## More About MS

2023 Patient Education Program



# THIS PROGRAM IS SPONSORED BY:















## YOUR HEALTHCARE TEAM



Randall Schapiro Neurologist



Kathleen Costello Nurse Practitioner



**Roz Kalb** Psychologist



Stephanie Buxhoeveden Nurse Practitioner



Mandy Rohrig
Physical Therapist



Megan Weigel Nurse Practitioner



Stephanie Nolan
Occupational Therapist

## PLAN FOR TODAY

#### Welcome & Mindful Moment

Panel Discussion & Your Questions Answered Understand the courses & management strategies for fatigue, pain, mood, & cognitive changes

BREAK

Make Use of a Moment Video & Live Demonstration

Workshops (In-Person)

Move Forward Key Take-Aways

Mix & Mingle (In-Person)

Happy Hour with Members of the Healthcare Team

## Managing Invisible Symptoms

## **Panel Discussion**

Randall Schapiro | Kathleen Costello | Rosalind Kalb | Mandy Rohrig



# What Do We Know About MS Fatigue?

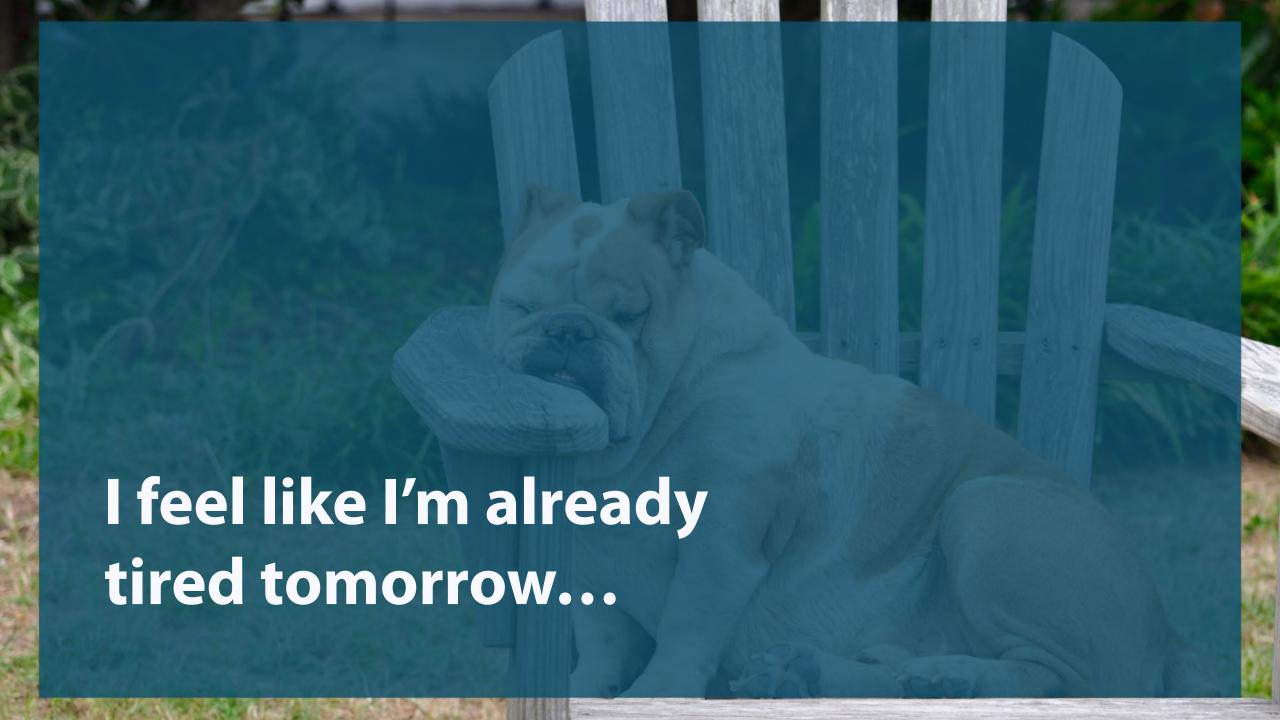
## Affects 90% or more of people living with MS

