

# MS Fatigue Explained

**CAN DO**  
MULTIPLE SCLEROSIS

**WEBINAR**   
WEDNESDAYS

THIS WEBINAR IS  
SPONSORED BY:

**EMD  
SERONO**



**Genentech**

*A Member of the Roche Group*



# UPCOMING PROGRAMS

**FEBRUARY 11**

**NEWLY DIAGNOSED/YOUNG ADULT MEETUP**

Diagnosed with MS... Now What?

**FEBRUARY 20**

**JUMPSTART**

Mastering MS Fatigue Management

**FEBRUARY 25**

**YOUR QUESTIONS ANSWERED**

MS Fatigue

**FEBRUARY 26**

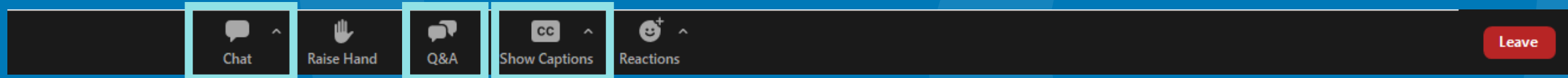
**MS MOVES MEETUP**



**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 SPEAKER



**Michelle  
Cameron**

**Neurologist/Physical  
Therapist**

Oregon

# LEARNING OBJECTIVES



1

Understand what fatigue in *MS* is

2

Become familiar with the causes of fatigue in *MS*

3

Learn how to manage *MS*-related fatigue



# POLLING QUESTION

**Do you have fatigue from your MS?**

- a) YES
- b) NO

# MS Fatigue: Prevalence and Nature





# Prevalence of Fatigue in MS

- Fatigue is one of the most common symptoms of MS.
- Around 80-95% of people with MS experience fatigue.
- Fatigue can be one of the most disabling symptoms of MS.

Symptom	% (At onset-advanced)
Sensory alterations	85-94
Fatigue	79-96
Cognitive dysfunction	63-81
Pain	57-85
Visual and brainstem symptoms (scotoma, diplopia, oscillopsia, vertigo, dizziness, etc.)	55-92
Motor alterations: spasticity, ataxia, tremor, impaired ambulation	50-91



# POLLING QUESTION

## How do you experience MS fatigue?

- a) Mental exhaustion
- b) Physical exhaustion
- c) Difficulty concentrating
- d) Heavy limbs
- e) “Hitting the wall”
- f) Needing more rest
- g) Other... put it in the chat

# How Does Fatigue Feel to You?

“Like trying to move your limbs through sand”

“That grogginess when you first wake up just stays all day!”

“My head feels heavy, like my reactions are in slow motion”

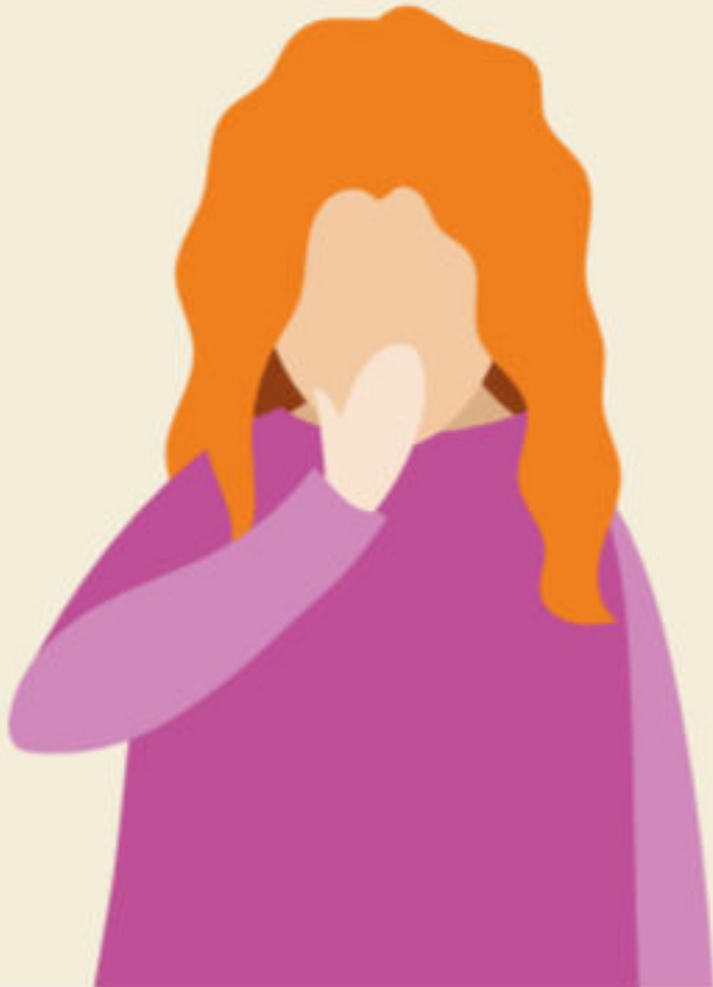
“Making a cup of coffee feels utterly draining”

