



WEBINAR   
WEDNESDAYS

# Why Am I So Tired? Fatigue & Other Invisible MS Symptoms

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# JULY PROGRAMS

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JUMPSTART – July 10  
*Managing Invisible Symptoms, Part I: Sleep & Fatigue*

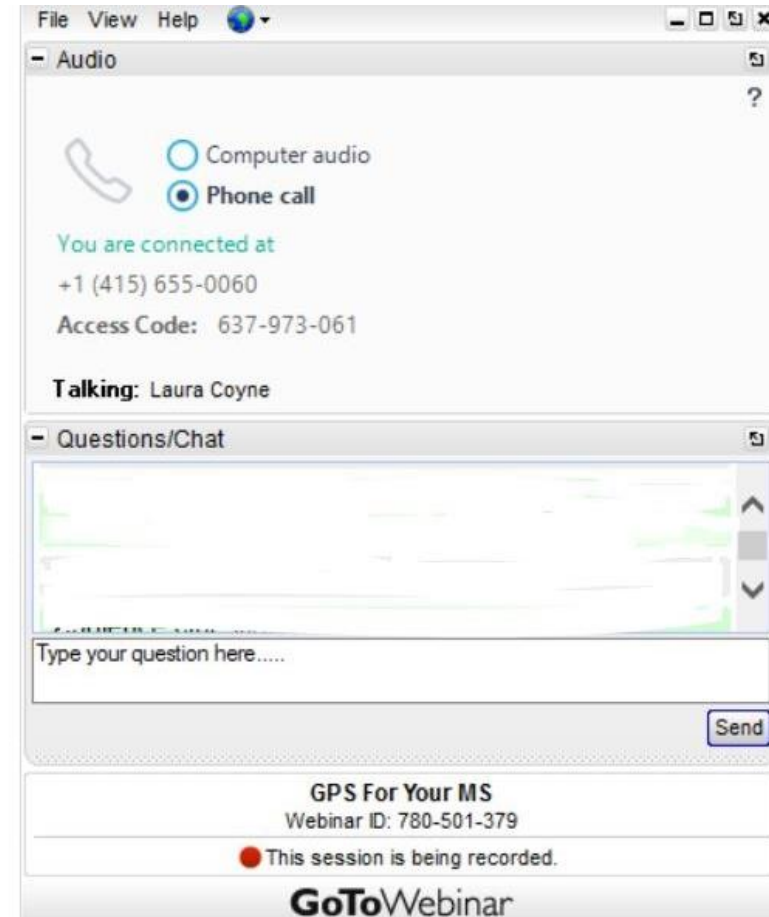
COACHING – July 14  
*Caring For Your Energy*

JUMPSTART – July 22  
*Managing Invisible Symptoms, Part II:  
Temperature Sensitivity, Pain, and Vision Problems*

COACHING – July 27  
*Your Questions, Answered: Invisible Symptoms*

# How to Ask Questions During the Webinar

Type in your questions using the  
**Questions/Chat** box





# Matthew Sacco, PhD

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- Psychologist
- Independence, OH



