Group Leadership Call: November 18, 2021  3PM EST

Hosted By:
Mollie Burns
Manager, Community Engagement
Philadelphia, PA
Group Leadership Call: November 18, 2021  7PM EST

Hosted By:
Sue Pandya
Manager, Community Engagement
Phoenix, AZ
Zoom Tips: Microphone and Camera

Click the microphone icon to unmute yourself and click the video icon to share your video
Zoom Tips: Viewing Options

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Speaker View

Gallery View
Today’s Call

• Program Announcements & Reminders
• Presentation: Self Care for Group Leaders
• Society and Leader Resources
• Questions, Feedback, and Discussion
Diversity, Equity & Inclusion Statement

The National Multiple Sclerosis Society is a movement by and for all people affected by MS.

Our voices and actions reflect diversity, equity, and inclusion.

We welcome and value diverse perspectives.

We actively seek out and embrace differences.

We want everyone to feel respected and be empowered to bring their whole selves to ensure we make the best decisions to achieve our mission.
New to MS: Navigating Your Journey

- Program for people New to MS
- Every 2nd Thursday of the month, 8pm ET
- Virtual program (Zoom)
- Program content is the same each month
- Educational and engaging
- Register and learn more at NationalMSSociety.org/NewToMS
Ask an MS Expert Program Series

• Weekly on Fridays from 1-1:30pm ET in English
• The 3rd Wednesday of each month from 7-8pm ET in Spanish
• Quarterly for Veterans

November 19 - Updates to MRI Recommendations – Part II
Join us and Dr. Scott Newsome from Johns Hopkins as we continue our conversation about the updated international MRI recommendations for people living with MS. We will talk about recommendations for monitoring treatment effectiveness in MS, and considerations for special populations like pediatric MS and MS during pregnancy.

www.nationalmssociety.org/MSExpert
Mary Gossett, MSW, LGSW
Manager, MS Navigator Service Delivery
YOU ARE WORTH IT!

Evidence Based Strategies to show care to yourself

Mary Gossett, MSW, LGSW
Manager, MS Navigator Service Delivery
“Am I losing my mind? Is this a normal thing with MS?”

“Anybody has stabbing or burning in soles of your feet?”

“What you hear:

“For me, MS fatigue is not because I didn’t get enough sleep, it’s from the constant battle with my muscles trying to get them do what they are supposed to do.”

“Does anybody’s knees lock as you walk?”

“Anybody has stabbing or burning in soles of your feet?”

“It’s tough settling in to a m.s. lifestyle of being on disability and home sitting in a chair all day.”

“I’m worried sick!”

“Does anybody know a good disability lawyer?”

“How do you handle this being on immune suppressing medication?”

“I think I’m somewhat in denial but it’s starting to sink in.”

“I passed out for a moment at work from heat exhaustion”

“Feeling really frustrated and looking for some advice.”

“I recently was forced to look for a new job, but, every time I go to apply, I constantly think to myself, ‘why even try, you’re probably gonna have to go back on disability anyway’”

“Some days I wake up thinking I am good, and then I shower and dress and that’s it. I am done for the day.”

“How do you handle this being on immune suppressing medication?”

“First injection of Kesempta didn’t go good defective pen try again tomorrow anxiety to bad and I shake to much to give it to myself.”

“Today is my birthday and I feel alone.”

“my most recent MRI showed signs of breakthrough disease”

“Today is already starting off rough the pain is horrible”

“The feeling of wanting to run and deny you have something like MS is real.”

“Perhaps I’m just plain crazy.”

“Today is already starting off rough the pain is horrible”

“I keep staying strong, but it is a losing battle”

“For me, MS fatigue is not because I didn’t get enough sleep, it’s from the constant battle with my muscles trying to get them do what they are supposed to do.”

“Today is already starting off rough the pain is horrible”

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“For me, MS fatigue is not because I didn’t get enough sleep, it’s from the constant battle with my muscles trying to get them do what they are supposed to do.”

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“For me, MS fatigue is not because I didn’t get enough sleep, it’s from the constant battle with my muscles trying to get them do what they are supposed to do.”

“Today is already starting off rough the pain is horrible”

“I keep staying strong, but it is a losing battle”

“For me, MS fatigue is not because I didn’t get enough sleep, it’s from the constant battle with my muscles trying to get them do what they are supposed to do.”
What you’ve seen:
What do you feel in your body?

- Feel frozen and can’t move
- Crawly skin
- Feels like everything is going really fast or really slow
- Heavy feet and hands
- Crying
- Burning feeling
- Ringing in ears
- Fast heartbeat
- Shortness of breath
- Prickly goosebumps
- Shaky and sweaty hands
- Butterflies in tummy
- Feel restless and jumpy
- Like a robot
- Tired
- Want to shout!
- Racing thoughts
- Burning feeling
- Crying
How do you feel emotionally?