# What Is MS fatigue?

- A persistent feeling of tiredness or exhaustion
- Your battery has run out
- Motor fatigue vs systemic fatigue




## Here are some common observations about MS fatigue:



- Tends to worsen as the day progresses
- Appears more easily and suddenly than 'ordinary' fatigue
- Is generally more severe than 'ordinary' fatigue
- Tends to be aggravated by heat and humidity
- Is more likely to interfere with daily activities than 'ordinary' fatigue

# Normal Tiredness vs MS-Related Fatigue



---

Doesn't necessarily go away with rest

---

Comes on sooner and quicker

---

Heat sensitive

---

Can impair cognitive function

---

Can impair motor function

# Causes of MS Fatigue



# Primary vs Secondary MS Fatigue

## Primary

- Direct result of the disease and its effects on the brain and spinal cord

## Secondary

- Downstream result of other factors e.g.
  - Sleep disturbance from spasticity, pain or bladder issues, sleep disorder
  - Depression
  - Medication side effects
  - Physical inactivity and deconditioning



## PRIMARY CAUSES

Inflammatory/Neurodegenerative Pathology of Multiple Sclerosis

Cytokine  
Production

Functional Effects  
on Limbic Systems

Neuron Loss  
Oligodendrocyte Loss  
Synaptic Degeneration

Lost Connectivity  
Delayed Processing  
Cortical Reorganization

Increased Brain  
Activation

Hypothalamic Lesions  
Autonomic Lesions

Altered Endocrine  
Function



Depression  
Sleep Disturbances



Fatigue

## SECONDARY CAUSES

Comorbidities  
Other Symptoms  
Treatment Side Effects



# Possible Mechanisms of Primary MS Fatigue



- Inflammatory chemicals – cytokines
- Demyelination and neuron and synapse loss
- Increases effort to compensate for losses
- Affects regions responsible for energy regulation
- Endocrine changes

# Fatigue Impact & Assessment



# How Does Fatigue Impact Your Daily Life?

- Challenges at home
- Challenges at work
- Challenges in social settings



# How Does Fatigue Impact Your Daily Life?

- Physical impacts:
  - challenges getting things done
- Cognitive impacts:
  - challenges with thinking, memory, decision-making
- Social & emotional impacts:
  - feelings of isolation, frustration, guilt

# Fatigue Assessment

- Fatigue severity scale – how severe is your fatigue?
- Modified fatigue impact scale – how much does fatigue impact your physical and cognitive function?
- Visual analog scale – 0 – 10
- Fatigue diary
  - Shows day to day variation
  - Helps track triggers and patterns
  - Helps tailor management strategies

# Red...Yellow... Green




You may find these examples useful to describe your MS fatigue:

## The traffic light explanation:

- **Green**  
You feel like a car that passes a green light and can continue on its journey as it has enough energy.
- **Amber**  
The car needs to think about stopping to avoid the risk of an accident.
- **Red**  
The car needs to stop and rest to be able to continue.



## The battery explanation:

-  The battery is **fully charged**, it is functioning normally and has all the energy it needs to complete day-to-day activities.
-  The battery is **running low**, it is slowing down so you need to limit its use and plan a recharging period.
-  The battery is **completely out of charge** so all activities come to a halt. The recharge time will take longer if a recharge didn't happen as and when necessary.



