

Webinar Series



Fatigue and Sleep

Tuesday, April 14, 2020

Presented by:



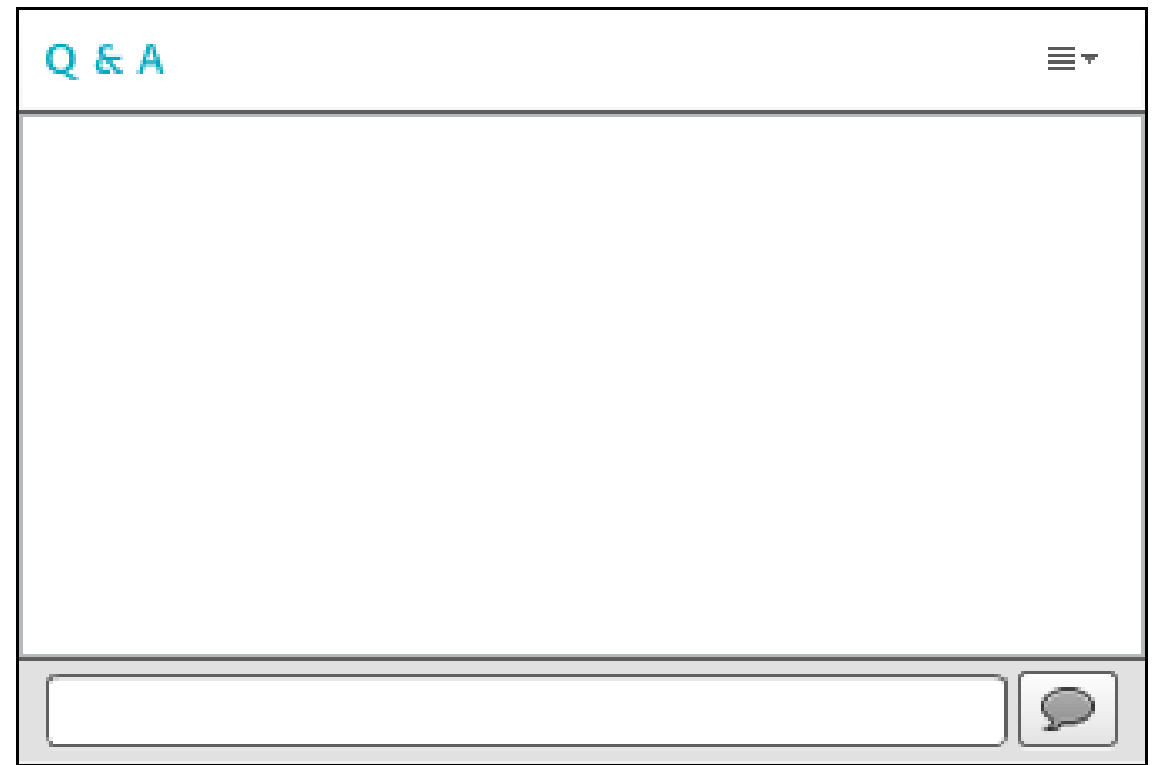
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How to Ask Questions During the Webinar:

- Type in your question in the Q & A pod

A screenshot of a Q & A pod interface. The top left corner displays "Q & A" in blue text. The top right corner features a hamburger menu icon. The main area is a large, empty white space for typing a question. At the bottom, there is a text input field and a speech bubble icon to its right.

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Webinar Learning Objectives

- Define and describe sources of fatigue in MS
- Describe the types of sleep problems most common in MS
- Describe the relationship between sleep and fatigue in MS
- Compare basic tools for assessing fatigue and sleep disturbance
- Implement a few strategies to manage fatigue and sleep disturbance

Define and Describe Sources of Fatigue in MS

Definition of Fatigue

- “A subjective lack of physical or mental energy that is perceived by the individual or caregiver to interfere with usual and desired activities.”¹



Prevalence of Fatigue in People Living with MS

- Almost 80% of patients with MS report fatigue in the first year of disease onset. Fatigue is a highly prevalent symptom in the early stage of the disease, with 55% of patients describing it as one of the worst symptoms they experience. With disease advancing 95% of patients report fatigue.*



