CAN DO Multiple® Sclerosis

PRESENTS:

WEBINAR WEDNESDAYS

Fatigue: How To Get More Energy and Keep It Up!

SPONSORED BY:

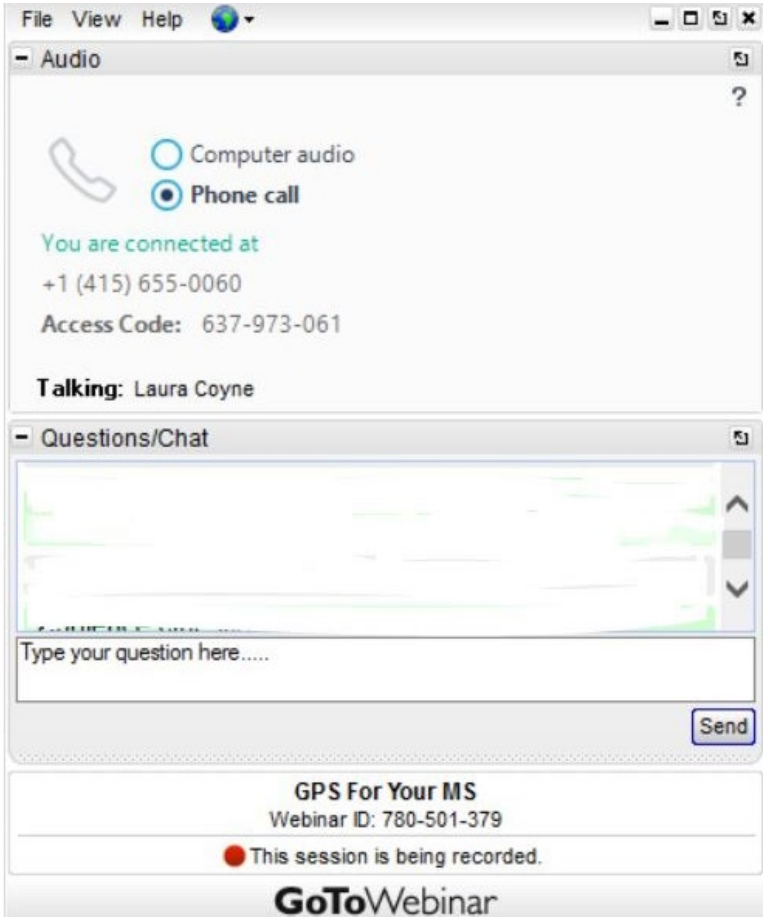
Biogen

EMD Serono

Genentech
A Member of the Roche Group

How to Ask Questions During the Webinar

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



Kathy SanMartino, PT, NCS, MSCS, CLT, ATP

Physical Therapist

Sierra Madre, CA

Stephanie Nolan, OTR/L

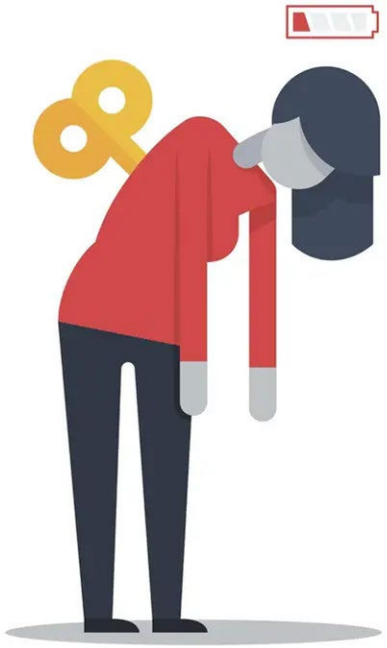
Occupational Therapist

Broomfield, CO

Learning Objectives

1. Identify all the factors that contribute to fatigue in people with MS.
2. Recognize signs of fatigue in the moment.
3. Learn energy management techniques and strategies to make the most of each moment.