# Fatigue Diary



## Fatigue diary template

To read more about using a fatigue diary, have a look at the MS International Federation's guide 'Fatigue: an invisible symptom of MS'.

Date: \_\_\_\_\_

Describe last night's sleep: \_\_\_\_\_

Time	Description of your activities	Fatigue score*	Comments

\* 1 = low to high fatigue = 10

## ROCHESTER FATIGUE DIARY

NAME: \_\_\_\_\_ DATE: \_\_\_\_\_

Instructions: Please mark a line each hour to rate your average energy level from energetic (high energy no fatigue) to exhausted (low energy, severe fatigue) during a 24 hour period (7 am to 7 am).

	AM (morning)					PM (afternoon)						
	7-8	8-9	9-10	10-11	11-12	12-1	1-2	2-3	3-4	4-5	5-6	6-7
Energetic, no fatigue												
Exhausted, severe fatigue												
Asleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### EXAMPLE:

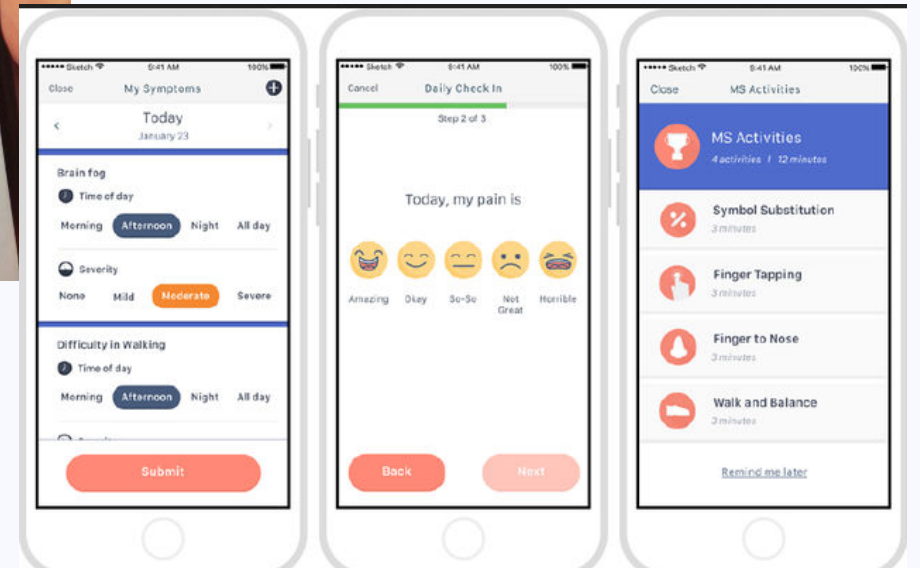
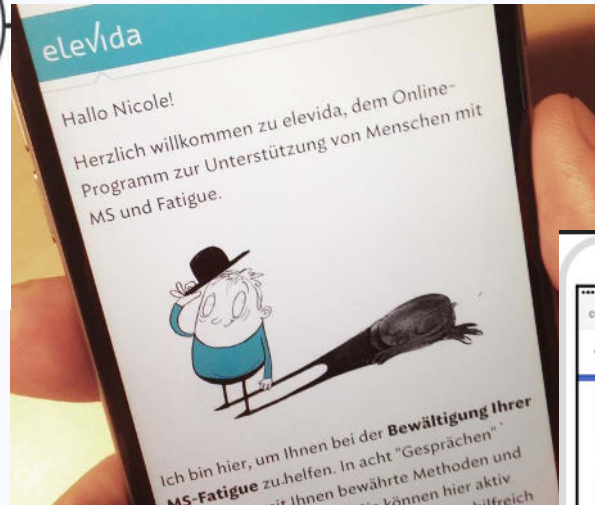
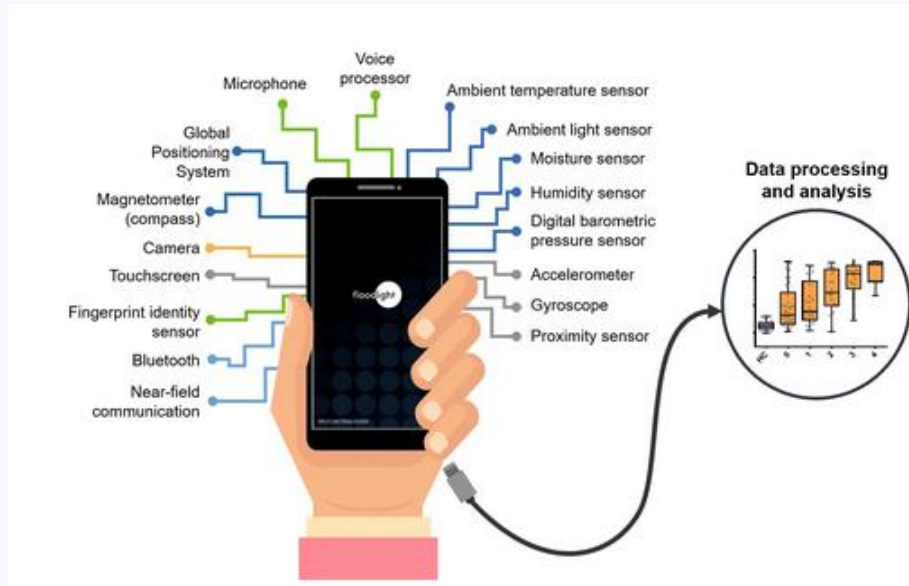
PM (evening)		
9-10	10-11	11-12
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

