M.S SEMINAR SERIES

THANKS TO OUR SPONSORS:







OUR AGENDA

4PM Live Music: Kevin Ryan

5PM Keynote Presenter: Dr Revere Kinkel
Guest Presenter: John Monteith
Moderator: Alice Astarita, Clinical Social Worker
7PM Event Concludes



Dr Revere Kinkel

Clinical Neurologist UCSD

John Monteith

Founder & CEO Adapt Movement

Alice Astarita

Clinical Social Worker UCSD MEET OUR TEAM

Our team of presenters and artists for MS Seminar: Part III







JOHN MONTEITH

FOUNDER & CEO ADAPT MOVEMENT

Electrical Muscle Stimulation

ADAPT

John Monteith Founder & Executive Director, Adapt



What is Electrical Muscle Stimulation (EMS)?

- **Definition:** Technique using electrical impulses to stimulate muscle contractions
- **Applications:** Rehabilitation, fitness enhancement, and therapeutic settings
- **Benefits:** Includes muscle strengthening, rehabilitation support, and pain management.

History of Electrical Muscle Stimulation

Ancient to Early Modern	18th Century	20th Century
From electric fish to Leyden jars for storing static electricity	Luigi Galvani's discovery of "animal electricity."	Advancements in medical and sports applications.
in An		







Mechanism of Electrical Muscle Stimulation

- Device Setup: Consists of a stimulator and electrodes
- Electrical Impulses: Mimic central nervous system signals to cause muscle contractions
- Targeted Action: Stimulates specific muscle groups based on electrode placement.



Broad Benefits of Electrical Muscle Stimulation

- Muscle Strength and Recovery: Enhances strength and aids in post-exercise recovery
- Pain Management: Reduces chronic pain through muscle relaxation
- Circulation Improvement: Boosts blood flow to stimulated areas



Using EMS in Rehabilitation

- Injury Recovery: Speeds up rehabilitation from muscle injuries
- Post-Surgery Recovery: Helps in regaining muscle tone and strength
- Neurological Rehab: Aids in treatment of conditions like stroke, MS, and spinal injuries



EMS Benefits for Multiple Sclerosis (MS)

Muscle Maintenance Prevents atrophy through regular stimulation

Mobility Improvement

Enhances muscle function and overall mobility

Benefits Reduces spa muscle tight

Reduces spasticity and muscle tightness, enabling easier daily tasks

Spasticity

Fatigue Reduction Conserves energy,

reducing overall fatigue

Safe and Effective EMS Use







CONTRAINDICATIONS: INCLUDES CONDITIONS LIKE PACEMAKERS AND EPILEPSY PROFESSIONAL SUPERVISION: ESSENTIAL FOR SETTING UP AND MONITORING EMS DEVICE SELECTION: CHOOSING THE RIGHT EMS SYSTEM BASED ON THERAPEUTIC GOALS.

Stim Equipment Overview



The Future of EMS

- Technological Advances: Wearable, and Alintegrated EMS systems
- Research and Development: Ongoing studies to expand EMS applications – TSS, SCS, DBS





DR REVERE KINKLE

CLINICAL NEUROLOGIST MS PRACTICE DIRECTOR UCSD UC San Diego Health

Seminars in Integrative Management of MS Seminar III: Understanding and Managing MS Symptoms

Revere (Rip) Kinkel MD Professor Emeritus of Neurosciences

Early MS Symptoms in > 10 % of patients

	Description	Medication Treatment		
Most commo	n <u>Sensory</u> : abnormal and sometimes painful sensations	Mild-Mod effective in 25 to 50 %		
	Vision Problems [*] :blurring, scotoma, decreased contrast sensitivity, decreased color vision, double vision, jumping vision, difficulty tracking objects, Uthoff's phenomenon	Not effective		
	Fatigue: mental, physical or both	Mild-Mod effective in 25 %		
	Impaired Gait: persistent or intermittent problems with walking due to weakness, imbalance, dizziness or loss of sensation	Mild-Mod effective in 25 %		
	Weakness: one or more limb	Not effective		
	Dizziness: Persistent or intermittent	Mild to moderately effective in 25 %		
	Pain: neuralgia and other headaches	Significantly effective in 50-75%		
	Depression: self reported	Significantly effective in 50-75%		
Least common	Bladder disturbance: urgency, hesitancy, urine retention and incontinence.	Significantly effective in 50-75 %		

