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## Introduction

Though clinicians noted mood changes associated with multiple sclerosis as early as the 19th century, symptoms associated with mood disorder have only recently begun to receive the same degree of attention from clinicians as physical symptoms. Mood disorder is a complex issue and despite greater awareness, continues to be under-diagnosed and under-treated. This “invisible symptom” can be a direct result of the disease process and can change over time.

We now understand that mood and physical functioning are intricately entwined and treating one area often brings profound improvement to other aspects of an individual’s life—and to the lives of their families.

We also now recognize that while changes in mood may not be readily apparent to outside observers, their impact on a person’s life can be profound: affecting physical, social, emotional, occupational and spiritual functioning.

Fortunately, mood changes are among the most treatable symptoms of MS. With the appropriate strategies and tools in place, people with MS can live their best lives and participate actively in their own care.

We are pleased to have the following doctors and researchers as the program's presenters:

**Anthony Feinstein, MD, PhD**  
Sunnybrook Health Sciences Centre

**Frederick W. Foley, PhD**  
MS Center at Holy Name Medical Center

We'd also like to thank Ann Marie Johnson, Maria Reyes-Velarde, and David and Staci Rosen for so graciously giving their time and sharing their stories with us.

## Presentation Format

If you're considering bringing in a speaker, talk to your Society staff partner about finding or coordinating a licensed mental health counselor, social worker, wellness coach or life coach.

The 14-minute video and accompanying book explore why and how people with MS experience changes in mood and provide the latest information on how to address these symptoms—from physical activity, medications and counseling to self-management strategies. In the video portion of the program, you will hear from clinicians at the forefront of MS research and treatment discussing the latest advances and recommendations, as well as from individuals who have experienced these symptoms and have lessons to share.

Please provide each participant with the companion book, which goes into more detail than the video, allowing you to delve deeper into the topics. If any participant would like to watch the video again, they can visit **[nationalMSSociety.org/moodchanges](https://www.nationalmssociety.org/moodchanges)**.

Discussion questions are provided to help facilitate conversation with your group after watching the video. For help with any questions that may arise, please utilize the list of frequently asked questions (FAQs) in this guide. These questions are not all-inclusive. Please refer unanswered questions (or questions that are outside the scope of the presentation) to an MS Navigator at 1-800-344-4867 or **[contactusnmss@nmss.org](mailto:contactusnmss@nmss.org)**, or to one's healthcare team.

## Program Survey

The National MS Society strives to provide information, resources and programs that are relevant and important to people living with MS. Your feedback, and that of your group, is vital. We want to know what is important in your lives and what you consider to be critical programming. Please send your group members an email following the meeting with a link to a short online survey. The following is an email template you can use:

We are very excited and want to thank you for participating in this year's National MS Society's **Mood Changes in MS Program**. The Society is constantly trying to make sure we are doing our best to help those with MS live their best possible lives – please help us achieve this goal by providing your feedback. It is important that you complete these evaluations so we can continue to strengthen and provide the most impactful programs for everyone affected by MS.

You can complete this short online survey prior to the program at **[www.surveymonkey.com/r/MoodChangesPreSurvey](http://www.surveymonkey.com/r/MoodChangesPreSurvey)**. After the program, please complete a post online survey on **[www.surveymonkey.com/r/MoodChangesPostSurvey](http://www.surveymonkey.com/r/MoodChangesPostSurvey)**.

Once again, we thank you for your time and efforts to help us better show the impact of this amazing program!

## Resources

The National MS Society has an extensive library of resources, including publications about treatment options, symptom management and the day to day challenges of living with the disease. For more information please contact an MS Navigator at 1-800-344-4867 or visit **[nationalMSSociety.org](http://nationalMSSociety.org)** and go to the Symptoms and Diagnosis or Living Well with MS sections.

## Group Discussion Questions

**Has anyone recognized mood changes in themselves or their loved ones?**

Optional follow up question might be:

**How did you first recognize something had changed with your mood?**

**TALKING POINTS:**

Allow people to share signs that something was wrong or felt different.

**How did that make you feel?**

**TALKING POINTS:**

The first signs that something is wrong could be very upsetting for people. They may not know what these changes mean or that there are ways to manage them. They may be embarrassed. There's a lot of stigma associated with mood changes, so people may be reluctant to talk about it and feel ashamed.

**How have your “changes in mood” impacted your family?**

**TALKING POINTS:**

Relationships between family members may be particularly affected, as spouses and children struggle to understand changes in the behavior of their loved one. Loved ones may be mystified at what they see as a sudden change in attitude and wonder what they might have done to bring it on. Family members also may feel their own spectrum of emotions, ranging from concern to resentment at having to “pick up the slack.” And of course, family members affected by MS can experience their own sadness, anxiety and even depression.

## **How long did it take before you discussed it with your doctor? If you haven't, why not?**

### **TALKING POINTS:**

People may hesitate to talk about it with their doctor because they don't think there's anything that can be done or they don't want to be labeled. However, proper diagnosis is important, as mood changes can be treated and managed in many ways.

## **Have you discussed what you were experiencing with your family and friends? If no, why not? If yes, how did they respond? How did you explain what was going on?**

### **TALKING POINTS:**

Many factors can contribute when making the decision to share changes in mood with loved ones or friends. We may not want to worry them or may not understand ourselves what's occurring. One may be embarrassed or worry about being treated differently. Because mood changes aren't visible, it is easier to keep them from others.