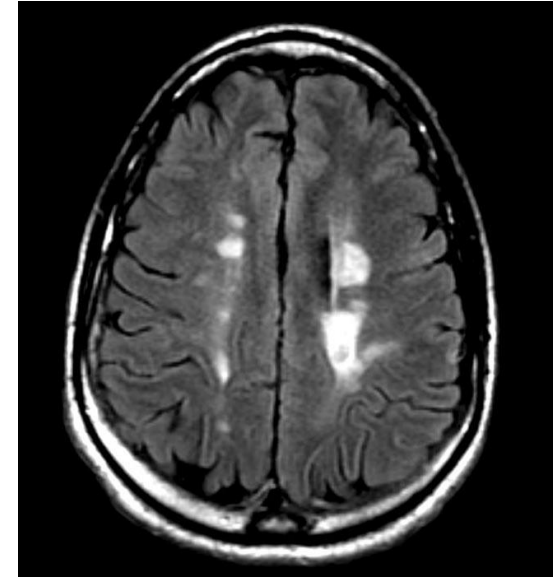
Fun Fact about Diagnosing MS

- Early on, when doctors were attempting to diagnose MS, they would use the “hot bath” technique.



Sources of Fatigue

- Fatigue can be caused by a variety of factors*
 - Neurologic fatigue
 - Nerve damage alters neuronal connections
 - Muscle spasms
 - Heat
 - Too much and too little activity
 - Emotional factors: stress, depression, anxiety
 - Sleep disturbance
 - Medication side effects



Lassitude

- Lassitude only occurs in people who are living with MS3
 - An extreme form of daily fatigue
 - Can occur even after a restful night's sleep
 - Can worsen as the day progresses
 - Tends to be aggravated by heat and humidity
 - Is more likely to interfere with daily responsibilities



Spoons Metaphor

- The spoons metaphor can be used to explain how there is a mental and physical reduction of energy, due to fatigue, that is available to you in order to perform your daily activities.



get out of bed



bathe



make & eat a meal



go to work/school

Describe Common Types of Sleep Problems in MS

Sleep Problems in MS

- Adequate sleep quantity and quality is an essential part of managing MS fatigue.
- Over 50% of people with MS have problems with sleep.
- Sleep disorders are more common in MS than in the general population and in other neurologic conditions.



Sleep Problems in MS

- Insomnia – difficulty falling or staying asleep, or waking too early
 - Acute
 - Chronic
- Sleep apnea – slowed or pauses in breathing during sleep
 - Obstructive sleep apnea
 - Central sleep apnea
- Restless legs – irresistible urge to move legs

