

# Addressing MS Discomfort From Numbness to Pain

**CAN DO**  
MULTIPLE SCLEROSIS

**WEBINAR**   
WEDNESDAYS

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# UPCOMING PROGRAMS

**Tuesday, August 19**

## **Newly Diagnosed Meetup**

Daily Life with MS: Employment, Family Planning, and Relationships

**Thursday, August 21**

## **JUMPSTART**

Tackling Pain and Discomfort in MS

**Tuesday, August 26**

## **YOUR QUESTIONS ANSWERED**

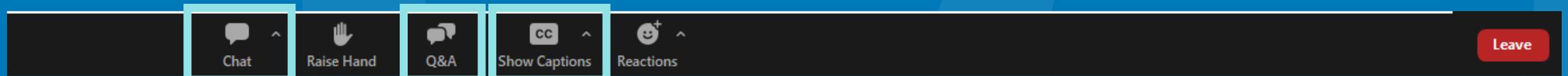
Uncomfortable MS Symptoms: Your Questions Answered



**CANDO-MS.ORG**

# How to Ask Questions During the Webinar

Type in your questions using  
the Questions Box



Provide comments and engage  
with the speakers and audience  
using the **Chat Box**

**NEW!** Closed captioning

# YOUR SPEAKERS



**Diana Vaughan- Nielsen**  
**Social Worker**

New Mexico



**Jenny Feng**  
**Neurologist**

Louisiana

# LEARNING OBJECTIVES



- 1 Become familiar with the types of uncomfortable symptoms that MS can cause.
- 2 Learn how to describe uncomfortable symptoms to others, including the healthcare team.
- 3 Learn about the treatment strategies for uncomfortable symptoms.
- 4 Become familiar with the members of the healthcare team who can help.

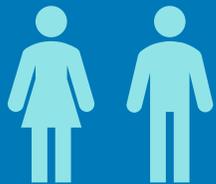
# Common Initial Symptoms That Lead To Diagnosis

- Vision changes
  - Loss of vision, double vision, eye pain
- Muscle weakness
  - Usually affect one side at a time, or below a certain level on your trunk
- Numbness or abnormal sensation
  - Usually affect one side at a time, or below a certain level on your trunk
- Trouble walking