## Tracy Walker, FNP-C, WOCN

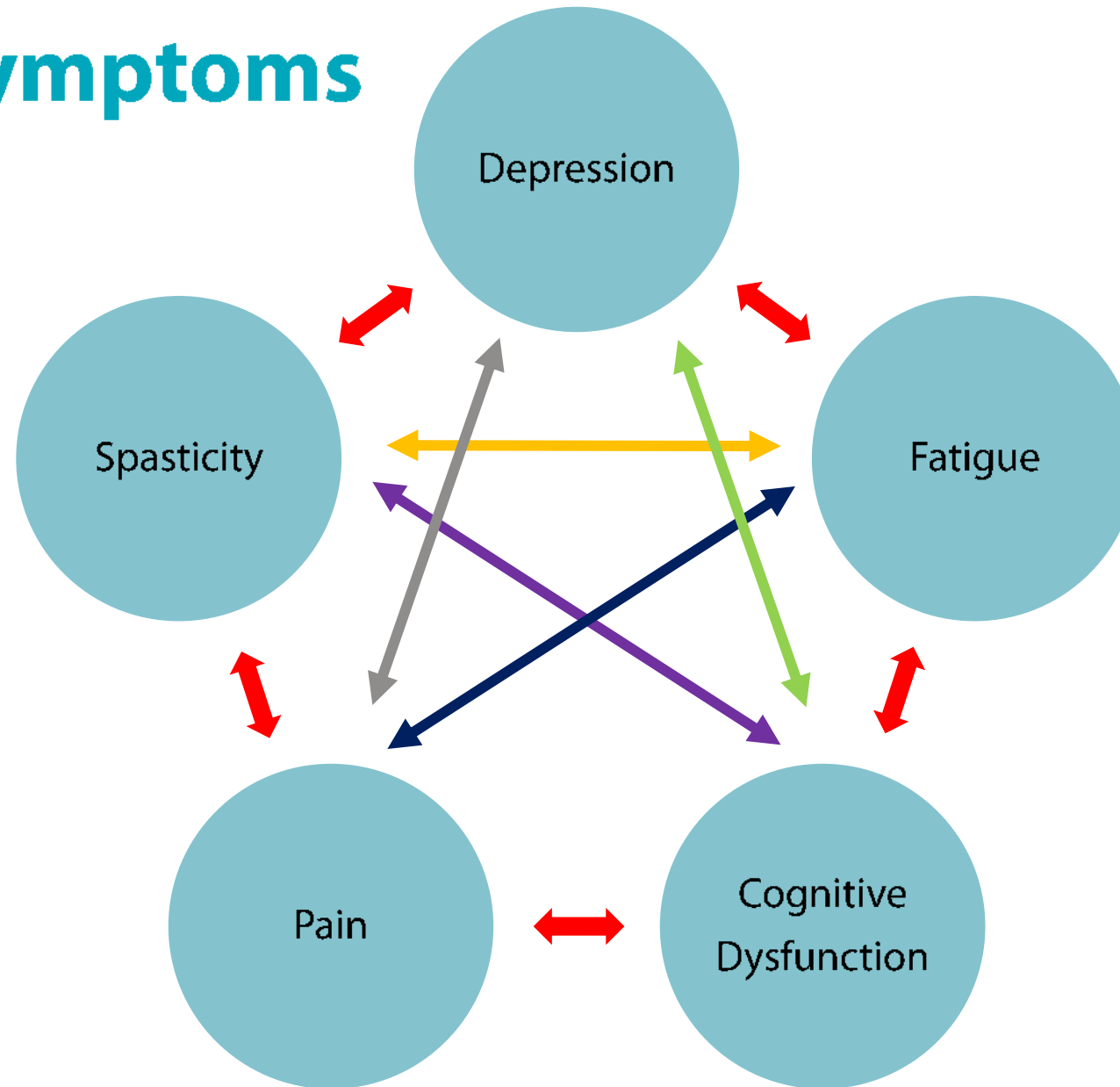
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- Nurse Practitioner
- Atlanta, GA

# Learning Objectives

- Recognize that many of MS's most common & impactful symptoms are invisible, including fatigue, depression, cognitive dysfunction, spasticity and pain.
- Overview of how MS creates these symptoms & common treatment/management strategies
- Impacts of invisible symptoms on support partners & tips to communicate about invisible symptoms

# Invisible Symptoms



# The Key to Effective Symptom Management is Knowledge and Skills

- Learning about symptoms helps you recognize, understand and discuss them
- Managing symptoms requires an individualized and flexible approach
- Effective management can improve quality of life promote realistic **Hope**



# Interactive Poll

**Which Invisible Symptoms have you experienced? (Check all that apply)**

- ✓ Fatigue
- ✓ Spasticity
- ✓ Pain
- ✓ Depression
- ✓ Cognitive Dysfunction

# Fatigue

## Symptoms

- Most commonly reported symptom in MS - Affects 80-90% of people with MS
- Often the first MS symptom people experience
- Over 50% of patients describe fatigue as their worst MS symptom

## Causes and Contributing Factors

- Reduced utilization of glucose in the brain
- De-conditioning
- Lifestyle Issues
- Medications that induce fatigue
- Fatigue from disrupted sleep
- Depression
- Cognition
- Pain
- Heat

## Problems Resulting from Fatigue

- Increased Depression
- Cognitive Dysfunction
- Sexual Dysfunction/ Loss of Libido
- Increased pain

# Strategies for Managing Fatigue

- Energy Conservation
- Regular Exercise
- Good sleep habits
- Proper Nutrition
- Cooling Strategies
- Medications
- Family education/ Counseling