The patient has recorded mild fatigue from 9 - 10 pm, substantial fatigue from 10 - 11 pm, and asleep from 11 - 12 pm.

	PM (evening)					AM (night)						
	7-8	8-9	9-10	10-11	11-12	12-1	1-2	2-3	3-4	4-5	5-6	6-7
Energetic, no fatigue												
Exhausted, severe fatigue												
Asleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



# Digital Apps



# Managing Your Fatigue

“I’m certainly not saying the symptoms are gone. I have just learned how to manage it a little better.”

The infographic features five tips for managing MS fatigue, each with an illustration and a text label:

- Use a calendar or diary to help keep track:** An illustration of a hand with a blue pen writing on a calendar with various colored blocks.
- Take frequent rest breaks:** An illustration of a woman sitting at a desk with a laptop, resting her head on her hand.
- Drink enough water:** An illustration of a blue glass filled with water.
- Prioritise, plan & pace your activities:** An illustration of a woman in a red dress holding a blue clipboard and looking thoughtful.
- Eat a healthy & balanced diet:** An illustration of a bowl of fresh vegetables and a carrot.

**Managing MS Fatigue**

...



# POLLING QUESTION

**What have you tried to manage your fatigue?**

- a) Energy budgeting
- b) Energy conservation
- c) Sleep hygiene
- d) Exercise
- e) Other... put it in the chat

# Strategies for Managing Fatigue

- Minimize fatigue triggers
- Energy conservation
- Pacing
- Sleep hygiene
- Diet
- Medications





# Recognize Your Fatigue Triggers

- Heat sensitivity
- Stress & anxiety
- Physical exertion
- Poor sleep quality
- Infection or other illness
- Diet & hydration



# Energy Conservation & Pacing

- Energy budgeting – spend it on what's worth it to you!
- Prioritize what's important
- Think about timing, when do you have the most energy?
- Break tasks into smaller, manageable steps
- Balance activity with rest
- Avoid overexertion
- Resist overcommitting
- Consider working with an occupational therapist to help with energy conservation

