety.ca

Canadian Counselling Association

www.ccacc.ca/ltoAssoc.htm and click on Find a Counsellor

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