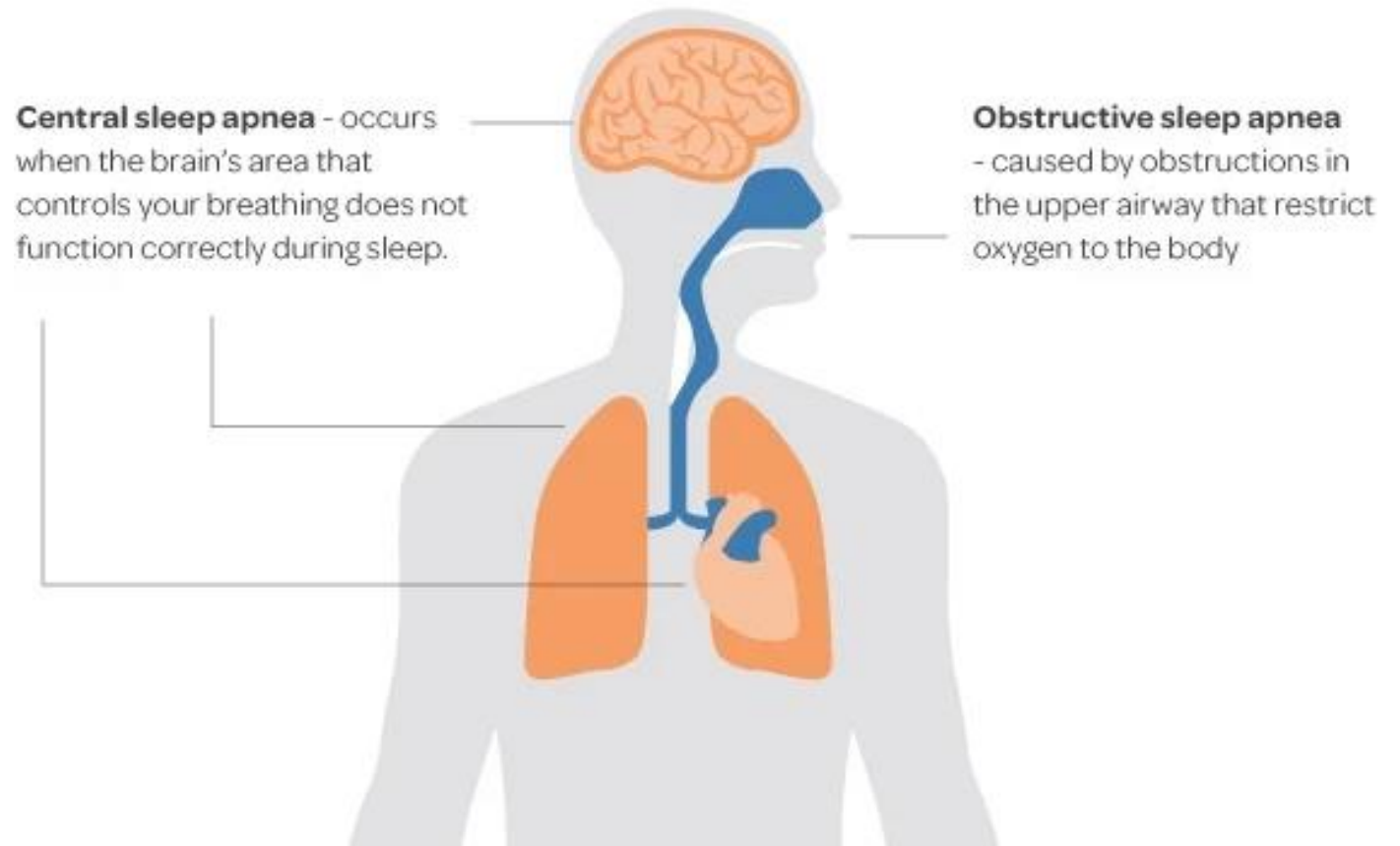
Insomnia

- Acute Insomnia
 - Medical event
 - New stressor
- Chronic Insomnia
 - >3 nights/week
 - >3 months
 - Daytime dysfunction



Sleep Apnea

- Pauses in or slowed breathing
- Can be caused by airway obstruction or lesions in the brain
- Bed partners can often observe these
- Waking with dry mouth
- Snoring
- Morning headaches



Restless Legs

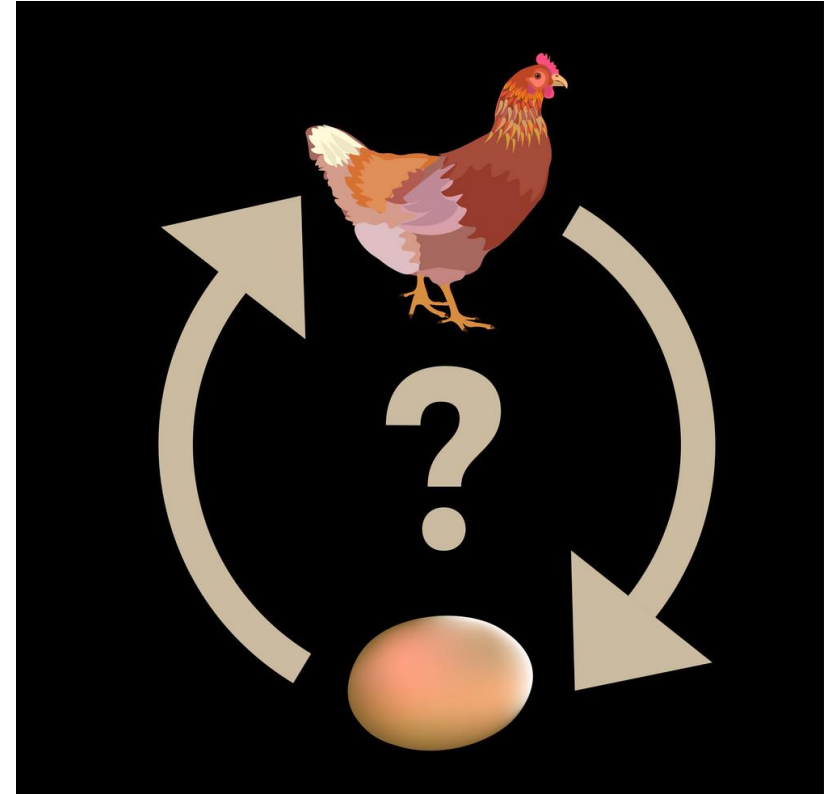
- Different from spasms/tremors (uncontrollable movements)
- The movement is voluntary, but its in response to a very uncomfortable sensation in the legs that only goes away when moving



What is the Relationship Between Fatigue and Sleep?