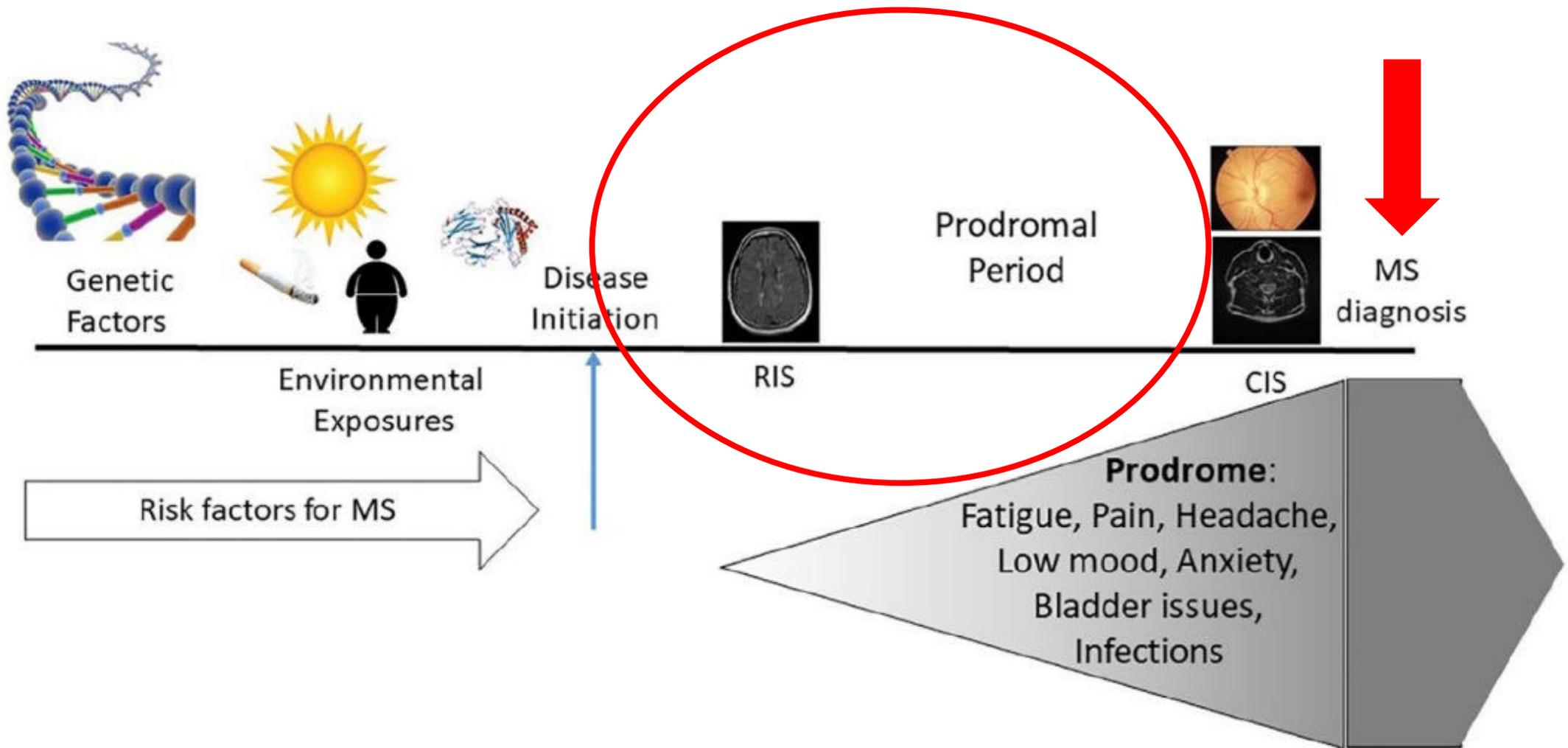


# Other Common Symptoms

- Fatigue
- Clumsiness, imbalance
- Dizziness
- Bladder problems
- Bowel problems
- Cognitive Problems
- Pain
- Sexual dysfunction
- Mood (depression, anxiety)
- Muscle stiffness and spasms



Number and severity of symptoms vary from person to person, and fluctuate from day to day.

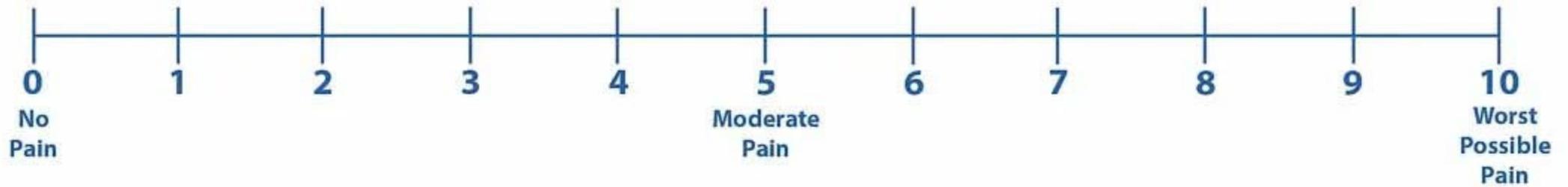


# Describing Symptoms



- Can lead to accurate diagnosis and appropriate treatment
- Contributes to a focused discussion with your provider
- Can help you begin to differentiate your own experience of a symptom
  - When did it begin and how long did it last?
  - Is it getting better, worse, or staying the same?
  - Is it new or old?
  - Is a treatment (medication, therapy, increase or reduction in activity) helping or making things worse?