# Aids & Home Modifications

- To conserve energy, organize



# Physical Activity & Exercise

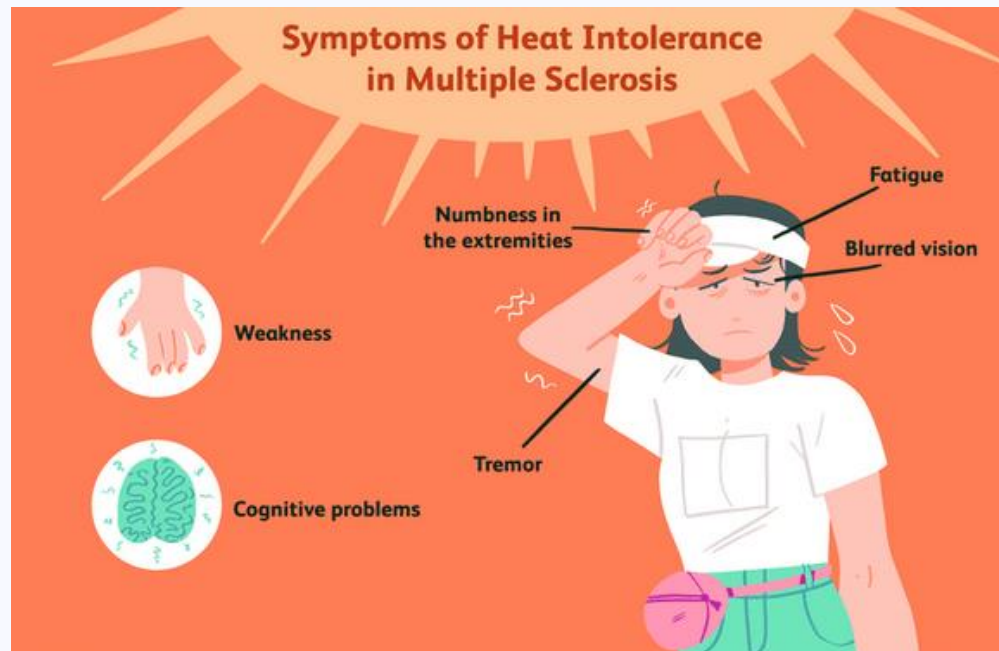
- Exercise gives you more energy to spend, but... it takes a while to build up endurance
- Start slow
- Keep your body moving with regular physical activity
- Exercise in cooler environments
- Consider working with a physical therapist to develop an exercise program that works for you





# Temperature Management

- Heat sensitivity
  - Heat can exacerbate fatigue
  - To stay cool – wear light clothing, use cooling vests, stay in a cool environment



# Sleep Hygiene & Diet

- Maintain a consistent sleep schedule
- Create a relaxing bedtime routine
- Manage sleep disorders e.g. sleep apnea, restless legs
- Avoid caffeine after 2pm
- Alcohol can worsen fatigue
- Avoid late heavy meals
- Stay hydrated throughout the day

# Get Better Sleep

## SLEEP HYGIENE TIPS



HAVE A  
ROUTINE

WEAR EAR  
PLUGS

TAKE A  
WARM  
BATH

LOWER  
YOUR  
ROOM  
TEMP

DARKEN  
YOUR ROOM



# Medications



- Most medications – like ones for spasticity, bladder symptoms, and anxiety – worsen fatigue
- Work with your provider to determine which medications might be causing more trouble than benefit
- No medications are FDA approved for MS fatigue
- Medications used for fatigue increase alertness but don't really reverse fatigue e.g. amantadine, modafinil, methylphenidate
- Dalfampridine may help with motor fatigue
- Medications used for fatigue have risks of side effects

# Building a Support System



**Connect with others who understand your experience**



**Work with your healthcare team**

Track your fatigue and its response to interventions

# Myths and Facts About MS Fatigue

**Myth:** Fatigue is just a normal part of MS, and nothing can be done about it.

**Fact:** Fatigue is manageable with the right strategies, treatment, and lifestyle changes.

**Myth:** Exercising will make fatigue worse.

**Fact:** Exercise can help improve energy levels and reduce fatigue over time.

# Key Takeaways



- Fatigue is common but manageable in MS.
- Many factors contribute to fatigue.
- Strategies like pacing, energy budgeting, and exercise can help.
- Medications and support are available for managing fatigue.



**Please Take  
Today's Survey**

**Thank you!  
We Appreciate Your Feedback!**



**Q+A**



# CONNECT WITH US

---



**TIKTOK**

@CanDoMultipleSclerosis



**FACEBOOK**

@CanDoMultipleSclerosis



**X**

@CanDoMS



**INSTAGRAM**

@CanDoMultipleSclerosis

THIS WEBINAR IS  
SPONSORED BY:

**EMD  
SERONO**



**Genentech**  
*A Member of the Roche Group*





The preceding program is copyrighted by Can Do Multiple Sclerosis. It is provided for your personal educational and referential use only. Any repurposing or dissemination of its content requires the consent by Can Do Multiple Sclerosis.

**© CAN DO MULTIPLE SCLEROSIS**