



Presenter's Packet & Frequently Asked Questions



National
Multiple Sclerosis
Society

Introduction

Welcome to the **2014 North American Education Program— Mood & Cognition in MS: What You Can Do**. We appreciate you taking the time to be a part of this important educational opportunity. To help with any questions that may arise, a list of frequently asked questions (FAQs) related to the subjects discussed in the video and program booklet was developed. In addition, discussion questions are provided to help facilitate conversation with your group after watching the video.

For planning purposes, the run time of the video is 34 minutes. This educational video shares personal stories of people living with MS and their experiences managing changes in mood and cognition. Medical experts explore the causes and science behind these changes, how they interact, treatment options, and exciting research into new treatments.

Please provide copies of the companion booklet to meeting attendees as a resource. The booklet goes into more detail than the video, allowing you to spend more time with the content and delve deeper in the topics. In addition, if any of your members would like the opportunity to watch the video again, they can request a copy of the DVD by calling an MS Navigator at 1.800.344.4867 or watch at nationalMSSociety.org/video.

These questions are not all-inclusive. If asked a question that is outside the scope of the presentation or that you or the presenter does not have an answer to, please refer the person to an MS Navigator at 1.800.344.4867 or her or his healthcare team. If you're considering bringing in a speaker, we encourage you to invite a neurologist, therapist, neuropsychologist, MS certified nurse or social worker knowledgeable about MS.

We want to thank Bayer HealthCare; Genentech; Genzyme, a Sanofi company; Mylan; Novartis Pharmaceuticals; Questcor Pharmaceuticals, Inc.; and Teva Neuroscience for providing generous educational grants to make this program possible.

Program Background

The National MS Society, in partnership with the MS Society of Canada, is pleased to bring you **Mood & Cognition in MS: What You Can Do**. This year's North American Education Program shines a light on cognitive and mood changes. It is our hope that by discussing them thoroughly and openly, people living with MS, along with their loved ones, will understand that these symptoms are both common and manageable. The expanded understanding of how and why these symptoms occur—as well as recent advances in treating them—are enabling more people with MS to continue to stay engaged in their lives and in their healthcare.

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

Charles Bombardier, PhD

University of Washington Medicine

John DeLuca, PhD

Kessler Foundation

Anthony Feinstein, MD, PhD

Sunnybrook Health Sciences Centre

Frederick W. Foley, PhD

MS Center at Holy Name Medical Center

Lauren Krupp, MD

MS Comprehensive Care Center at Stony Brook Medicine University

We'd also like to thank the following individuals for so graciously giving their time and sharing their stories with us:

- **Glenn & Rhondell Domici**

- **Ann Marie Johnson**

- **Maria Reyes-Velarde**

Program Outcome Measurement

Each year the National MS Society strives to provide educational programming that is relevant and of interest to people living with MS. As a self-help group leader, 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 provide your feedback on this and future programming by completing our short online survey at www.surveymonkey.com/s/moodcognition or completing one of the enclosed surveys. Please mail all completed surveys to:

National MS Society

Doris Lill

900 S. Broadway, Suite 200

Denver, CO 80209

Resources

The National MS Society has an extensive library of resources about MS, 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 (1-800 FIGHT MS) or visit nationalMSSociety.org and go to the *Symptoms and Diagnosis* or *Living Well with MS* sections.

Frequently Asked Questions (FAQs)

What is the prevalence of mood and cognitive changes in MS?

About 65 percent of people living with MS experience some degree of change in cognition, and more than half of people living with MS experience mood changes at some point in the course of their disease.

Do mood and cognition impact each other?

Yes, mood and cognition don't exist in isolation—mood affects cognition, and vice versa. For example, a person who is depressed is more likely to have difficulty staying focused on a task, may process information more slowly, and will have more difficulty than usual in planning and problem solving. Likewise, a person with memory problems may feel increasingly anxious about forgetting important events, or may become depressed because of his or her changing abilities. It can become a perpetuating cycle.

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). More information on PBA is available on page 5.

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, however, just as the symptoms of MS itself will vary.

How can unmanaged depression worsen or cause disability?

Depression can cause its own disability. People who have depression as well as MS may have poorer functioning and diminished 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 a person with MS has been experiencing any of the symptoms of depression for more than a few weeks, it's worth discussing them with your a health professional. Some of the symptoms, such as difficulty concentrating and fatigue, are hallmarks of depression and of MS, and a doctor will be able to 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 ones mood impact people around him/her?