## Numeric Rating Scale



## Wong-Baker FACES® Pain Rating Scale



**0**

No  
Hurt



**2**

Hurts  
Little Bit



**4**

Hurts  
Little More



**6**

Hurts  
Even More



**8**

Hurts  
Whole Lot



**10**

Hurts  
Worst

# Going Beyond Scales: Give More Detail And Use Analogy or Metaphor

## Where on or in your body do you feel the symptom?

- The left leg - inner or outer side of the left leg? From the hip down? Knee down?
- Can you point to the area or outline the area or trace the route of the symptom?

## How does it feel? What does it feel like?

- “Like a burning sensation in my thigh.”
- “Like someone is poking the skin on my knee with a needle.”
- “Like I’m carrying a 50 lb. weight when I try to lift my leg.”
- “Like an electric shock in my thigh when I’m lying in bed.”

# Words To Describe Pain

ACHY BURNING  
RAW STABBING  
DULL PIERCING  
THROBBING TIRING  
CRAMPING SORE TENDER  
TINGLING HEAVY  
SICKENING RADIATING  
SHOOTING

## Words to describe pain

Aching	Piercing	Stinging
Cramping	Pinching	Stretching
Crushing	Prickling	Superficial/shallow/surface
Deep	Pulsing	Tearing
Dull	Radiating	Tender
Excruciating	Sharp	Throbbing
Gnawing	Shooting	Tight
Heavy	Sickening	Tingling
Hot or burning	Splitting	Tiring or exhausting
Intense	Squeezing	Waves
Nagging	Stabbing	Wrenching

# Comparison Can Help You Put The Experience In Context



- What's the worst pain you've ever experienced? How does it compare?
- When was (symptom) the worst and how would you have rated it? How does it compare now?
- Maybe it's not as intense as your worst experience of the symptom but it's more bothersome now because
  - It's lasting longer
  - It's getting in the way of you doing things you need or want to do
  - It's affecting other symptoms in a new, different, or worse way

# Track Your Day: How The Symptom Affects Your Life?

- Does it change throughout the day?
- Does it interfere with certain activities but not others?
- What makes it worse or better (i.e.: position changes, temperature)?
- When during the day is it worse or better? What contributes to this change?
- Do you notice it affecting your mood, your energy or motivation, or your desire to do certain activities?
- Duration – constant, intermittent, lasts for hours or minutes after it begins

# Tools For Tracking Symptoms



MEDIA JOURNAL ESSENTIALS

# TRACK MULTIPLE SCLEROSIS

A DETAILED ONE YEAR JOURNAL  
TO RECORD MS SYMPTOMS,  
TRIGGERS, MEDICATIONS  
AND MORE



# Who Describes It Better?

## Sandy

“I’m in so much pain. My body hurts so bad that I can’t do anything. I’m miserable and I just want it to go away. Nothing works!”

## Tawanda

“I’m in a lot of pain. It started about 3 days ago while I was weeding the garden. I noticed a sharp pain in my low back and now it’s less sharp but more gripping and achier. It’s constant but walking and standing make it worse. Sitting decreases the intensity – maybe 20%. I took Ibuprofen but it doesn’t help at all.”

# Who Describes It Better?

## Jackson

“I’m having trouble with urinary incontinence. I have an urgency to go at least 10 times a day. If I wait until I feel that urgency, I can’t make it to the toilet in time. It’s worse when I drink caffeinated drinks or when I’m having a stressful day. It’s worse in the morning and afternoon.”

## Martin

“I’m having trouble with urinary incontinence. I have to go all the time! I’m so sick of this; it’s embarrassing!”