* Ajdacic-Gross, V. et al Frontiers in Neurology 2021

Residual or Reactivated MS Symptoms vs Disease Activity or Worsening

Symptom	Disease Activity or Worsening
Caused by prior demyelination, axonal loss or synaptic dysfunction	Acute or chronic inflammatory activity or neurodegeneration
Transient or <u>intermittent</u>	Subacute or progressive onset w/o improvement over days, weeks or months of time
Aggravating & alleviating factors present	No obvious cause or modifying factor
Positive sensory or motor phenomenon	Negative sensory or motor phenomenon
Non-MS & external factors often contribute	Non-MS & external factors often contribute
Interrelated symptom clusters common	Symptoms linked spatially & temporally by anatomic rules, usually with corresponding findings on exam
DMTs may have no effect	DMTs have a major effect

Common factors aggravating MS Symptoms

- Medications
- Chronic Stress
- Depression and anxiety
- Insomnia
- Infections
- Hormonal cycles
- Inactivity/immobility
- Pain
- Diet
- Hot or cold ambient temperature

Circadian Rhythm in Body Temperature



Take a closer look at Individual MS Symptoms and Symptom Clusters

Focus on Quality of life (QOL)

Association of Symptoms with Neurological Exam Severity

These

symptoms tend

to occur in clusters

Not Associated with Neurological exam

- Fatigue
- Sleep Disturbance
- Depression
- Anxiety
- Perceived cognitive dysfunction
- Sensory symptoms (paresthesia)

 Associated with Worse neurological exam

- Bowel and Bladder disturbance
- Spasticity
- Decreased ambulation
- Cognitive dysfunction
- Chronic Pain

Factors associated with lower QOL

- Lower Income
- No secondary education
- ・ 个 Fatigue
- ↑ Physical impairment
- Psychiatric disease
- Health related co-morbidities
- \checkmark Social support
- \downarrow *Psychological flexibility (acceptance and active coping)*

Early MS Symptoms associated with a worse QOL Trajectory

Physical QOL	Mental QOL	Both
Older age at diagnosis	Younger age at diagnosis	Income < \$50,000
Male		Diagnostic lag
Worse fatigue early		Worse neurological impairment
Progressive disease		No college education
		Co-morbid medical conditions
		Co-morbid psychiatric conditions

O'Mahony J, Marrie RA., et al Neurology 2022:99(14); e1538-e1548





Gait and coordinat Memory/cognition Dependence/abuse Sensory changes Sleeping/fatigue Motor changes Psychiatric sx Parasomnia Depression Headache Insomnia Seizure Suicide х х х Х х х Х х х х х х Alprazolam x х Amitriptyline х Х Х х Х Х х Х Х Chloral hydrate Х Х Х Х Х Х Х Clonazepam Х х Х х х х Х х х X X х Х х Х Diazepam х Х Х X Х X Diphenhydramine Х Х х Х Х Х Х х Х Х Doxepin Х Х Х х Х Х Х Estazolam Х Х х Х Х Х Х Х х Х Х Х Х Х Х Х Eszopiclone х Х sleeping pills Х Х Х Х х Х Х Х Flurazepam Х Х Х Х Х Х Х Х Х Lorazepam Х X Neuropsychiatric х Х Х Х Х Mirtazepine Х Х Х Nefazodone Х Х X X х Х Х Х X Nortriptyline Х Х Х X Х Х Х Х Х Х Х Х X Х Х Х Х Oxazepam Quetiapine Х Х Х Х Х Х Х Х Х X Х Ramelteon Х Х Х Х Х Х Х х Х Х Х Х Temazepam X Х х X х Х Trazodone х X X X Х Triazolam Х х X Х Х Х х Х Х х Zaleplon Х Х X X Х Х Х Х X Х Zolpidem Х х Х Х Х Х Х Х Х х х Caffeine Х X Х Х Dexmethylphenidate х Х Х х х Х stimulants Dextroamphetamine X Х Х Х Х Х Dextroamp/amphet Х Х Х Х х Lisdexamfetamine Х Х Х Х Х X Х х Methylphenidate x х Х Х X Х Х Modafinil х Х х Х Х Х Х Х Х Х Х Gabapentin х х х X GHB х х Х Х X Х Х x х х Х Х х х х х Х Pramipexole х х х х Х Х Х Х Ropinirole x х Х Х X