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 their loved one's 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) is typically treated with either antidepressants or Nuedexta®, 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 does the term cognition mean?

The term cognition refers to the many mental processes the brain performs. These include attention, memory, information processing, planning, organization, problem solving, visual and spatial perception, executive functions such as planning and organizing, and language use. Typically intellectual functioning is not impaired.

What impact can cognitive changes have on daily life?

A change in cognitive skills can affect:

- **Social and personal relationships**- if a person has difficulty expressing his or her thoughts, tracking lengthy or complex conversations, or remembering something a friend or family member talked about recently, both people in the relationship can feel frustrated.
- **Family roles**- people may find that they need to rely on a partner more, which could shift the balance of the relationship so it no longer feels equal. This can lead to resentment and, in some instances, a loss of respect for or trust in the person with MS.

- **Performance at work**- according to a classic 1991 study by Stephen Rao, PhD, and his colleagues, impaired cognitive skills are one of the main reasons people leave the workforce early.
- **Driving**- if a person's thinking has slowed down, if speed of processing information has been affected, and that's coupled with poor judgment and perhaps a degree of neurological impairment, it's understandable why driving might be hazardous for certain people.
- **Self-esteem**- for many people, their self-image changes when they realize that their memory or reasoning ability is not as sharp as it once was.

Why is it important to have cognitive changes assessed?

The earlier that cognitive changes can be addressed, the less opportunity they will have to significantly interfere with life. While cognitive dysfunction can be a direct result of MS, it can also be worsened—or masked—by other factors common in MS, such as fatigue, depression, pain or even some medications used to treat MS symptoms. If a person is experiencing cognitive difficulties, a visit to the neurologist is in order. He or she can assess the influence of these other factors, and take steps to begin resolving them.

How are cognitive changes assessed?

Because cognition involves so many skill sets, there's no single brief measure of cognitive function. However, neuropsychologists do have several in-depth tests to test various cognitive functions. Not only can these evaluations assess areas of strength and weakness, but they can also provide a baseline measure—either to compare against periodic assessments in the future, or to assess the effects of a treatment. A neuropsychologist, speech-language pathologist or occupational therapist who has experience with MS can conduct a cognitive evaluation.

What treatment options are available to manage cognitive symptoms?

Treatment for cognitive symptoms takes several approaches. These include medication; rehabilitation, including developing compensatory strategies; and patient and family education.

Some of the medications used to treat the physical symptoms of MS have been studied for their effects on cognition, and to date, the most promising results come from drugs used to treat fatigue such as amantadine, modafinil (Provigil®) and armodafinil (Nuvigil®). Cognitive rehabilitation has long been used as part of the therapeutic program for people

recovering from traumatic brain injury or stroke. The success of this type of rehabilitation relies on a property of the brain known as neuroplasticity, which means that unimpaired areas of the brain can begin to perform some of the functions of the damaged regions after sufficient practice. Techniques include:

- **Self-generation**-people learn to periodically quiz themselves about something they want to remember
- **Spaced learning**-a person reviews the information multiple times, but with a delay between each learning episode
- **Self-directed strategies**- compensatory strategies to work around cognitive challenges

What role does fatigue play in mood and cognitive changes?

Not only is fatigue prevalent in about 90% of people with MS, but its impact is far-reaching because fatigue is inextricably linked with cognition and mood; an increase or decrease in any one of these symptoms affects the others.

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.

Suggested group discussion questions:

1. How did you first recognize something had changed?
2. How did that make you feel?
3. How have changes in mood and or cognition impacted your family?
4. How long did it take before you discussed it with your doctor? If you haven't, why not?
5. Have you discussed what you were experiencing with your family and friends?
 - a. If no, why not?
 - b. If yes, how did they respond?
 - c. How did you explain what was going on?
6. Do you find these symptoms more difficult to discuss than other MS symptoms?
7. Have you discussed undergoing a neuropsychological evaluation with your doctor?
 - a. Why or why not?
 - b. If yes, describe what the evaluation was like and the outcomes.
8. What strategies have you used to manage cognitive challenges and/or mood issues?
9. What messages most resonated with you from this video?