Fatigue: The Invisible Symptom



"Overwhelmed"

"My hands won't work"

"I'm trudging through snow"

"Hit the wall"

"Unplugged"

"Wet noodle"

"I can't think"

Fatigue is different for everyone

CAN DO Multiple® Sclerosis

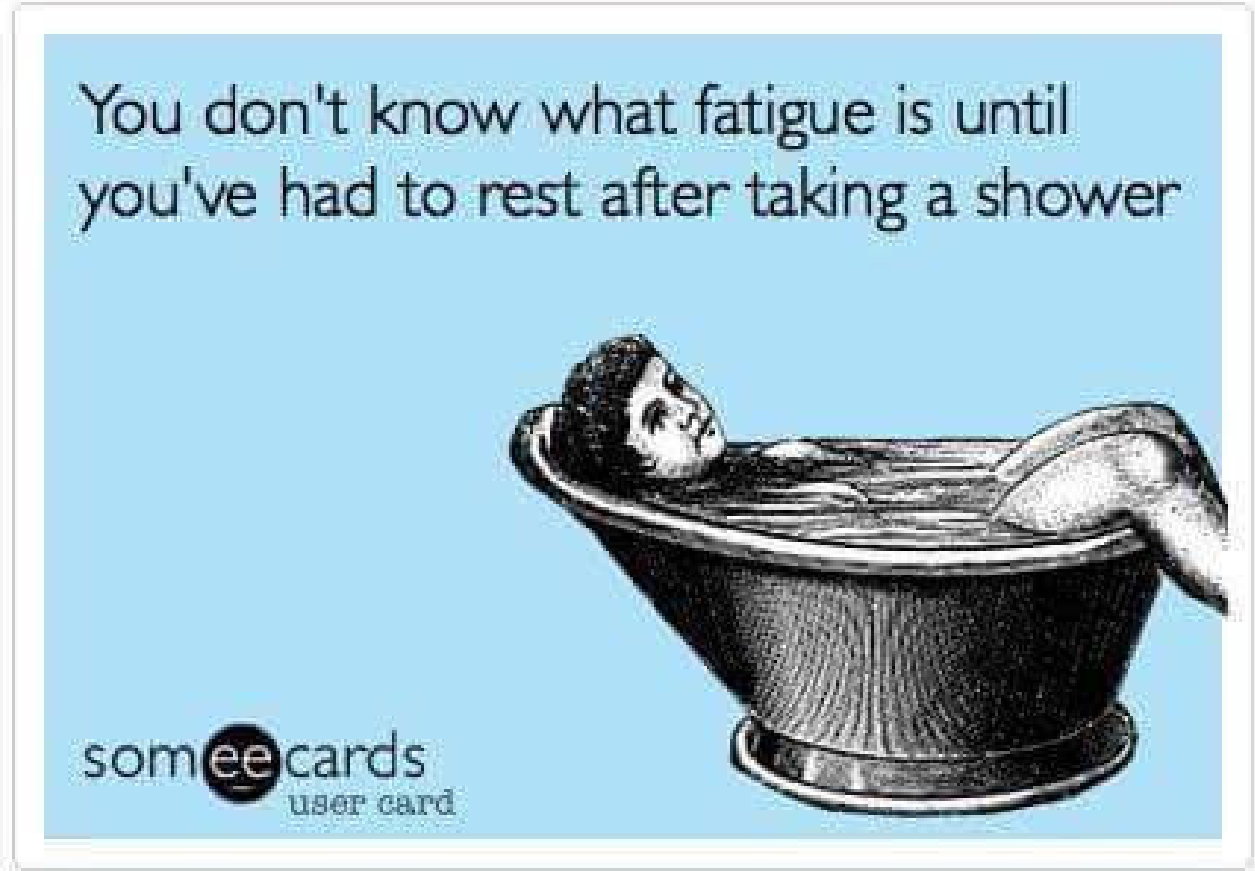
Fatigue and MS

- 75-95% of people with MS are affected by fatigue
- 50-60% state that fatigue is their worst symptom
- One of two major reasons for leaving the workforce
- Listed as a disability by the Social Security Administration

Primary Fatigue

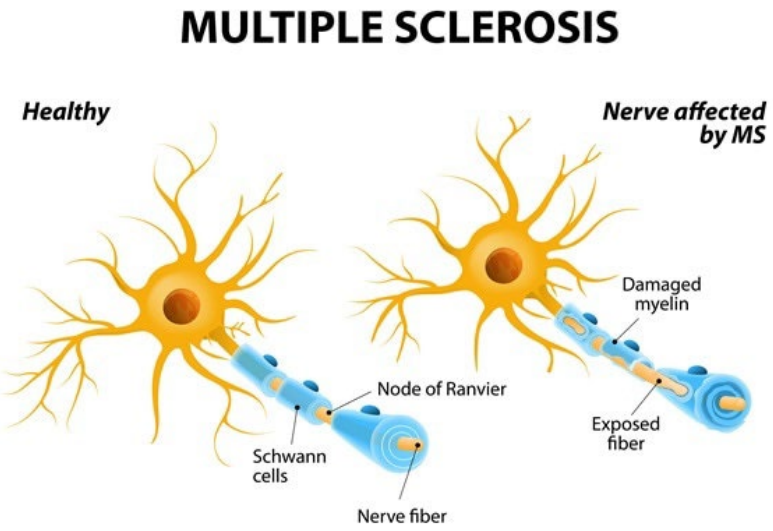
vs.