Phase III trial of Amantadine **Modafinil and Methylphenidate For MS related Fatigue**

-No significant effect of Amantadine, Methylphenidate or modafinil on fatigue (MFIS or NeuroQol) in PwMS.

-Marginal benefits of Modafinil and Methylphenidate in PwMS reporting **Excessive Daytime Sleepiness**

-More AEs with all these Meds

-Despite negative study results PwMS favored using Modafinil and Methylphenidate over placebo: WHY?

X	Serious
X	<1%
Х	1-10%
x	>10%

effects

ISRN Pharmacology 2012

Nourbakhsh, B. Lancet Neurol 2021; 20(1): 38-48

Summary of most common MS Symptoms

- Occur early, often many years before any evident disability
- Occur in interrelated symptom clusters (> 5 symptoms in 25 % of pwMS)
- Associated with early & progressive decline in QOL, if not managed
- Most MS symptoms are <u>Not</u> well managed by medications
- Both daily MS symptoms and MS disease activity can be modified by behaviors

If medications directed at specific MS Symptoms are of limited benefit, how can you better manage your MS related symptoms, improve your QOL and achieve better long-term outcomes ?

Self-Management Skills

- Life-long Learning
 - Self-monitor symptoms through journaling
 - Enhance your neurological reserve
 - Be proactive, not passive & reactive
 - Learn effective decision making
- Stress Management
 - Relaxation response
 - Cognitive restructuring
 - Environmental control & rearrangement
 - Nurture social support network & improve communication
- Reduce Co-Morbidity
 - Healthy diet: Mediterranean Diet
 - Weight loss
 - Eliminate smoking or excessive ETOH
 - Eliminate unnecessary drugs (legal & illegal)
 - Regular PCP screening visits
- Exercise & Functional Movement
 - 150 minutes per week moderate vigorous exercise
 - Functional movement and balance programs



Mind Full, or Mindful?







Evidence Supporting Specific Self-Management Strategies

Diet and Nutrition: Overview

- The effect of Diet on the MS disease process
 - Direct effect on immune cells (GALT)
 - Anti-inflammatory and anti-oxidative effects on CNS cells (astrocytes and microglial cells) : Flavonoids (Cruciferous veggies, berries, tea, coffee, wine)
 - Effects on Gut Microbiota: SCFA (produced from fiber, fermentation and protein)
 - Effects on Co-Morbidities: vascular disease, HTN, DM, obesity
- Mediterranean/MIND: Diet most supported by evidence at present
 - High in plants, nuts, legumes, fish, unsaturated and monounsaturated (EVOO) fats
 - Low to Moderate red wine
 - Low intake dairy, red meat, saturated fat, refined grains (processed food in the aisles) and sugars

Mediterranean Diet Score Tracker

MEDITERRANEAN DIET SCORE TOOL

A Mediterranean dietary pattern is typically one based on whole or minimally processed foods. It is rich in fruits, vegetables, legumes, wholegrains, fish and olive oil and low in fast food, sugar-sweetened beverages, refined/processed grain products with moderate red meat and alcohol intake.

Evidence shows overall dietary pattern (reflected in TOTAL SCORE) as well as individual components reflect risk; a higher score is in response to dietary advice and support.

