

Webinar Series



Achieving Emotional Wellness

Tuesday, February 11, 2020

Presented by:



Genentech






**National
Multiple Sclerosis
Society**



How to Ask Questions During the Webinar:

- Type in your question in the Q & A pod



The image shows a user interface for a Q & A session. It features a header with the text 'Q & A' and a menu icon. Below the header is a large, empty white box for entering questions. At the bottom of the interface is a text input field and a speech bubble icon, indicating where to type and submit a question.

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Living with MS



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Learning Objectives

- Describe common challenges to emotional wellness
- Understand the interrelationships among fatigue, mood, and cognition - three of the most common invisible symptoms
- Learn “Go To” strategies for coping effectively with these challenges
- Recognize stress- and mood-related symptoms, when to take action, and how to communicate with your support people about this

What is Emotional Wellness?

- An important part of overall health and well-being
- Awareness of emotions, stressors and challenges in life and their impact
- Recognizing how you react to stressors, emotionally, physically, and behaviorally
- Adapting and responding to stressors effectively
- Includes self-care, relaxation, stress reduction, and connecting to self and others as well as meaningful pursuits

Jean's MS

- First symptoms at age 25
 - Optic Neuritis
 - Sensory symptoms/changes
- Diagnosis at age 30
- Primary symptoms
 - Fatigue and associated mood disturbance and cognitive challenges
 - Sensory symptoms
 - Recurrent Optic Neuritis
- Treatment (DMT) since diagnosis except during pregnancies



Biggest Challenges to Jean's Emotional Wellness

- Invisible and unpredictable symptoms
- Management of fatigue both physical and cognitive
- Expectations of self, overvaluing productivity
- Professional goals vs health
- Management of irritability and anxiety
- Talking about and explaining MS to others

Common Challenges in MS

- Unpredictability
- Losses
 - Changes in functioning
 - Need to leave workforce before you are ready
 - Changes in self-esteem and self-confidence
 - Giving up valued roles and responsibilities
- Wrestling with “should’s” about how you spend your energy
- Talking with others about MS
- Sorting out one symptom from another, chicken vs egg
- Invisible symptoms, “Oh, but you look so good”

Invisible Symptoms: The “Catch 22” in MS

- You may well feel and look “normal”
- You don’t fit people’s perceptions of “sick”
- Invisible symptoms are often difficult for you to describe and for others to understand
- People, including you may underestimate and minimize your symptoms
- Disclosure may feel like more of a choice
- Functions, roles, responsibilities, relationships, and self-image can still be affected

How Mood and Cognition Relate

“I was early in my career when first diagnosed and my difficulties formulating thoughts in meetings and word finding issues caused me significant anxiety. I was afraid it reflected on my professional competence.”



What We Know About Invisible Symptoms

- Changes in mood, fatigue, pain, and cognitive changes occur frequently in PwMS.
 - More than 50% will experience major depression
 - The rates for anxiety are very similar to depression
 - Fatigue occurs in 80%
 - 65% experience some cognitive changes
- These symptoms are often interrelated so that when you experience an increase in the frequency and severity of one, you also experience increases in another.

Managing Invisible Symptoms

- Increasing your awareness about invisible symptoms is a good start.
- There is much you Can Do to reduce frequency and severity of these symptoms and their impact.
- Doing something that has a positive effect on one symptom may well result in improvement in another symptom.
- Developing “Go To” strategies for these symptoms can go a long way in reducing their negative impact on your emotional wellness.

How Fatigue Impacts Mood and Coping

“Parenting young children when irritable and overwhelmed due to MS fatigue was a challenge. Meditation was a lifesaver.

I discovered that only 10 minutes of focused deep breathing before my husband left for work was enough to make a difference and enable me to be more present and *respond* to my children instead of *react*. I'd usually realize by 10am if I had neglected to do it.”



Paying Attention to Mood

- Moods both good and not-so-good are universal.
- Changes in mood come in many shapes and sizes.
 - Depressed, anxious, irritable, high levels of tension, downright moody
- When people experience these mood states:
 - Taking care of themselves and others becomes difficult
 - Functioning well at work and at home is more difficult
 - This can negatively effect how you feel about yourself
 - Relationships become more challenging
- Regularly monitoring your mood can be helpful.

Risky Times For Mood

- Before and during exacerbations
- When you can't meet expectations
- Specific MS-related losses
 - Giving up valued roles and responsibilities
 - No longer participating in life in the way you want
 - When your body doesn't cooperate
 - Leaving the workforce before you're ready
- Life transitions, even positive ones

Depression and Anxiety in MS

- Depression can have multiple causes including neurologic, immune dysfunction, life stressors, and medications.
- Symptoms often include a combination of emotional, physical, and cognitive changes.
- Many people experience both anxiety and depression.
- Depression can be life-threatening.
- Mood problems are under-diagnosed and under-treated.

Regardless of cause, depression and anxiety in people with MS and their partners respond well to treatment!

When To Take Action:

- When symptoms are interfering with activities, functions and relationships
- When you are regularly experiencing “toxic” emotions like guilt, shame, resentment
- When you feel stuck with old strategies that aren’t working
- When you find yourself replaying the same thoughts, conversations, and future events over and over
- If you feel hopeless and/or have thoughts of harming yourself

What You Can Do

- Ask someone you trust to describe their concerns about your recent mood and behavior.
- Talk with someone from your MS care team or your primary care provider.
- Call the National MS Society (800-344-4867) to reach an MS Navigator for screening of your symptoms and help finding mental health professionals in your area.
- ***If you are concerned about your mood and how it's affecting you, tell someone!***

Treatment of Depression and Anxiety

Recommendations:

- Psychotherapy/counseling
- Medication
- Exercise

Support group participation is *not* sufficient for treating significant mood changes

Self-medicating with substances is *not* a substitute for treatment



Benefits of Talking About Mood

- Doing so could help you feel more connected to other people.
- You become a role model for others by being open about your emotional health.
- This sends a clear message that you are aware of your symptoms, the severity, and the impact.
- People are more likely to be understanding.