Secondary Fatigue



Primary MS Fatigue Lassitude

- An over-response of the immune system producing flu-like symptoms & fatigue.
- Demyelination makes the body work harder through the nervous system, thus producing fatigue.
- Lassitude is often experienced daily and is out of proportion to the person's level of activity or sleep.
- This fatigue is specific to MS and those without MS won't experience this type of fatigue.



Secondary Fatigue Contributing Factors

- Poor temperature regulation
- Mental/Cognitive exertion
- Sleep disruption
- Poor sleep hygiene
- Medications
- Mood/Emotions
- Physical over-exertion
- Physical deconditioning
- Comorbidities
- Stress
- Illness
- Diet

Early Warnings of Fatigue

- Weakness
  - e.g. Foot drop
- Slowed movements
- Decreased coordination
- Balance changes
- Vision changes
- Pain
- Muscle tightness/ spasticity
- Difficulty speaking
- Increased task errors
- Cognitive changes
- Emotional changes
- General tiredness

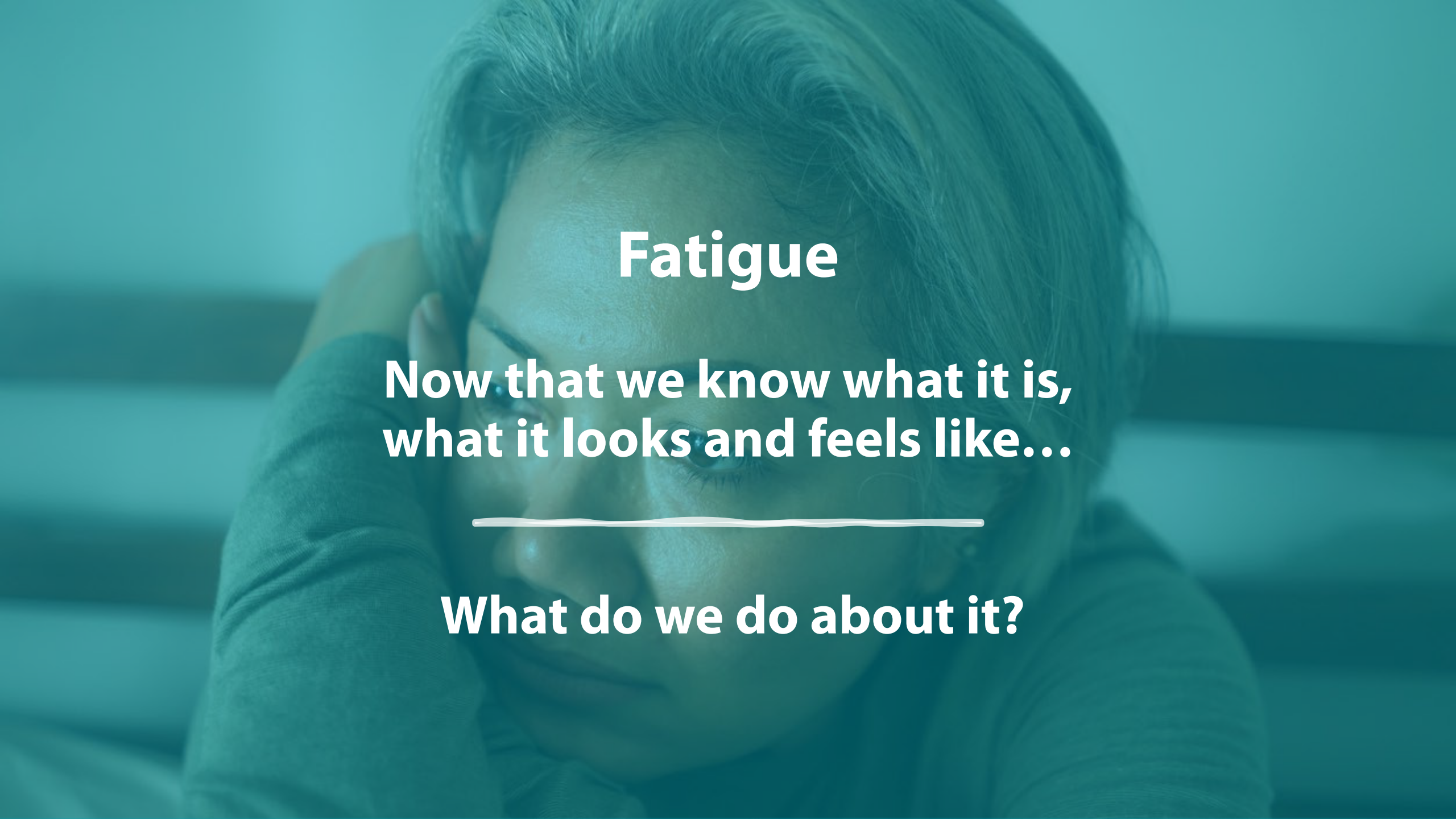
Learn To Recognize Your Warning Signs

- Keep a journal
- Set reminders to do self check-ins
- Create lists of your warning signs
- Ask friends and family to point out changes
- LISTEN TO YOUR BODY!
  - It's communicating more than you may realize

CAN DO Multiple® Sclerosis

How Support Partners Can Help!

- Look for warning signs
- Communicate in a caring way
- Ask the person with MS how they are feeling
- Offer support
- Be creative with solutions
- Avoid judgment
  - This can lead to someone trying to push through the symptoms resulting in more damage



Fatigue

Now that we know what it is, what it looks and feels like…

What do we do about it?

Banking & Budgeting

Learn how to SAVE and SPEND your energy wisely

If MS gave you $1 a day...

Imagine that dollar represented the energy you have each day…

- Where do you spend your pennies?
- Where are you overspending?
- How could you save some pennies?
- What special things do you want to save up for?
- Where can you find the DISCOUNTS!?

Budgeting

Planning and choosing how to spend your energy

Are your “bad MS days” just poorly managed?

Budgeting Strategies

- Be flexible
  - Things wont always go as planned
- It's OK to say No!