# Treatment Strategies

## Weakness and gait difficulty

- Physical therapy, exercise programs
- Adaptive devices, assistive devices, neuromodulators
- Modifying home environment to reduce injury risk

## Pain

- Nerve pain: antiseizure or antidepressant medication
- Muscle pain: muscle relaxers, NSAIDS
- PT, heat/cold packs, pain management, topical creams
- Wellness approaches

## Tremors

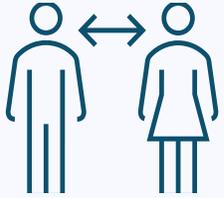
- Beta-blockers, antiseizure medications, movement clinic evaluation
- Occupational therapy
- Assistive devices

# Fatigue

- Evaluate for alternative causes such as medication side effects, depression and stress, sleep deprivation, medical comorbidities (infection, thyroid issues, anemia, vitamin deficiency)
- Aerobic exercise
- Energy conservation
- Cooling devices
- Medications: amantadine, modafinil, antidepressants, dalfampridine, amphetamines (use with caution)



# Uncomfortable MS symptoms



Sexual Dysfunction:

Assess medication side effects

Treat pain, vaginal lubrication, pelvic floor therapy

Libido issues: Medication to treat hypoactive sexual desire disorder or erectile dysfunction



Bladder:

Non-pharmacologic management: scheduled voiding, pelvic floor exercises, fluid management, avoiding diuretics, smoking, alcohol

Medications and urological procedures



Vision:

Low vision adaptations (e.g. increase lighting levels, increase contrast, large print, carry flashlight, remove glare)

Occupational therapy

Neuro-ophthalmologists and optometrists

# Treatments

- Mood changes: counseling, medication management, psychiatry/psychology
- Cognitive dysfunction:
  - Assess for medication side effects
  - Evaluate for other medical commodities
  - Neuropsychological evaluation for cognitive screening
  - Cognitive rehabilitation therapy
  - Cognitive engagement (learning new skills, social interactions, etc)



# Lifestyle Changes

- Diet
  - Mediterranean style (limit sugar and processed foods, increase fresh vegetables, fruits, lean proteins)
  - Vitamin D
- Exercise:
  - Gait training, balance training, stretching/flexibility, aerobic, resistance training
  - Chair or floor-based exercises
  - Aquatic therapy



# Wellness Approaches

- Meditation, relaxation techniques
- Sleep hygiene
- Acupuncture
- Smoking cessation, alcohol cessation
- Cognitive behavioral therapy, support groups
- Weight management



# Health Care Team

## MS Specialist (MD, NP, PA-C)

- Most knowledgeable about common symptoms and treatments for those symptoms
- Can begin assessment and refer you to other specialists for non-MS symptoms or those better treated by another specialist

## MS Nurse

- Can triage your calls and messages and help you describe accurately what you're experiencing before relaying concerns to your physician



# Behavioral/ Mental Health Provider



Can help you discuss and manage the emotional and physical aspects of discomfort

- Breath work
- Addressing unhelpful thoughts about discomfort and pain
- Mindfulness education and training
- Treatment for related issues that affect and are affected by pain

# Pain Medicine Specialist



- May prescribe medications that your MS provider is less comfortable prescribing
- Administer specialized assessments of pain
- Perform minimally invasive procedures – like nerve blocks
- Coordinate with specially trained PT/OT/mental health services

# Healthcare Team



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Massage Therapist

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Acupuncture and Acupressure Therapist

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Pharmacist

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Assistive Technology Professional

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Orthotic and Prosthetic Specialist

# Rehabilitation Specialists



- Physical and Occupational Therapists
  - Assess and train in proper body mechanics to reduce pain and discomfort, likelihood of injury
  - Make recommendations for your environment which can improve comfort
  - Create and guide you in safe home exercise plan

# Other Medical Specialties



- Treat related or comorbid conditions that are contributing to discomfort and pain
  - Urologist – can better manage chronic UTIs, incontinence
  - Rheumatologist – can diagnose and treat other autoimmune conditions causing uncomfortable symptoms
  - Physical Medicine and Rehabilitation Specialist

**Q+A**



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# MS Treatment:

## Which DMT Is Right for You

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