		-		~ 4 1
	Question	Yes	No	Nutritional issue to discuss in response
1.	Is olive oil the main culinary fat used?			Choosing Healthier Fats Olive oil is high in monounsaturated fat. Using unsaturated fats instead of saturated fats in cooking and preparing food is advisable.
2.	Are ≥ 4 tablespoons of olive oil used each day?			Healthy fats are better than very low fat Med diet is more beneficial than a very low fat diet in prevention of CVD. So replacing saturated with unsaturated fat is better than replacing it with carbohydrates or protein.
3.	Are \geq 2 servings (of 200g each) of			Eat plenty of fruits and vegetables
4.	Are ≥ 3 servings of fruit (of 80g each) eaten each day?			Eating a wide variety of truit and vegetables every day helps ensure adequate intake of many vitamins, minerals, phytochemicals and fiber. Studies have shown that eating plenty of these foods is protective for CVD and cancer.
5.	Is < 1 serving (100-150g) of red meat/ hamburgers/ other meat products eaten each day?			Choose lean meats and consider cooking methods Red and processed meats are high in saturated fat, can be high in salt and are best replaced with white meat or fish or vegetarian sources of protein.
6.	Is < 1 serving (12g) of butter, margarine or cream eaten each day?			Keep saturated fat low
7.	Is < 1 serving (330ml) of sweet or sugar sweetened carbonated beverages consumed each day?			Excessive consumption of sugar-sweetened beverages can worsen many risk factors for CVD: keep consumption to < 1/day.
8.	Are ≥ 3 glasses (of 125ml) of wine consumed each week?			Moderate alcohol intake with meals
9.	Are ≥ 3 servings (of 150g) of legumes consumed each week?			Include soluble fiber These foods are high in soluble fiber and other useful nutrients. Regular consumption is advisable for raised cholesterol.
10.	Are ≥ 3 servings of fish (100-150g) or seafood (200g) eaten each week?			Eat more oily and white fish Oily fish is an excellent source of essential omega-3 fats.
11.	Is < 3 servings of commercial sweets/pastries eaten each week?			Eat less processed food These foods are usually high in saturated fat, salt or sugar and often contain trans fats.
12.	Is ≥ 1 serving (of 30g) of nuts consumed each week?			Snack on modest servings of unsalted nuts Nuts are rich in unsaturated fat, phytosterols, fibre, vitamin E and iron, e.g. walnuts, almonds, hazelnuts
13.	Is chicken, turkey or rabbit routinely eaten instead of veal, pork, hamburger or sausage?			'White meat' choices are lower in saturated fat. Remove the skin and consider your cooking method.
14.	Are pasta, vegetable or rice dishes flavoured with garlic, tomato, leek or onion eaten ≥ twice a week?			Using a tomato and garlic or onion or leek-based sauce regularly is a key feature of the Med diet.
тот	AL SCORE (total no. of 'yes' answers)			

Adapted from tools produced by Alison Hornby and Katherine Paterson BACPR 2012 and the PREDIMED study www.Predimed.es, Estruch et al. Primary Prevention of Cardiovascular Disease with a Mediterranean Diet Supplemented with Extra Virgin Olive Oil and Nuts. N Engl J Med 2018; 379;1387-1389. DOI: 10. 1056/NEIML308971.

26.09.13 Version 1

- Lots of EVOO (> 4 tabs per day)
- 16 ounces (2 cups) veggies per day
- 8 ounces (1 cup) fruit per day
- 16 ounces (2 cups) of legumes per week (split in 3)
- 21 ounces of seafood per week (split in 3)
- 1 ounce of unsalted nuts per week
- 3-5 glasses of wine per week
- Reduce red meats, butter, margarine, cream, cheese, sugar, sweetened beverages and salt

Mediterranean/MIND Diet

- Med Diet Pilot: Katz-Sand (2019)
 - RCT: MIND Diet (n=18) vs control (n=18) X 6 months
 - 90 % adherence
 - Significant improvements in EDSS, Fatigue & QOL
- MIND (Mediterranean-DASH Intervention for Neurodegenerative Disease) Diet: Katz-Sand (2021)
 - 180 people with RRMS/CIS
 - Higher MIND scores associated with greater thalamic volume on MRI
 - Greater Omega-3 intake associated with greater NAWM integrity
- MEDA Score Observation study: Katz-Sand (2022)
 - N=563 consecutive patients
 - MEDA score correlated with MSFC and Component scores
 - MEDA score attenuated effect of disease duration & progressive course on MSFC
 - EVOO important driver of benefit

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Exercise and Multiple Sclerosis: Overview