## Factors that contribute to fatigue in people with MS:

- Disrupted sleep
- Extra exertion required for everyday activities
- Heat sensitivity
- Muscle fatigue
- Depression and other mood changes
- Medication side effects
- Primary MS fatigue (lassitude)
- Different from other types of fatigue
- Can be physical and/or cognitive

Fatigue is also common in support partners, but for different reasons





# Steps To Managing Fatigue

#### Manage Lassitude

- Exercise and physical activity
- The 4 P's
- Mobility aids and other adaptive devices
- Cooling devices
- Medication

#### **Manage Cognitive Fatigue**

- Cognitive rehabilitation strategies
- Adequate sleep
- Address mood issues

#### Address the symptoms & other factors that interfere with sleep

- Bladder problems
- Pain
- Depression
- Spasms
- Primary sleep disturbances e.g., sleep apnea, insomnia

# What Do We Know About Pain in MS?

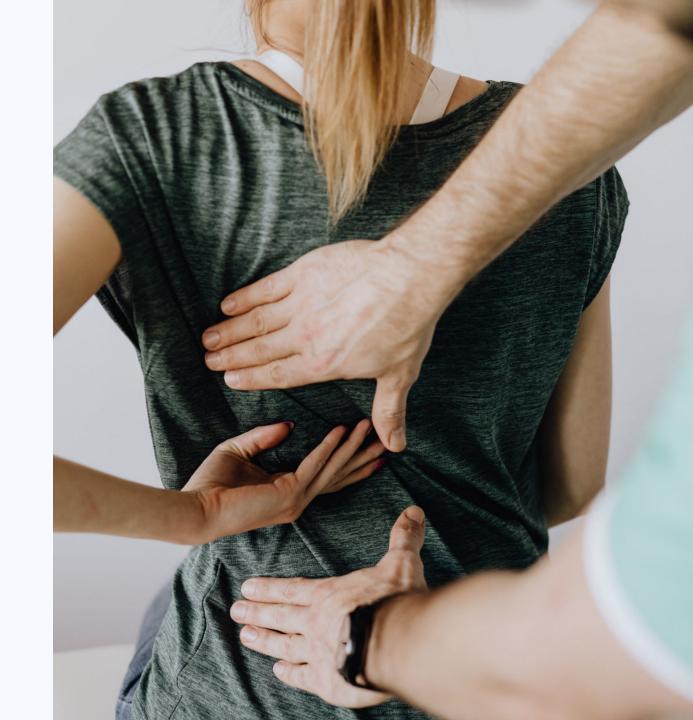
Almost 80% of people experience pain

### Musculoskeletal pain caused by:

- Muscle stress and strain
- Gait and/or postural changes
- Incorrect use of mobility aids

## Neuropathic pain caused by:

Disrupted signals between the CNS and the body



## Steps To Managing Pain

### Musculoskeletal

- Exercise stretching, range of motion, core strengthening
- Gait and postural training
- Mobility aids and bracing
- Other modalities
- Massage therapy
- Acupuncture
- Electrical stimulation

## **Neuropathic**

- Anti-seizure medications
- Behavioral interventions
- Cognitive behavior therapy (CBT)
- Mindfulness
- Meditation
- Stress management
- Application of ice or heat

## What Do We Know About MS Related Mood Changes?

Mood changes are common in people with MS

Occur at any point in the disease course – even as a first symptom

### Have many causes:

- Changes in the brain and the immune system
- Reactions to the challenges of life with MS

### Mood changes matter!

- They can make other symptoms feel worse (e.g., fatigue, pain, cognitive issues)
- And impact relationships and quality of life