# Depression

## Symptoms

- Depression-one of the most common symptoms of MS
- Can occur at any point in course of disease
- More common with MS than general population

## Causes and Contributing Factors

- Pre-existing depressive symptoms
- Reaction to having chronic illness
- Direct result of disease processes
- Medications
- Major life changes

## Problems Resulting from Depression

- Makes other symptoms worse
  - Fatigue
  - Pain
  - Cognitive difficulties
- Relationship difficulties
- Health Issues
- Self-Harm

# Strategies for Managing Depression

- Exercise
- Staying socially connected
- Engaging in activities that make you feel good or have made you feel good in the past
- Eating Healthy
- Get outside
- Working with mental health professional
- Avoid alcohol and illicit substances
- Medication



# Cognitive Dysfunction

## Symptoms

- More than half of those with MS likely to develop difficulties
- NOT Alzheimer's or Dementia!
- Correlates with Number of lesion/lesion area and atrophy
- More likely in Progressive MS
- More likely during exacerbation

## Causes and Contributing Factors

- Disease process/progress
- Medications
- Depression & Anxiety (and other mental health issues)
- Environmental Factors (too much stimulation)
- Alcohol use

## Problems Resulting from Cognitive Dysfunction

- Slowed processing speed
- Memory impairment
- Impaired attention/concentration
- Impaired executive functions
- Impaired spatial relations
- Impaired word-finding ability

# Strategies for Managing Cognitive Dysfunction

- Effectively managing mental health
- Physical Activity
- Cognitive Rehabilitation
- Stop trying to rely on ineffective strategies
  - Write lists instead of trying to rely on memorization. There WILL NOT be a test at the grocery store!!
  - Use your smart phone, calendar, dry erase board, put your keys in same spot
- Talk to your health care team about medications that can help or may be interfering with cognitive functioning



# Spasticity

## Symptoms

- Muscles are tight and resistant to stretch
- Often includes active spasms
- May be perceived as painful
- Worsens after periods of inactivity such as sleeping, sitting, traveling

## Causes and Contributing Factors

- MS lesions in the spinal cord
- Often accompanied by muscle weakness or pain that reduces range of motion leading to more stiffness and spasms

## Problems Resulting from Spasticity

- Increased energy expenditure leading to increased fatigue
- Contractures/ permanent restriction in range of motion leading to difficulty with self care and mobility
- Increased pain and weakness
- Skin breakdown



# Strategies for Managing Spasticity

## Non-Pharmacologic

- Stretching
- Positioning
- Seating
- Range of motion
- Orthotics
- Physical therapy

## Pharmacologic

- Baclofen (Lioresal)
- Tizanidine (Zanaflex)
- Gabapentin (Neurontin)
- Levetiracetam (Keppra)
- Diazepam (Valium)
- Botulinum Toxin (Botox)

## Surgical

- Baclofen Pump

# Pain

## Overview

- NARCOMS reported >80% of people with MS experience some type of pain
- Common cause of disability
- Under-recognized and can be inadequately managed
- Not well understood and difficult to treat
- MS-related pain is multifactorial

## Symptoms

- **Acute symptoms**
  - Neuralgic pain (trigeminal neuralgia)
  - Painful optic neuritis
  - Lhermitte's syndrome
- **Chronic symptoms**
  - Neurogenic pain (example: dysesthesia)
  - Musculoskeletal pain (example: low back pain)
  - Spasticity/spasms

## Emotional vs. Physical Pain

“Our bodies use the same neural system to detect and feel pain regardless of whether it is emotional or physical...”

Dr. Alan Fogel, Ph.D.  
Professor of Psychology  
University of Utah

# Strategies for Managing Pain

- Medications
- Physical/Occupational Therapy- sensory retraining
- Counseling, Education
- Mind Body Medicine, Relaxation, Stress Management
- “Alternative and Complimentary” Therapy :
  - Acupuncture
  - Massage Therapy



# Impact on Relationships

- Can affect many types of relationships and in many different ways
  - Family
    - Wife/husband/partner
    - Children
    - Extended family
  - Friends
  - Work
  - Other social relationships
- Communicating invisible symptoms begins with good communication skills
  - [Can Do-Relationships & Communications](#)

# How to Communicate Your Needs

- People most affected day to day
  - Partner
    - Make time (not during a crisis)
    - Attend appointments
    - Read resources
    - Attend support groups
    - Can Do MS Programs [cando-ms.org](https://cando-ms.org)
  - Children
    - Age appropriate information
      - [Keep S'myelin-NMSS](#)
      - [Mommy's Story](#), [Daddy's Story](#)
    - Proactive Communication
      - Don't wait for them to approach you

