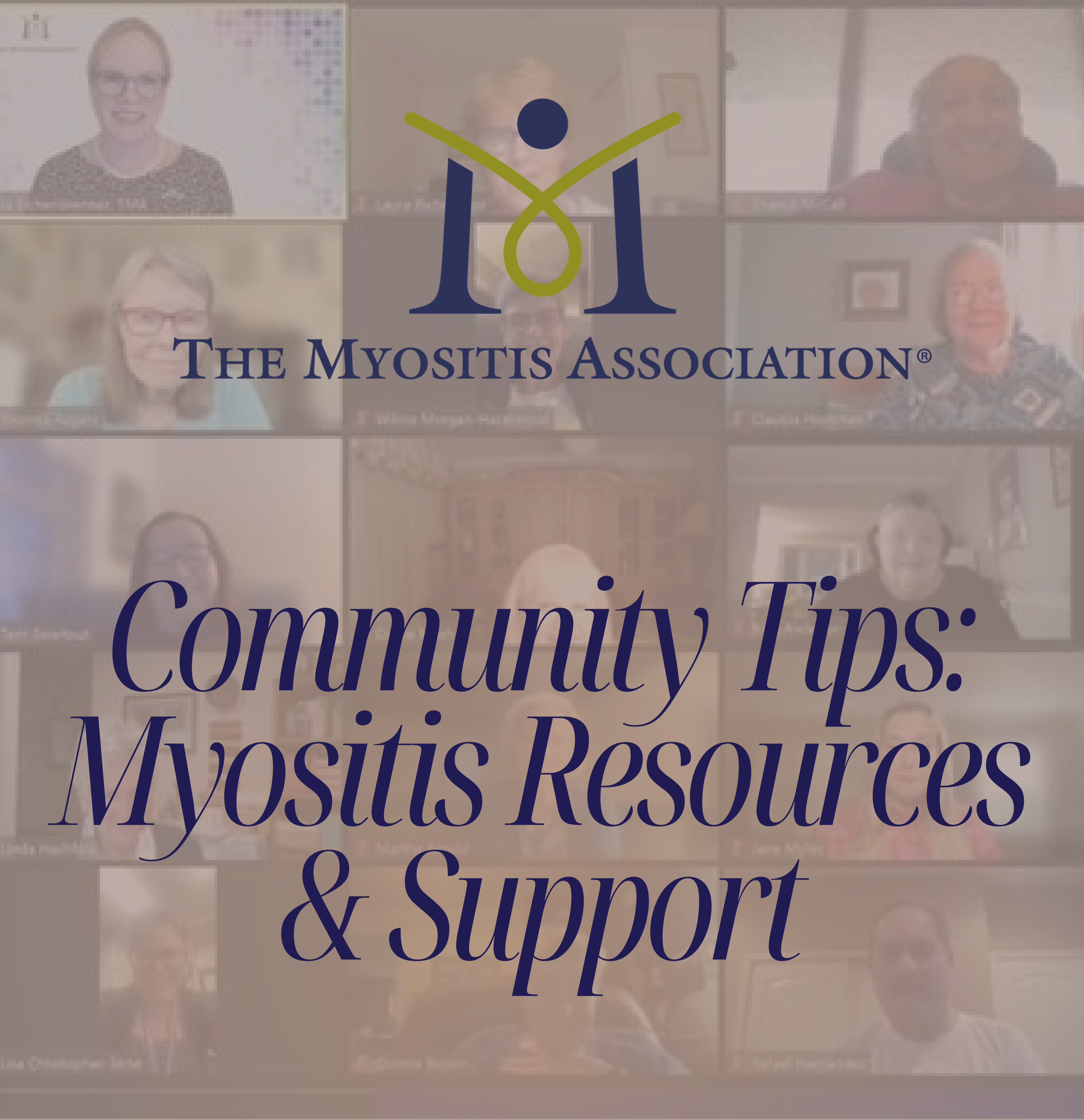

THE MYOSITIS ASSOCIATION®

Community Tips: Myositis Resources & Support

REAL VOICES.
PRACTICAL HELP.
SHARED STRENGTH.