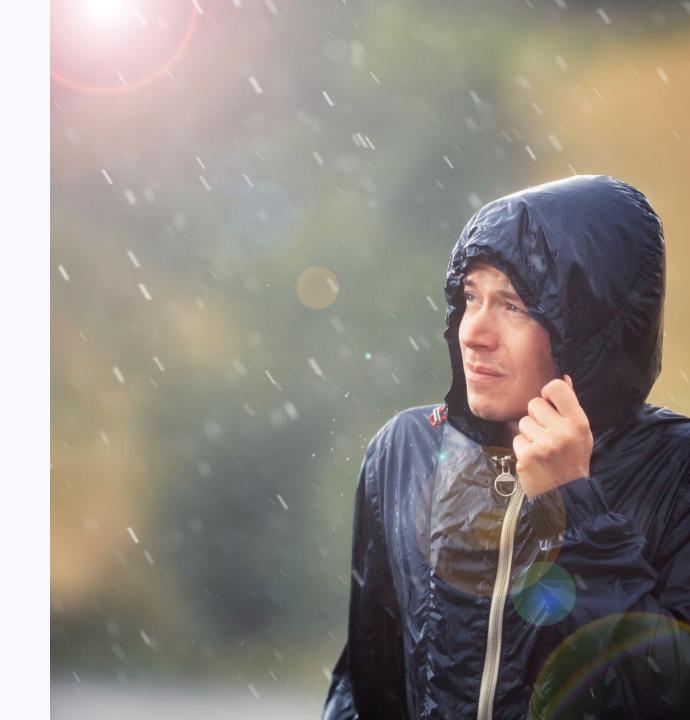
Support partners can experience significant mood changes as well



# What Do We Know About Grief & Depression in MS?

Grief – a normal, response to losses

Depression – a common symptom of MS



# What Do We Know About Anxiety & Irritability in MS?



### Anxiety is equally common, but receives less attention

- Excessive worrying
- Difficulty sleeping & restlessness
- Tension & irritability
- Increased heart rate/palpitations
- Feelings of terror or impending doom
- Inability to concentrate

Irritability and moodiness can be signs of depression or anxiety – or exist on their own

Support partners can also experience mood changes, although the reasons are different



## How Are Mood Changes In MS Managed?

- Early and ongoing screening
- Cognitive behavior therapy or other talk therapy
- Medication, if needed
- Physical activity
- Social support

#### What is next?

- Step 1 to managing mood issues is to acknowledge them
- Step 2 is to talk with your healthcare provider



# What Do We Know About Cognitive Changes?

At least 65% of people with MS will experience changes

While more common in progressive disease, cognitive disability and physical disability can occur independently



# What Do We Know About Cognitive Changes?

## The most common changes include problems with:

- Information processing
- Learning and memory
- Attention and concentration
- Executive functioning (planning, prioritizing, decision-making, problem-solving)
- Word-finding



## How Are Cognitive Changes Managed?

# Early and ongoing screening (at diagnosis & every 6–12 months after)

Positive screening in-depth evaluation of cognitive difficulties and strengths

## Personalized cognitive remediation

- Memory and attention training
- Compensatory strategies and tools

## Lifestyle interventions

- Healthy, balanced diet
- Physical activity
- Stress management
- Mental stimulation

## Tips For Talking About Invisible Symptoms

Remember – they're called invisible for reason

No one can read your mind or your body

Be prepared to describe how the symptom affects you:

- When it is most likely to occur
- How it can change from hour to hour or day to day
- Why having a Plan B for every Plan A is a good idea
- Consider using a signal to show how you're doing

Offer reading materials for those who would like them

# WORKSHOPS





- HOW TO CREATE & WORK WITH YOUR HEALTHCARE TEAM
  Colorado Ballroom A (Main Room)
- 2 STAYING ACTIVE TOGETHER
  Colorado Ballroom A (Main Room)
- HOW TO NAVIGATE THE DMT MAZE
  Pre-Function Room
- HOW TO THRIVE & SURVIVE AS A SUPPORT PARTNER
  Colorado Ballroom B (Next Door)

## **Key Take-Aways**



### Each symptom is complex

Varies from person to person AND over time

## Good management strategies are multi-dimensional

- Benefit from an interdisciplinary treatment approach
- Often required patience and persistence on your part and your providers'

### Pay attention to your personal cues

- When are you most tired?
- What seems to trigger your pain or grief?
- Which situations are more difficult, cognitively?

## **CONNECT WITH US**











# THIS PROGRAM IS SPONSORED BY:

















The preceding program is offered 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