# Communicating Needs Beyond Family

- To what extent the relationship might be affected by symptoms?
- Friends
  - Who needs to know and what do they need to know?
    - Close friends
    - Casual Acquaintances
- Work
  - If/When to disclose ([Work Disclosure-NMSS](#))
  - Proactive and Interactive Process ([Working with MS-Can Do](#))

# Communicating with Your Healthcare Team

- Assertive Communication!
  - Prepared and Proactive
    - Learn and know yourself and your symptoms
      - Monitor your experience of invisible symptoms
    - Make a list of changes as they occur
      - New symptoms
      - Worsening symptoms
  - Tell them about any changes in mood
  - Ask partner to share what they have noticed
  - **Invisible does not mean imagined and/or untreatable!**

# Resources

- <https://www.nationalmssociety.org/>
- <https://mymsaa.org/>
- <https://www.cando-ms.org/>





## Key Take-Aways

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- Invisible Symptoms are common and can affect one another
- Effective management strategies can include a multi-disciplinary wellness approach
- Ask for help and use your support system

# Cited Sources

- 1 Adapted from: *My Cognitive Changes Because of Multiple Sclerosis* by Devin Garlit April 13, 2017, <https://multiplesclerosis.net/living-with-ms/my-cognitive-changes-because-of-multiple-sclerosis/>
- 2 Adapted from, "Am I Cognitively Impaired" by Prof G, <https://multiple-sclerosis-research.org/2021/04/am-i-cognitively-impaired/>
- 3 "Treatment and Management of Cognitive Dysfunction in Patients with Multiple Sclerosis" (Review article by DeLuca, Chiaravalloti, & Sandruff, 2020)
- 4 "Mindfulness training for emotion dysregulation in multiple sclerosis: A pilot randomized controlled trial" (Schirda et al., 2020)
- 5 Emotion Regulation Skills Training for People with MS and Support Partners (unpublished study, Hughes, Beier, & Botanov, 2020)

# Q & A





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**CanDo-MS.org**



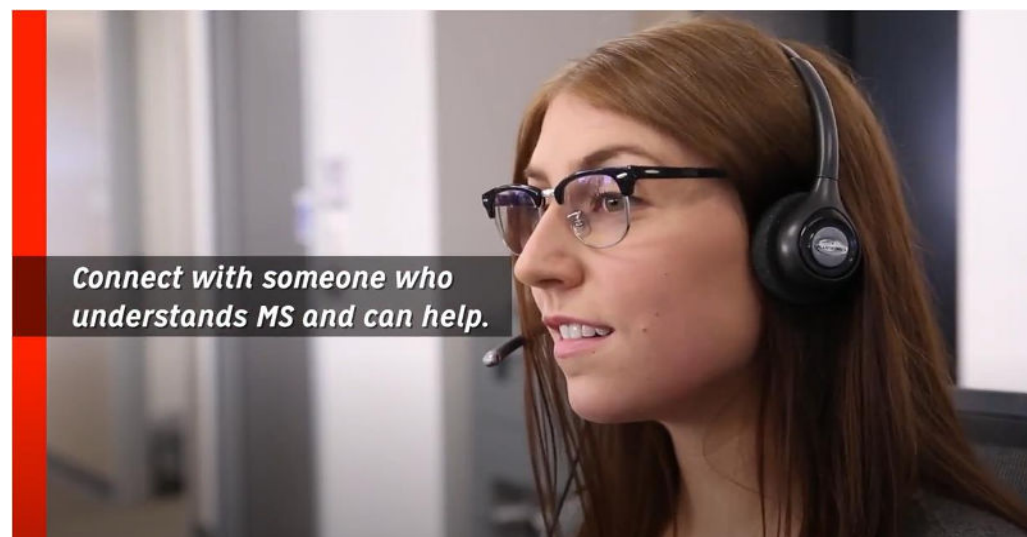


**Connect**  
When and Where You  
Need Us

The National MS Society exists because there are people with MS. **Our vision is a world free of MS.** Everything we do is focused so that people affected by MS can live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever.



**National  
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WEBINAR   
WEDNESDAYS

# New Ways to Manage Your MS

Wednesday, August 4 at 8pm ET

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