  - Set boundaries for yourself and others
- Evaluate your standards
  - Type A personality?
- Evaluate your priorities
  - Family, Health, Exercise, Spirituality, Work, Leisure, etc.

Banking

Every time you use a technique, tool, or device to save energy you are "banking" those pennies!

Energy Management and Strategies

- Healthy nutrition
- Medication management
- Energy conservation techniques
- Adaptive equipment
- Stress management
- Effective communication
  - (family, friends, healthcare team)
- Temperature regulation
- Exercise
- Cognition
- Sleep

Healthy Nutrition

- Did you put enough gas in your tank?
- Do you eat a good balance of short and long-acting energy?

Medication Management

- Would you benefit from medication to improve your alertness?
- Review your complete medication list with your doctor to see how it's affecting your fatigue.

Energy Conservation Techniques

- Proper posture and body mechanics
- Sit when possible
- Use orthotics, mobility devices, and other adaptive equipment
- Organize your home
  - Avoid unnecessary walking, reaching, bending, carrying
- You don’t always know what fatigues you until you stop doing it

Adaptive Equipment

- Search "Adaptive equipment for _____" or "Adapted _____"
- **Adapted clothing:** Zip shoes, magnetic buttons, foot funnel, elastic waist pants
- **Bathroom:** Tub transfer bench, grab bars, toilet rails, bidets,
- **Kitchen tools:** Rocker knife, mesh gloves, Swedish cutting board
- **Chores:** Rolling laundry baskets, long handle broom/dustpan, long handle scrubbers for tubs, light weight vacuums
- **In the yard:** Self propelled mowers, benches for sitting while gardening, umbrellas and cooling vests for cooling
- **Miscellaneous:** Reachers, dycem for gripping, stools, rolling carts
    - Alexa, Echo and Siri are also great adaptive tools!

CAN DO Multiple® Sclerosis

Stress Management

- It is ok to say no
- Set boundaries
- Plan leisure activities too
- Communicate
- Spread out your To Do List
- Avoid being a perfectionist. Cut corners when possible.

Effective Communication

- Be honest with yourself and others
- Negotiate
- Don’t wait for a crisis
- Discuss situations in advance whenever possible

Heat Management: Keep Your Cool!