Self-Care Helps You Care For Others

- 35yo married woman with 3 daughters recently diagnosed with MS, primarily invisible symptoms.
- Referred to psychology for depression worsened since MS and now with feelings of guilt about her parenting.
- Treatment recommendations included therapy and medication.
- After a few sessions, she arrives with a sealed envelope sent by her daughters to be delivered “unopened” to psychologist.
- Enclosed note says, “Please don’t stop talking to our mother. She hasn’t called us any bad names since coming to see you.”

Effectively Managing Stress

- An important component in the treatment of depression and anxiety and preventing recurrences
- Regular practice of relaxation strategies such as deep breathing and meditation to:
 - Reduce tension and anxiety
 - Increase self-awareness
 - Decrease reactivity to stress
- Generating alternative responses to recurring stressors
- Making a healthy lifestyle a priority

Sorting It Out: Is It Me or MS?

“Because I struggled so much with productivity, I had a lot of negative self-talk about my lack of motivation, organization, and laziness. Eventually, I became aware that my fluctuating ‘effort’ was also related to my fatigue so I had to develop strategies for that.”



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Losing the Battle with Fatigue

- Behave as if you don't have MS
- Do as much as you can now, "just in case"
- Focus on the benefits of overdoing and ignore the costs
- Consistently put yourself last
- Persist in doing things like you have always done them
- Equate asking for help with weakness and making changes with giving in

Jean's "Go To" Strategies for Fatigue Management

- Choose wisely by thinking about what is important and meaningful
- To-Do lists with priorities, including time for self-care, i.e., exercise
- Listen to your body and use energy-conservation strategies
 - Combine errands
 - Sit when possible
 - Break up tasks into steps
- Practice asking for, expecting and accepting help
 - Delegate and share responsibilities
 - Teach children to do chores
- Adjust your standards

Vicious Cycles Impacting Sleep, Mood, and Fatigue

“I had years of insomnia due to concerns about my performance and over focus on getting enough sleep. Some of it came with the territory of having young kids and interrupted sleep, but a lot was due to my sleep habits, negative thoughts, and anxiety.”



Better Self-Care for Better Sleep

- Maintain regular bedtime and wake-up time
- Limit naps to no more than an hour, before late afternoon
- Reserve your bedroom for sleep and intimacy
- Practice a good wind down routine (e.g., make your To-Do list or “worry time” earlier in the evening)
- Aim for comfort in a cool, dark, and quiet bedroom
- Avoid caffeine, smoking, alcohol and screens before bed
- If you cannot fall asleep or return to sleep within 30 minutes, GET OUT OF BED and do something non-stimulating (e.g., light reading)

“Go To” Strategies for Communication

- Make communication a priority.
- Respect and acknowledge that people have different coping and communication styles.
 - Some people just want to fix things rather than discuss
 - Some people are uncomfortable with strong, negative emotions or other people’s pain, both emotional and physical.
- It’s essential to be a good listener as well as a good talker.
- Do not expect people to read your mind.

Remember, You're the Expert!

- It's OK to keep it simple.
- Being matter-of-fact about having a chronic illness and decisions about what you do and how you spend your time can work.
- People do not have to understand how you feel to respect your self-care related needs.
- Before you commit to something, ask for more information and take time to decide.

Resources for Dealing with Challenges

- Personal resources
 - Courage to acknowledge problems and ask for help
 - Resilience, bouncing back from adversity
 - Good self-care without waiting for permission
 - Flexibility in thinking and problem solving
 - Challenging yourself to try new things and nurture your creativity
- Other people in your life
 - Family, friends, co-workers
 - Being clear about what you need and accepting help
- Professionals
 - Formal counseling/therapy

<https://www.cando-ms.org/online-resources/can-do-library/the-process-of-therapy>

Some Relaxation Strategies

- **Quick and Easy Breath Exercises**

- Slowly breathe in “I am”, breathe out “at peace”, repeat
- Breathe in slow count of 1-2-3-4, breathe out slow count of 4-3-2-1, repeat

- **Meditation with focus on breath**

- Sit in a quiet place in comfortable position with eyes closed if comfortable
- Focus on any aspect of your breath (e.g., rise and fall of chest or abdomen, sensations in nose or throat, sounds made by breath)
- When your thoughts wander, “kindly” return to your breath
- Add a mantra if you like, such as a phrase from a prayer or something like one, ocean, love, or peace
- Start with 5 minutes and build up to 20 or 30 minutes once or twice daily

Additional Resources

Can Do MS Webinars:

[*Landing on your Feet When Your World is Turned Upside Down*](#)

[*MS Path 2 Care: Mood, Cognition, and Spirituality*](#)

[*Managing Your Mood*](#)

[*Learning to Be Resilient in the World of MS*](#)

[*Flying Solo with Multiple Sclerosis*](#)

Books:

Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness by Joh Kabat-Zinn

The Wellness Book, The Comprehensive Guide to Maintaining Health and Treating Stress-Related Illness by Herbert Bensen and Eileen M. Stuart

Podcast:

Relaxation Program: Find helpful podcasts from Cleveland Clinic doctors on proper behaviors and techniques for relaxation—[Clevelandclinic.org/relax](https://clevelandclinic.org/relax)

Q & A



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