Overwhelmed? Hopeless?
Depressed? Anxious?
Exhausted? Resentful?
Angry? Defeated? Rage?
Numb? Helpless? Bitter?
Alone? Misunderstood?
“I’ve said that before…”

“I’ve felt that way…”

“How could this happen to me?”

“I don’t know what to say…”

“They have it worse than me.”

“My situation is worse.”
Self Care?

Today I will live in the moment. Unless the moment is unpleasant, in which case I will eat a cookie.

The best part of yoga class.

The worst part of yoga class.

Gratitude list:

- Delicious food
- Good health
- Warm shelter

Good mood:

- Not starving
- Not sick
- Not homeless

Bad mood:
Stress Response
The VAGUS NERVE
5 Practices

- Deep Breathing
- Meditation
- Pause
- Movement
- Awareness
Deep Breathing

Inhale

Exhale

How you'll get through it

Breathe in breath out

Just focus on the breath
Meditation

MEDITATION
Because punching people in the face is not allowed.
Pause
Movement

SHAKE IT OFF, BABY.
Awareness
THANK YOU!

Questions?

Comments?
Society & Leader Resources
Resources for November Group Meetings

Caregiver Month

Veterans Recognition

Resources for Veterans with Multiple Sclerosis

https://www.multiple-sclerosis.org/veterans

Ask the MS Expert: Military Rehabilitation with MS. What You Should Know

US Air Force Veteran, Early Cop, who shared his story of experierencing symptoms of MS while on active duty and being diagnosed after leaving the service. Copgege-Created 12/22/2020 by the Veterans MS Center of Excellence. Highlights services available to veterans living with MS and how to access resources within the VA system.

The edible Warrior Project is a community with VA and a CRISPR. High-performance athletes, US service members, and veterans share their stories and strategies to keep them as fit as possible. The warriors discuss ways to recover, fight back, and thrive with MS.

News, Blogs, and Podcasts

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including the VA’s Medicare for Veterans with Multiple Sclerosis

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Resources from the VA MS Centers of Excellence

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Featured Resources and Services for Veterans with MS

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VA MS Centers Connect® Blog. Veterans with MS Blog. Home

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Caregiver Group Recognition

Care Partners- North Metro Group (Cedar, MN)- Sandee
Perham Care Partner Group (Perham, MN)- Colleen
Virtual Care Partners Group (CT/NY)- Paul & Patricia
Coping with MS (Bronx, NY)- Patricia
Family Members Group (Carle Place, NY)- Vicki
Caregivers Group (Garden City, NJ)- Lucia
Friends & Family MS Care Giver Group (Arlington, TX)- Teresa
Carepartners Group (Cincinnati, OH)- Susan
Strongsville MS Connection Group (Parma, OH)- Debbie
Virtual MS Care Partners Group (Mansfield, MA)- Wendy
Algonquin Care Partners (Lake in the Hills, IL)- Jan
MS Caregiver Support Group (Seattle, WA)- John
Tacoma Self-Help Group (Tacoma, WA)- Jeff
MS Care Partners (Spokane, WA)- Leslee
Columbia Self-Help & Supportive Partners Group (Columbia, MD)- David & Joanne
Virtual Caregiver Support Group (Washington DC)- Kevin
A place for National MS Society volunteers to interact with other Self-Help Group leaders, MS Friends, and Peer-to-Peer volunteers. This group provides access to valuable resources and offers a safe environment for collaboration and idea-sharing so you can best support your group members and fellow MS community.
In Person Meeting Guidelines

Resources for Meeting in Person

Like the rest of the world, the National MS Society is navigating how best to ramp back up and move through our transition to normalcy. These resources are intended for self-help groups who want to meet in person. By implementing guidelines consistently across the country, we hope to advance Society priorities, increase connection opportunities, and bring groups back together safely.

For questions about bringing your group together in-person or any of the resources listed below, please reach out to your staff partner or peerconnections@nmss.org.

- June 17, 2021 (In-Person Meeting Training & Society Guidelines) call recording and slides
- Volunteer In-Person Meeting Guidelines (PDF)
- FAQ Resource Document (PDF)
- National MS Society Self-Help Group Safety Flyer (PDF)
- Self-Help Group Meeting Disclaimer: IN PERSON (PDF)
- CDC prevention recommendations
- MS and COVID-19
Connect with the National MS Society

facebook.com/nationalMSsociety

instagram.com/MSsociety

twitter.com/MSsociety

youtube.com/nationalMSsociety

linkedin.com/company/national-MS-society
Upcoming Group Leadership Call Dates

Next call: December 16, 2021

Quarterly in 2022:
January 20, April 21, July 21, October 20

2 sessions to pick from:
3pm ET/2pm CT/1pm MT/12pm PT
7pm ET/6pm CT/5pm MT/4pm PT