Fatigue and Sleep: Chicken or the Egg?

- Yes
- Fatigue → daytime napping, caffeine/stimulant use, frustration, stress → difficulty falling asleep
- Sleep problems → fatigue



Basic Tools for Assessing Fatigue and Sleep

Fatigue: The Fatigue Severity Scale

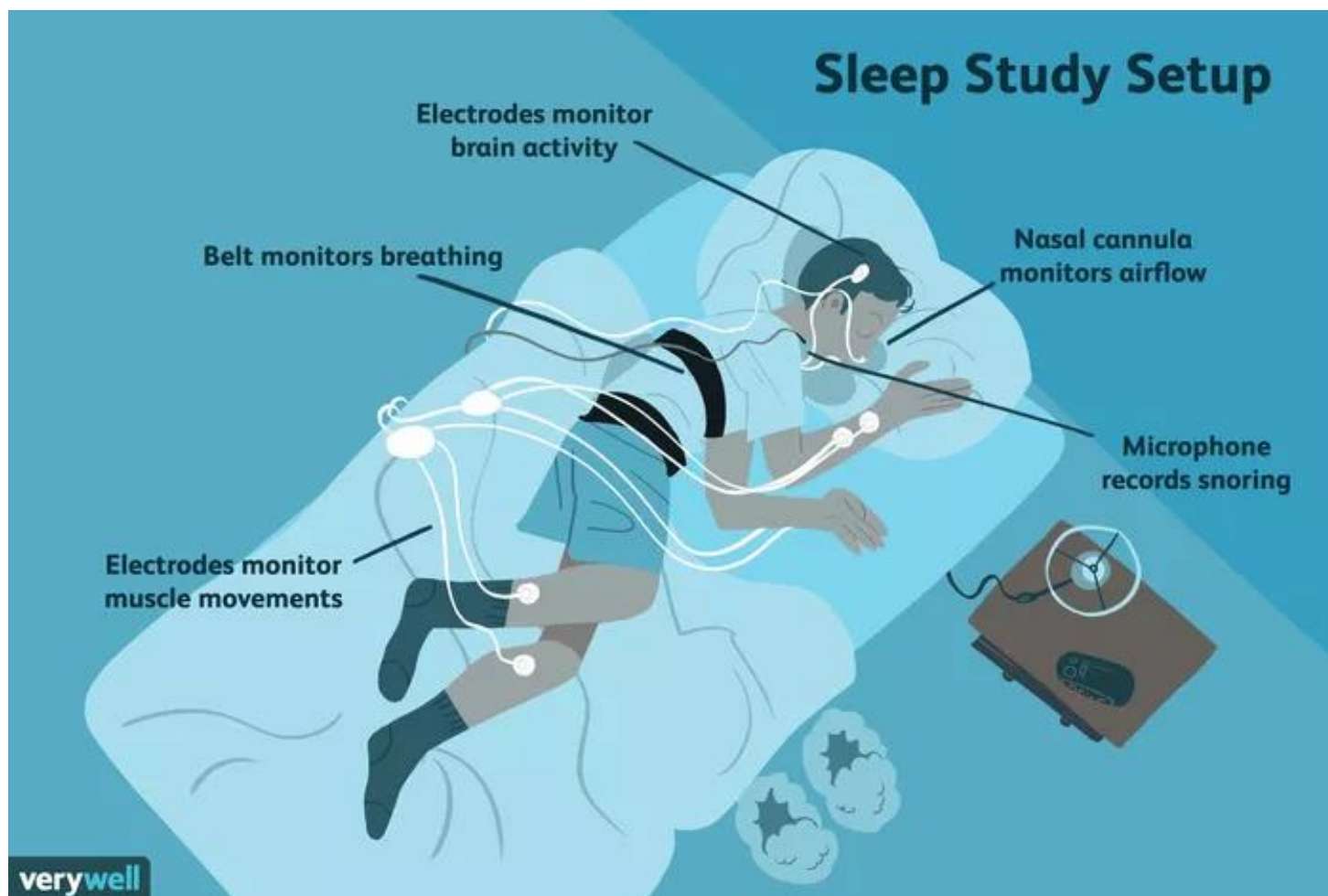
	Scores						
	1 = Strongly Disagree; 7 = Strongly Agree						
1. My motivation is lower when I am fatigued.	1	2	3	4	5	6	7
2. Exercise brings on my fatigue.	1	2	3	4	5	6	7
3. I am easily fatigued.	1	2	3	4	5	6	7
4. Fatigue interferes with my physical functioning.	1	2	3	4	5	6	7
5. Fatigue causes frequent problems for me.	1	2	3	4	5	6	7
6. My fatigue prevents sustained physical functioning.	1	2	3	4	5	6	7
7. Fatigue interferes with carrying out certain duties and responsibilities.	1	2	3	4	5	6	7
8. Fatigue is among my three most disabling symptoms.	1	2	3	4	5	6	7
9. Fatigue interferes with my work, family, or social life.	1	2	3	4	5	6	7