- 18 Randomized Clinical Trials assessing Aerobic Exercise, Resistance Training, or Physiotherapy
- MS patients show improvements in disability level with exercise (EDSS)¹
 - Standardized Mean Difference -0.19 (CI: -0.34, -0.03)
- Exercise associated with Improvements in the following areas
 - Mood, Well-being and Sleep
 - Fatigue and endurance
 - Weight
 - Overall health and multiple physiological and biochemical parameters
 - Functional independence
- Exercise in mouse models of aging attenuates the effects of age on mitochondrial and antioxidant damage in many organs including the brain

¹Hempel S et al. Multiple Sclerosis Journal 2017 DOI:10.1177/1352458516690271

Stress, Anxiety and Depression on MS : Overview

- Anxiety (30 %) and Depression (50 %) associated with increased MS symptoms, impaired function and socialization and decreased ability to follow recommended treatment plans
 - Self efficacy ; enhanced feeling of control and acceptance lessens impact of disease
- Stressful life events precede the development of new Gad-enhancing lesions on MRI
- Anxiety and depression are higher in those with MRI activity (with or without relapses) and higher anxiety levels predict disease reactivation (MRI activity or relapses) over the next 6 months
 - Steroid treatment for relapses reduces anxiety and depression within 7 days compared to no treatment
- A randomized trial of stress management rapidly reduced the development of new lesions on MRI
 - 48 week RCT with 24 week treatment, N=121 relapsing remitting patients

Marrie RA et al. Multiple Sclerosis 2009; 15(3) 385-92 Mohr DC et al. Neurology 2012; 79(5): 412-9 Rossi S et al. Neurology 2017;89:1-10

Psychological Interventions for Fatigue in MS

- Meta-analysis reviewed 20 studies with 1249 PwMS*
 - CBT reduced fatigue compared to non-active controls and active controls (relaxation and psychotherapy)
 - Relaxation and mindfulness reduced fatigue compared to non-active controls

*Aung Zaw Zaw Phyo et al. Frontiers in Neurol 2018

How can Cognitive Behavioral Therapy (CBT) principles assist in MS Symptom Management?

Skills all People with MS need to acquire

- <u>Self-monitoring</u>: Learn about MS and learn conditions and situations that worsen and those that improve your symptoms or problems.
- <u>Diet Adjustment & Control</u>: often requires analysis of effects of diet on symptoms through rational elimination or substitution. It also may require eliminating ingrained behaviors
- <u>Exercise and functional movement</u>: not only do some people need to learn this skill but many people with MS must learn new ways to continue these activities
- <u>Cognitive restructuring</u>: learning to modify thoughts about situations to minimize negative attitudes and responses
- <u>Relaxation Response</u>: learn to use deep breathing, meditation and/or mindfulness to reduce stress, anxiety and symptom activation
- Environment control & rearrangement: learn to organize home and work to establish cues for healthy behavior and create barriers to unhealthy behaviors
- <u>Social support</u>: learn to improve communication with your medical team, family and friends about your health concerns and the needed behavior changes you are attempting to make



Goals of MS Symptom Management

- Decrease persistence of symptoms, and perhaps the severity of symptoms when they occur
- Decrease dramatic fluctuations in symptoms
- Decrease impact of symptoms on mood, activities and relationships
- Gain greater sense of control over symptoms
- Improve well-being and QOL

Thank You



ALICE ASTARITA

CLINICAL SOCIAL WORKER MS CENTER UCSD



UCSD Self-Management Program:

Overview and Outcomes

Alice Astarita, PhD, MSW Clinical Social Worker Multiple Sclerosis Center UC San Diego Health August 5, 2024

Goals for Self-Management Program



To **develop a sense of agency** over your health and wellbeing through psychoeducation, coping tools, and social support



To **implement lifestyle modifications** that improve your overall health and Quality of Life by the reduction of your symptomatic experience



To **feel empowered** in your self-management with the encouragement, support, and empathy of peers

Self-Management Group Basics

What & Why:

- Intentional smallgroup sessions
- adjunctive therapy to medical treatments
- reduce symptom experience

Who:

- 4-6 patients
- all diagnosed with MS or similar diagnosis
- all experiencing similar symptom clusters

When:

- 6 sessions
- Weekly
- In person, may offer online if needed

Where:

- Conference Room in La Jolla next to Café
- Conference Room in Encinitas next to Pharmacy

Self-Management Group Session Outlines

Journaling/Locus of Control (1)

- Raise Consciousness around lifestyle choices and +/- impact on symptoms
- Develop feelings of agency & self-efficacy

Focusing on Goals / Cognitive Restructuring (3)

- Set SMART goals for symptom management and identify steps needed to reach them
- Values-informed decision making to reach goals
- Modifying negative thoughts to influence behaviors & feelings

Acceptance/Mindfulness (2)

- Accepting limitation(s) & figuring out ways to adapt
- · Cultivating mindfulness to shift symptom experience
- Living a values-driven life



Raise consciousness through journaling

- What is the impact of taking a long hot shower on my fatigue?
- What can I do differently throughout the week to avoid needing a "crash day?"
- How can I adapt my favorite leisure activity to be more energetically sustainable?
- I don't have any hobbies to journal about. Why did I stop doing things I enjoy?

Set SMART goals for symptom self-management:

- Specific, Measurable, Achievable/Attainable, Relalistic/Relevent, Timebound/time-limited
- Identify steps needed to reach SMART goal

Assess your values and adapt usual activities to manage symptoms

- oLiving a values driven-life
- $\odot \mbox{Love of ocean: Prone paddle boarding vs. Standing paddle boarding/surfing$
- $\odot Spending time with family: choose a manageable physical activity rather than over-exert on traditional hike$

oAddress any values misalignments with loved ones (ex. mowing the lawn)

Address negative thoughts

- $\circ \text{Learn}$ how our negative thought impact our feelings and behaviors
- oCognitive Restructuring techniques: Reframe
- $\circ \ensuremath{\mathsf{New}}$ metaphor: flowing or dancing with symptoms rather than fighting or battling them
- •Symptoms may not go away & they may even get worse, but your experience of them can shift to be less bothersome/impactful on your life





Acceptance though:

- Peer support
 - Group Motto: "See it. Break it. Work on it. Laugh at it."
 - A new way to answer that dreaded question: How are you? "I'm MS fine."
- Mindfulness
 - Moment-to-moment neutral acknowledgment of what is
 - Cultivating Gratitude
 - Breathing exercises
 - Creative activities that require full attention



Self-Management Group Feedback from "Graduates" (1)

...I have a better handle on managing my environment and mindset. I have much more confidence that I can be in control of my behavior and thoughts. The tools discussed in the workshop are highly valuable to me and I feel I can implement them immediately and longer term. It was difficult taking the time away from work to participate but it was absolutely worth it.

... I've learned how NOT to exacerbate my symptoms although sometimes they can appear somewhat randomly. And I've learned that even if I have these symptoms the rest of my life, I can get by. It was nice to be with a group of people who had similar symptoms and could understand. I would recommend a group for the sense of community and sharing. It helps to hammer in that you are not alone in this.

Getting others ideas or ways to cope with issues with MS was great...coming especially from others with MS as opposed to just a MD, who generally doesn't have MS tells me what to do or take more medication. Having others with MS in a support group made me feel like I was not alone in my symptoms and there are others who know what I am going through...I also loved the laughter of our group. It was a very positive experience compared to others.



Self-Management Group Feedback from "Graduates" (2)

It made me realize other people had to manage their symptoms just like I do and I didn't feel alone. The group gave me a lot of great ideas how to handle specific situations that someone in our condition deals with.

A big value of participating in an in person support group is the connections you make. Research shows that building good habits with friends is more effective than doing it on your own. I have no hesitations to recommend support groups to others.

[The facilitators] were amazing and made me feel very comfortable as well as challenged [me] to dig deeper with my thoughts when answering their questions...I would definitely recommend this to anyone with MS, regardless if they are recently diagnosed or a veteran.



Interested in participating in the UCSD Self-Management Program?

Contact:

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M.S SEMINAR SERIES

NEXT SEMINAR: OCTOBER 7