MYOSITIS.ORG

Finding Strength Each Day

The Myositis Association®

Dear Myositis Community,

Each year, The Myositis Association (TMA) invites members to share their lived experience; the challenges, daily wins, and practical wisdom gained along the way. This toolkit collects that wisdom in your own words so that anyone living with myositis, and every Care Partner who walks alongside, can find encouragement and usable ideas. We hope these reflections remind you that you are not alone.

— The Myositis Association

Mission

To improve the lives of persons affected by myositis, fund innovative research, and increase myositis awareness and advocacy.

Introduction

Living with myositis means navigating both the physical and emotional effects of a rare, often invisible illness. The Myositis community reminds us daily that strength is not just in our muscles, it's in our mindset, our relationships, and our willingness to care for ourselves and one another.

This collection of community-shared tips highlights creative ways people manage life with myositis and protect their mental health. Whether it's a reminder to rest, an inspiring quote, or a simple home-life hack, every word here was offered from experience and from the heart.

You're not alone in this journey.
Each small step forward counts,
and together we keep moving.

01

Coping & Emotional Wellness

William H. said, “I've learned so much since my diagnosis:
- It was imperative that I allow myself to process the grief and anger
- I keep immense gratitude for all the support I have received
- being my own best advocate
- how important it is to listen to my body and rest when I need to”

Many living with myositis describe a daily balance between acceptance and perseverance. Healing isn’t linear, but compassion for yourself makes each day lighter.

Community Tips

“I start each day with a positive quote and include meditation mindfulness videos throughout my week as needed. I also strive for7-8 hours of sleep each night.”

“I journal my feelings and life with Myositis.”

“I have learned that setting healthy boundaries in every aspect of my life has been very beneficial!”

“I learned to understand that this sickness comes with a grieving process that occurs everyday. You realize that everyday you need to overcome the loss of your past self and what you "were supposed" to be able to do. This helped me understand that it will be normal to have breakdowns in mental and body health.”

Mindfulness Moments

Mindfulness is simply paying attention—to your breath, your sensations, your surroundings—without judgment. Members shared daily practices that help them stay grounded:

- Enjoy the little things: a book, a good cup of coffee, or a quiet morning.
- Sit for a few minutes and focus on breathing.
- Listen to your body: rest when tired, eat when hungry.
- Step outside—notice the feel of the air and the color of the trees.
- Keep a gratitude journal.

The Myositis Association®

01

Coping & Emotional Wellness

Community Tips

“I have learned to ask for help when needed, even it’s emotional support! I encourage my family to do the same!”

“I ask, do you want to be heard, helped, or hugged?”

“Have a plan for your life but write it in pencil and carry a big eraser. Expect changes.”

“I walk outside as much as possible! Nature nurtures my soul, and requires nothing from me! I get to enjoy nature!!!”

“Always remember that there is no other person in the world like you. So, cherish yourself and give grace to others.”

“Keep looking until you find what you need. Don't be intimidated by a provider who isn't what you need.”

“There are many types of therapists. If you don't like the first one you meet, that's OK. Look for another one.”

“Participating in support groups & the Blog at TMA and the MyoCon have been the most helpful to me. We can really relate to each other. “

Managing Stress

During Stress Awareness Month, community members shared practical strategies to reduce overwhelm:

- Get regular exercise that feels good for your body.
- Sleep enough to let your muscles and mind recover.
- Take time away from screens and constant alerts.
- Connect with friends or family for a break in routine.
- Make a hobby a habit—something creative, playful, or peaceful.

“I prioritize whatever my body and mind need at the moment. I have learned to be still and reflect, and listen to what my body feels that it needs.”