Insomnia: The Insomnia Severity Index

Insomnia Problem	None	Mild	Moderate	Severe	Very Severe
1. Difficulty Falling Asleep	0	1	2	3	4
2. Difficulty Staying Asleep	0	1	2	3	4
3. Problems Waking Up Too Early	0	1	2	3	4

4. How satisfied/ dissatisfied are you with your CURRENT sleep pattern?	Very Satisfied (0)	Satisfied (1)	Moderately Satisfied (2)	Dissatisfied (3)	Very Dissatisfied (4)
5. How noticeable to others do you think your sleep problem is in terms of impairing the quality of your life?	Not at all Noticeable (0)	A Little (1)	Somewhat (2)	Much (4)	Very Much Noticeable (4)
6. How worried/distressed are you about your current sleep problems?	Not at all Noticeable (0)	A Little (1)	Somewhat (2)	Much (4)	Very Much Noticeable (4)
7. To what extent to you consider your sleep problems to interfere with your daily functioning currently?	Not at all Noticeable (0)	A Little (1)	Somewhat (2)	Much (4)	Very Much Noticeable (4)

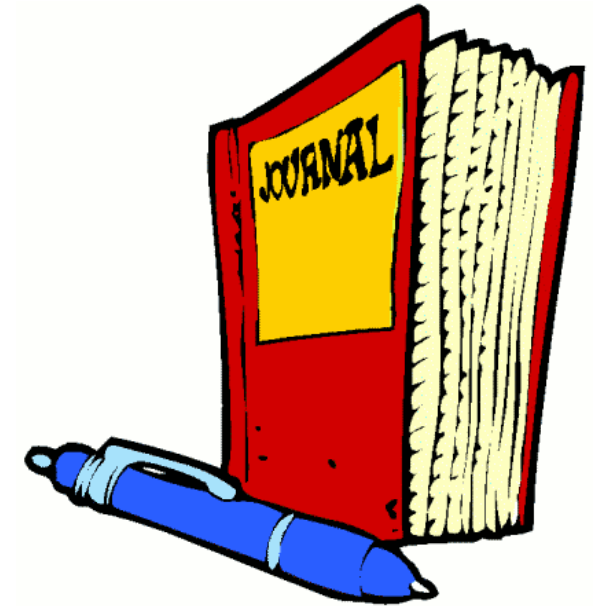
Sleep Apnea: Sleep Study



Strategies for Managing Fatigue and Sleep

Keeping a Fatigue & Sleep Diary

- Keeping track of your fatigue and sleep on a daily basis can help you:
 - See trends for causes of fatigue or sleep problems
 - Adjust your activities to maximize your energy and sleep
- See diary handouts



Fatigue Diary

Fatigue diary

Every day, rate how tired you're feeling on a scale of 0-10. 10 is the most tired you can imagine and 0 is not tired at all.

You might find it useful to share this with your doctor or nurse. It can also be helpful to show it to your family and friends, so they can see how fatigue affects you.