- Do outdoor activities when temps are low
- Cooling Equipment
- Wicking clothing
- Hydration
- Cold snacks or meals
- Personal fans and misters
- Dress in layers
- Stay in the shade
- Cool your car

CAN DO Multiple® Sclerosis

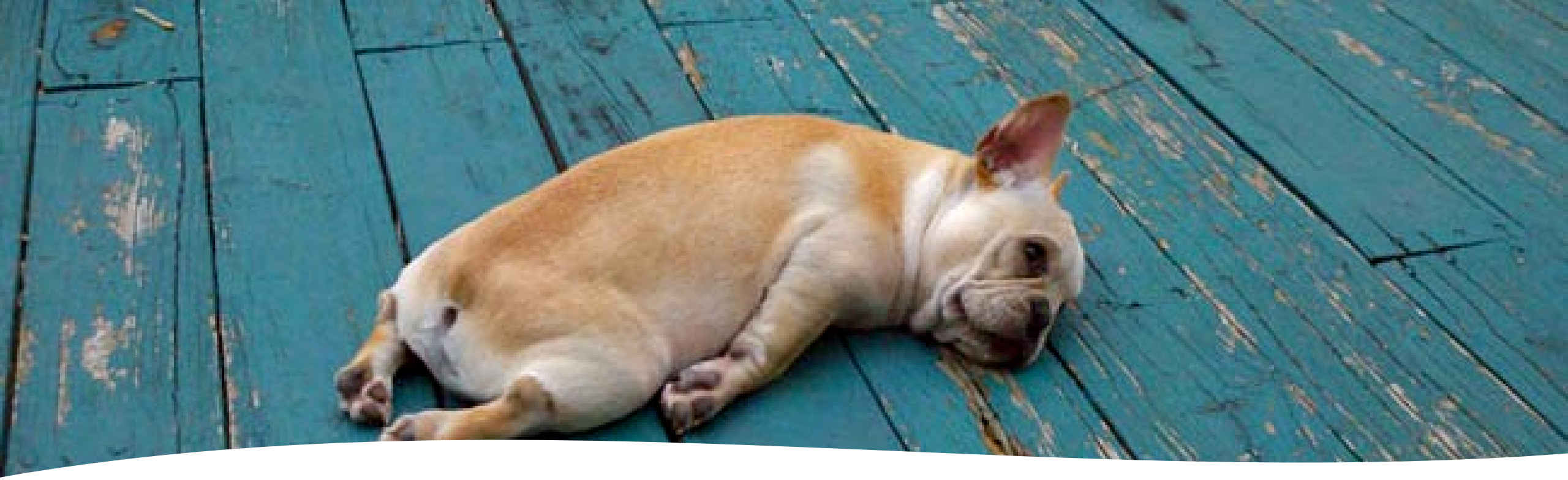
Exercise for Energy

Exercise can

- Reverse some strength loss
- Increase endurance
- Improve quality of sleep
- Decrease spasticity
- Decrease depression, anxiety, stress
- Improve balance and general mobility
- Help manage pain

Cognition

- Make lists (electronic ones are reusable!)
- Use calendar, reminders on your phone, apps
- Write it down, take screen shots, take photos
- Pace yourself when performing cognitive tasks
  - Complex tasks earlier in the day



Sleep

- Provides the body (including the nervous system) time to rest, recover and repair.
- Sleep problems have been reported to be 4X higher in people with MS
  - Sleep apnea
  - Insomnia
  - Restless leg syndrome
  - Nocturia (nighttime urination)
  - Spasms
  - Pain