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02

Living Well with Myositis

Fueling Body and Mind

Food can power both mood and muscle. Registered Dietitian Kim Murray offered simple anti-inflammatory nutrition ideas:

- Fruits & Veggies: Berries, leafy greens, broccoli, tomatoes.
- Healthy Fats: Olive oil, avocados, omega-3-rich fish.
- Nuts & Seeds: Walnuts, almonds, chia, flaxseed.
- Whole Grains & Legumes: Brown rice, quinoa, oats, beans.
- Spices & Herbs: Turmeric, ginger, cinnamon, garlic, rosemary.
- Probiotics: Yogurt, Kefir, Kimchi, Sauerkraut, Miso.
- Green Tea: For its natural anti-inflammatory EGCG compound.

Chronic inflammation is a key factor in conditions like myositis, as it keeps the immune system locked in a constant state of attack. Making thoughtful food choices, though, can naturally help reduce inflammation and support your overall health.

Energy and Movement

Other community suggestions include:

- Use adaptive tools—grabbers, shower chairs, walkers—to ease strain.
- Hydrate with electrolytes to reduce cramping.
- Try gentle stretching, water therapy, or resistance bands.
- Apply compression or heat therapy for stiffness.
- Batch-prep meals or tasks on good days.
- Use voice-to-text or smart devices to save energy.

Community Tips

NEVER GIVE UP. WHEN THE DOCTORS DO NOT LISTEN TO ME, I FIND SOMEONE WHO WILL LISTEN.

TAKE ONE DAY AT A TIME AND LEARN AS MUCH AS YOU CAN ABOUT YOUR DISEASES. JOIN SPECIALTY SUBGROUPS [LIKE THE TMA SUPPORT & AFFINITY GROUPS].

MIX DAILY ACTIVITIES TO AVOID BURNOUT WHILE COMPLETING NECESSARY TASK. EXERCISE IS CRUCIAL SO DO WHATEVER NECESSARY TO GET IT DONE & LIKE IT.

[I'VE LEARNED THAT IT'S IMPORTANT TO] SAY NO AND LEARN NOT TO FEEL GUILTY ABOUT IT. YOU HAVE TO CHOOSE YOURSELF.

IT'S OKAY TO REST WHEN NEEDED WITHOUT GUILT.

THE MYOSITIS ASSOCIATION®

02

Living Well with Myositis

Safety and Comfort at Home

People living with myositis offered creative solutions to everyday challenges:

- **Toileting help:** GoGirl device, Lux bidet Neo120, GentleBoost Commode, or LiftSeat system.
- **Pain relief:** Magnesium malate, hand-held massagers, T.E.N.S. units, peppermint oil, ice packs.
- **Sleep & support:** Memory-foam pillows, AlignMed posture supports, compression wear.
- **Fall prevention:** Remove clutter, install grab bars, use non-slip shoes, and practice balance exercises.

Staying Connected & Supporting Others

When living with a rare disease, isolation can creep in quietly. The Myositis community reminds us that connection — with others who truly understand — is one of the strongest forms of medicine.

- Reach out to local or online support groups. TMA's Affinity Groups and **Facebook** communities are a great place to start.
- Share your story — others might need to hear exactly what you've learned.
- Keep friends and family informed; they'll want to help if they know how.
- Stay connected to purpose through volunteering, mentoring, or advocacy.
- Remember: companionship = strength.

02

Living Well with Myositis

Community Tips

"The more you put yourself out there, the more opportunities you have to connect. Being ready is a choice, not a feeling."

"Ask for therapist recommendations and look around until you find the one who makes you feel heard."

"Participating in support groups & the Blog at TMA and MyoCon have been the most helpful to me."

"Do you want to be heard, helped, or hugged?"

"Laughter helps—and really listening to their needs."

"Just listen."

"Provide practical support when you can."

Care Partner Wisdom

Caring for someone with myositis is both an act of love and an emotional marathon. Community care partners shared what helps them stay balanced:

1. Learn about myositis. Knowledge empowers both of you.
2. Prioritize communication. Ask and listen without judgment.
3. Take care of yourself. You can’t pour from an empty cup.
4. Build a support network. Connect with other care partners.
5. Celebrate small wins. Laughter counts as progress.