Date _____	Mon	Tue	Wed	Thu	Fri	Sat	Sun
Early morning							
Late morning							

Write down the activities you do throughout the day. Include resting as an activity.

Date _____	Activities
Monday	Example: <i>Had a shower</i>

Look at your fatigue diary to see when you might be likely to feel tired. Try and plan your activities so that they're spaced out throughout the week. It might be helpful to plan a rest after any activities that make you feel very tired. You might find it helpful to share your weekly planner with your friends and family, so they can support you with your activities.

	Morning	Afternoon	Evening
Monday Date	Example: <i>Rest</i>	<i>pick up K from school</i>	<i>Watch a film</i>

Sleep Diary

	<i>sample</i>	
Today's date	04/01/17	
1. What time did you get into bed?	22:15 p.m.	
2. What time did you try to go to sleep?	11:30 p.m.	
3. How long did it take you to fall asleep?	55min.	
4. How many time did you wake up, not counting your final awakening?	3 times	
5. In total, how long did these awakening last?	1 hour 10 min.	
6. What time was your final awakening?	6:35 a.m.	
7. What time did you get out of the bed for the day?	7:20 a.m.	
8. How would you rate the quality of your sleep?	<input type="checkbox"/> Very poor <input type="checkbox"/> Poor <input type="checkbox"/> Fair <input type="checkbox"/> Good <input type="checkbox"/> Very good	<input type="checkbox"/> Very poor <input type="checkbox"/> Poor <input type="checkbox"/> Fair <input type="checkbox"/> Good <input type="checkbox"/> Very good

Avoid Heat

- Stay inside when it is hot outside
- Have cool snacks
- Wear cooling garments
- Stay well hydrated
- Turn up the air conditioner or use fans to circulate the air.



Keep the Bedroom Pro-Sleep

- Cool (~65 degrees)
- Comfortable (how old is your mattress?)
- Dark (blackout shades?)
- Quiet (white noise machine)



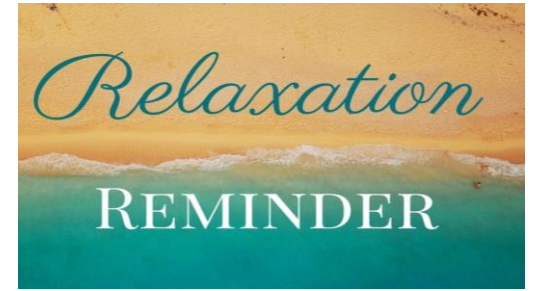
Exercise

- Studies have reported that people with MS benefit from regular exercise. Try things like Yoga, Tai Chi and water aerobics.



Use Your Health Care Team





The Four P's of Energy Conservation

- Prioritize
- Plan
- Pace
- Position

Prioritize Your Activities

- For example, it's the weekend and you really want to clean your office and clean your guest bedroom. Which one takes priority? Do you have family activities that you want to participate in on Saturday night? Will that impact what you do earlier in the day?



	URGENT	NOT URGENT
IMPORTANT	Quadrant I Urgent and Important	Quadrant II Not Urgent but Important
NOT IMPORTANT	Quadrant III Urgent But Not Important	Quadrant IV Neither Urgent nor Important