## **Do you find these symptoms more difficult to discuss than other MS symptoms?**

### **TALKING POINTS:**

These symptoms can be more difficult because they're invisible, making it hard for others to understand. Mobility issues are front and center and more easily attributable to the disease. How MS impacts mood isn't always understood, so the correlation between MS and mood changes isn't always taken into consideration.

## **What strategies have you used to manage your mood changes?**

### **TALKING POINTS:**

The first step toward feeling better is having a full evaluation. If you've been experiencing any of the symptoms of depression for more than a few weeks, it's worth discussing them with your neurologist. Some of the symptoms, such as difficulty concentrating and fatigue, are hallmarks of depression and of MS, and

your doctor will be able to help you take the first steps toward determining their root cause. He or she may refer you to a psychiatrist, psychologist, social worker or other counselor for further evaluation or treatment. These professionals have a wealth of resources available to treat depression.

**What resonated with you from this video?**

## Frequently Asked Questions (FAQs)

### What is the prevalence of mood changes in MS?

More than half of people living with MS experience mood changes at some point in the course of their disease.

### What types of mood changes occur in MS?

Some of the most common mood changes that may affect a person with MS are: grief, depression, anxiety, moodiness and irritability, bipolar disorder and pseudobulbar affect (PBA).

### How does depression differ from “the blues?”

It’s common to hear people use the phrase “I’m so depressed,” perhaps when their favorite sports team loses or when a date doesn’t work out. But in truth, depression involves more than just a temporary feeling of sadness or disappointment, or even a period of “blues” that lasts a few days. Usually, those emotional states lift when something pleasant happens.

Depression, however, is persistent and unaffected by external events or enjoyable interactions. Though feelings of sadness or irritability are the most recognizable characteristics, depression also involves a loss of interest in activities that once brought enjoyment, such as hobbies, time with friends or sexual activity; depression can also bring about physical symptoms, such as changes to appetite, sleep, energy level and ability to concentrate. The specific symptoms will vary with each individual just as the symptoms of MS vary.

## How can unmanaged depression worsen or cause disability?

Depression can cause its own disability. People who have depression and MS may have poorer functioning and quality of life. They may have poor relationships. They may be less independent. They may stop working. Depression is associated with people being less adherent to medications—they may take them less frequently or not be willing to start disease-modifying therapies in a timely manner. In addition, the emotional pain that depression causes can make people feel their physical pain more acutely.

## Why is it critical to diagnose mood changes?

If you've been experiencing any of the symptoms of depression for more than a few weeks, it's worth discussing them with your neurologist. Some of the symptoms, such as difficulty concentrating and fatigue, are hallmarks of depression and of MS, and your doctor and therapist with integrated treatment can focus on helping you take the first steps toward determining their root cause.

Because depression is associated with suicidal feelings, it's imperative not to ignore it or hope it will go away. In fact, depression is more strongly linked with suicide than wheelchair use, vision loss, or any other symptom or result of living with MS. Because depression is so common, people with MS may have as much as 7.5 times the risk of suicide as people in the general population. And with treatment so effective and readily available, no one should have to remain depressed.

## How does mood impact those around you?

Moods play a central role in most people's lives, whether or not they have MS. A person's emotional state can influence his or her physical and cognitive functioning. In fact, moods affect our overall quality of life. People who feel depressed or anxious are often reluctant to participate in social or community activities, which can lead to a sense of isolation, which in turn creates even more depression or anxiety.

Family and personal relationships are affected as well. Loved ones may be mystified at what they see as a sudden change in your attitude and wonder what they might have done to bring it on. This is true of children as well as adults. Family members also may feel their own spectrum of emotions, ranging from concern to resentment



at having to “pick up the slack.” And of course, family members affected by MS can experience their own sadness, anxiety and even depression. It’s important to keep lines of communication open, and to consider family counseling.

## What treatment options are available to manage mood issues?

While we need more research to help us understand the best strategies for treating depression, experts typically recommend using a three-pronged approach: medication, talk therapy and exercise.

Many antidepressant medications effectively treat both depression and anxiety. Specific anti-anxiety medications can work well for short periods of time, but carry the risk of dependence. Cognitive behavioral therapy (CBT) and other forms of psychotherapy can be very effective for anxiety disorders. Yoga, meditation, and exercise can help with depression and anxiety.

Pseudo-bulbar affect (PBA), a condition where one experiences involuntary bouts of laughing or crying that happens suddenly and frequently, is typically treated with either antidepressants or Nuedexta<sup>®</sup>, a medication approved in 2010 that is thought to work in the areas of the brain that control emotion. PBA has not been shown to respond to CBT or other talk-based approaches.

## What role does fatigue play in mood?

Not only is fatigue prevalent in about 90 percent of people with MS, but its impact is far-reaching because fatigue is inextricably linked with mood; an increase or decrease in either of these symptoms affects the other.

Fatigue is one of the most common symptoms of depression. Many people with MS find that when they attempt to concentrate on something for a long period of time, they feel mentally wiped out. This phenomenon, known as cognitive fatigue, is distinct from the more common physical fatigue experienced by so many people with MS.

## What should you do if someone is suicidal?

If you or someone else are having thoughts about harming yourself or another person, call the **National Crisis Hotline at 1800-273-TALK (8255)** or text **“ANSWER” to 839863**.