"Stay engaged in your own interests and reach out, ask for help."

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03

Equipment & Daily Living Aids

Daily Life Support

Myositis community members shared helpful tools and adaptations that make daily tasks more manageable:

- **Mobility and Exercise:** Cubii leg exerciser, byACRE Carbon Ultralight Rollator, Drive Medical 4-Wheel Rollator Walker with Seat, recumbent bikes, and a lift-to-stand chair.
- **Home Modifications:** Spacious, open home layouts, kitchen chairs with arms, large drawers for easy access, and bed rails with storage pouches.
- **Bathroom and Personal Care:** Eosprim Rolling Shower Chair, handrails for the toilet, toilet seat risers, GoGirl device, LiftSeat system.
- **Household Helpers:** Hamilton Beach Electric Jar Opener, elastic hook-and-loop straps for grip, baby pull-up rings for lifting lids.
- **Therapy and Support Tools:** Electronic Muscle Stimulator (EMS), Red Light Therapy devices, ankle-foot orthotics (AFOs), fitness apps, memory foam cushions.
- Everyday Convenience: Crossbody phone wallets, smart devices for hands-free help.

These adaptations are not signs of weakness—they're smart ways to preserve energy, improve safety, and stay independent.

Gratitude & Perspective

Practicing gratitude turns ordinary days into reminders of resilience.
The community suggests:

- Keep a gratitude journal — three small joys per day.
- Thank someone out loud.
- Reframe challenges as lessons.
- Create a nightly gratitude ritual.
- Pause and truly notice something beautiful around you.

04

Hope & Encouragement

Finding Purpose and Joy

Purpose often begins with small sparks — something to look forward to, something that makes you smile.

- Reconnect with activities you love: painting, gardening, music, volunteering.
- Make a “Joy Calendar” — fill it with future events, no matter how small.
- Learn something new just for fun.
- Reach out to friends or neighbors; shared stories lighten the load.

“We cannot change the cards we are dealt, just how we play the hand.” - Randy Pausch

Gentle Reminders

- It’s okay to rest. Healing is work.
- Ask for help without guilt.
- Cry when you need to — and laugh when you can.
- Celebrate progress, not perfection.
- Keep moving in whatever way your body allows.

"After rain, there will be sun - never give up!”

Self-Advocacy & Organization Tips

Keep a medical binder with doctor contacts, test results, surgeries, labs, medications, and summaries of each appointment.

Share the TMA eBook with physical therapists or new doctors to bridge knowledge gaps. Advocate for yourself. Myositis is rare, and your voice is essential to your care team.

“Knowing that you are not alone in your Myositis journey is comforting!”

The Myositis Association®

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Community Tips

"FOR THOSE STRUGGLING WITH MENTAL HEALTH, KNOW THAT YOU ARE NOT ALONE AND DO NOT HAVE TO SUFFER IN SILENCE."

"THERE IS LIGHT AT THE END OF THE TUNNEL."

THE JOURNEY MAY SEEM NEVERENDING BUT [YOU CAN] FIGHT THE PROBLEMS OF TODAY WITH THE STRENGTH OF TODAY. TOMMORROW WILL BRING ITS OWN STRENGTH.

"HANG IN THERE AND WORK THROUGH EACH DAY AS IT COMES. DON'T DWELL ON THE PAST OR WORRY ABOUT THE FUTURE."

"NEVER GIVE UP. I WAITED 15-20 YEARS FOR A DIAGNOSIS."

"LIVE LIFE TO THE FULLEST YOU CAN."

"LIVE LIFE!!!"

"TAKE CARE AND STAY POSITIVE."

"YOU ARE SO MUCH MORE THAN A PERSON WITH A DEBILITATING DISEASE, SO DON'T LET IT DEFINE YOU."

"YOU'RE NOT ALONE."

"TRY NOT TO LET IT DEFINE YOU."