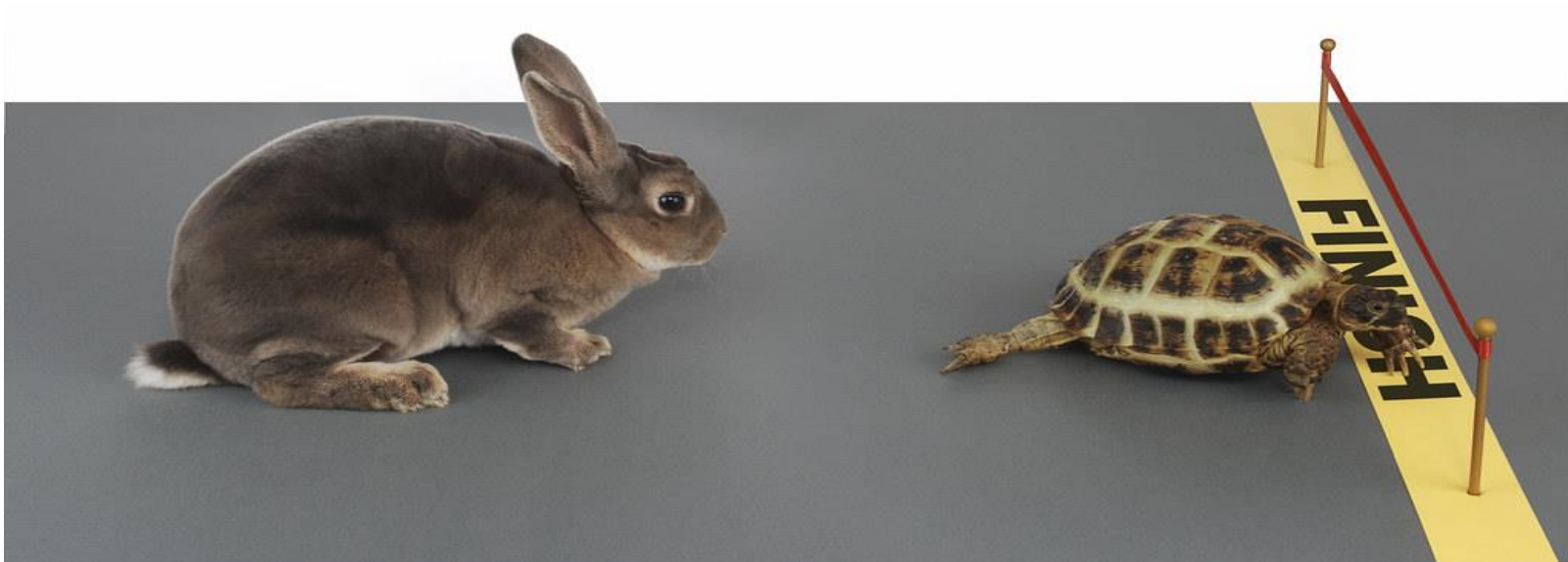
Plan Your Activities

- After working on prioritizing your activities, then you need to decide when the best time of day is for you is to do the task.
- Try alternating easier/more complicated tasks, as this can also be beneficial.
- Make sure to calculate rest breaks into your day.



Pace Your Activities

- Remember that slow and steady wins the race!



Watch Your Position During Activities

- Do as much from sitting as possible.
- Sitting requires 25% less energy than standing.
- Use lightweight tools to clean.



Sleep Hygiene

- Consistent sleep and wake time
- Use the bedroom only for sleep and sex
- Avoid large meals, caffeine, and alcohol before bedtime
- Prioritize physical activity earlier in the day (>3 hrs before bedtime)
- Avoid caffeine 8 hours before bedtime
- If you can't sleep, get out of bed and do a quiet activity (retrain your brain to associate your bed with sleep)

Take Care of Your Mental Health

- Untreated depression can impact fatigue and sleep
- Use the NMSS's website to find mental health practitioners in your area who are knowledgeable about the impacts of MS.
- Ask your insurance company about telehealth
- Check out some online platforms:
 - Deprexis (<https://deprexis.com>)
 - Beating the Blues (www.beatingtheblues.co.uk)
 - MoodGYM (www.moodgym.com.au)

Simplify / De-Clutter Your Life

- The impact of de-cluttering your environment can be helpful.



Ask for Help

- When you ask for help, it can reduce your fatigue level by not having to complete part or all of a task.



Most of All...

- Be kind to yourself!!!
- Acceptance doesn't mean resignation; it means understanding that something is what it is and that there's got to be a way through it.

Michael J. Fox

*No act of kindness,
no matter how small,
is ever wasted.*
- Aesop

References

1. Angela S, Tullia SD, Giorgia F, Valter S, Teresa P. Occupational therapy in fatigue management in multiple sclerosis: an umbrella review. Multiple sclerosis international. 2019;2019.
2. Taken from: <https://www.nationalmssociety.org/Symptoms-Diagnosis/MS-Symptoms/Fatigue> on 1/25/2020.
3. <https://www.nationalmssociety.org/Symptoms-Diagnosis/MS-Symptoms/Fatigue> on /25/2020.
4. Taken from: <http://mult-sclerosis.org/fatigueseverityscale.html>
5. All photos were accessed on Online Pictures Powered by Bing.

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