CAN DO Multiple® Sclerosis

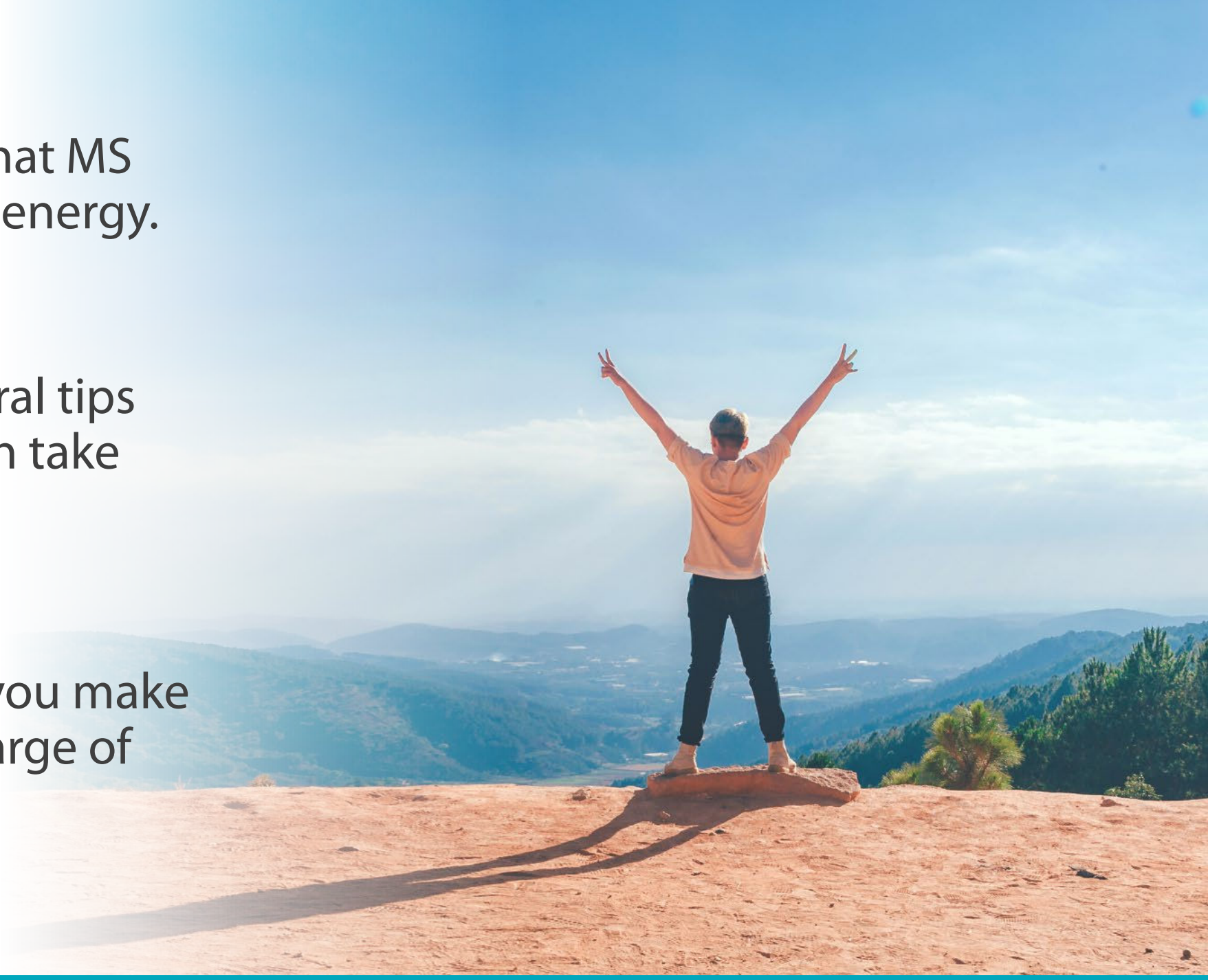
4 P's

- **Prioritizing**: Determine what you need and want to do during the hour, day or week. What can wait till another day or for another person?
- **Pacing**: Measure each activity to determine how much energy it will consume. Try to alternate the difficult and easy tasks to avoid burnout early on.
- **Planning**: Schedule everything possible! Write it down and look at your day. Are you going to overdo it? Can you move things around so you can squeeze some breaks in there?
- **Positioning**: Sit or lay when possible. Use gadgets, tools or mobility devices to help you save energy for other tasks.

Often people fear that MS will take away their energy.

Now you have several tips and tools so you can take that power back!

What changes will you make so that you're in charge of your energy?



Q & A

Connect With Us

Twitter
@CanDoMS

Facebook
@CanDoMultipleSclerosis

Instagram
@CanDoMultipleSclerosis

MARCH PROGRAMS

JUMPSTART – March 10
Fatigue: Get Started With Everyday Energy Tips

YOUR QUESITONS ANSWERED – March 15
Fatigue and Energy

CAN DO Multiple® Sclerosis PRESENTS:

WEBINAR WEDNESDAYS

Cognition: How To Improve Your Thinking, Attention, and Memory

Wednesday, April 6 at 8pm ET

SPONSORED BY:

Biogen

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