I GIVE MYSELF GRACE. IT'S A JOURNEY, NOT A RACE. MENTAL HEALTH IS A PILLAR IN YOUR LIFESTYLE, JUST LIKE PHYSICAL, EMOTIONAL, AND SPIRITUAL HEALTH. YOU MUST ADDRESS IT, MAKE ANY NECESSARY ADJUSTMENTS, AND REASSURE YOURSELF THAT EVERYTHING WILL BE OKAY.

05

Trusted Resources

Education & Empowerment

Myositis 101 - Video Series
Dr. Rohit Aggarwal explains myositis management and treatment in clear terms.
https://www.myositis.org/myositis-101-for-patients/

Myositis 101 - Free E-Book
Basic guide to diagnosis, treatment, and daily living. A great tool to share with clinicians.
https://www.myositis.org/myositis-library/tma-publications/

60 Seconds to Impact
Storytelling empowerment clinic by journalist Lindsay Guentzel.
https://youtu.be/kzJup2VDYeI

Rare Disease Day YouTube Playlist
Expert insights and patient stories from TMA.
https://youtube.com/playlist?list=PLC7vBNLVigcAe4JA2tuDgBM9eQT28o7z

Myositis Resources for Rare Disease Day
Toolkit of tips and resouces from Rare Disease Day 2025
https://www.myositis.org/wp-content/uploads/2025/02/Living-with-Myositis_-Community-Tips-Trusted-Resources-for-Rare-Disease-Day-1.pdf

Navigating Health & Life

NAMI Helpline
1-800-950-6264 | https://nami.org/help

Mental Health America
https://mhanational.org

988 Suicide & Crisis Lifeline
Call or text 988 anytime.

TMA Support Groups & Affinity Circles
https://www.myositis.org

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Top Blogs in 2025

Bartlett Challenges TMA to Give Power to Its Purpose
Protect Yourself This Flu Season
Pushing for an Answer
Patient Stories
How to qualify for Social Security Disability benefits with myositis
Immune-boosting supplements can make autoimmunity worse
CAR T-cell therapy: A viable option for myositis treatment?
Dermatomyositis: Not my whole life
Celebrating World Myositis Day: Myositis Africa
Patient-reported quality of life study results
Patients make a difference in myositis research
Changing the landscape of antisynthetase syndrome and ILD forever
Using food to help your body heal
Remembering Nori
Rare Disease Advocacy During Rare Disease Week 2025
New Study Reveals Impact of Inclusion Body Myositis on US Veterans
TMA's 2025 Patient Ambassador Awardee
Poor Sleep May Make Mobility Worse
MyoCon: We Are Not Alone
Poor sleep may make mobility worse
TMA's top 10 travel tips for 2025
Seeing the other side: On being a clinical trial participant
MyoCon 2025: Melissa's List
Rare disease research depends on you
Living in the Present
Unshakeable optimism
My medical binder
A tribute to Marianne Moyer
CAR T: A promising new frontier for myositis treatment
Rare diseases need more research, not less
TMA board vice chair testifies in support of Georgia's Hope for Patients Act
Finding strength in the shadows
How to qualify for Social Security Disability benefits with a rare disease
Turning Grief into Purpose
Finding the Good
Digital Vacation
TMA year in review: Reader favorites from the blog
A treatment that's almost too good to be true
Tips for thinking about joining clinical trials

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Notes

Thank You

Thank you to every member of the myositis community who shared their voices, tips, and experiences. Your words make this journey less lonely and more hopeful for everyone who reads them. Together, we remind the world that living with myositis means living with courage, curiosity, and grace.

Connect with TMA

TMA Support Groups & Affinity Circles
https://www.myositis.org

TMA Event Calendar
https://www.myositis.org/events/

TMA Blog
https://www.myositis.org/blog/

Facebook
https://www.facebook.com/

Instagram @themyositisassociation
https://www.instagram.com/themyositisassociation/

LinkedIn
https://www.linkedin.com/company/the-myositis-association/

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