

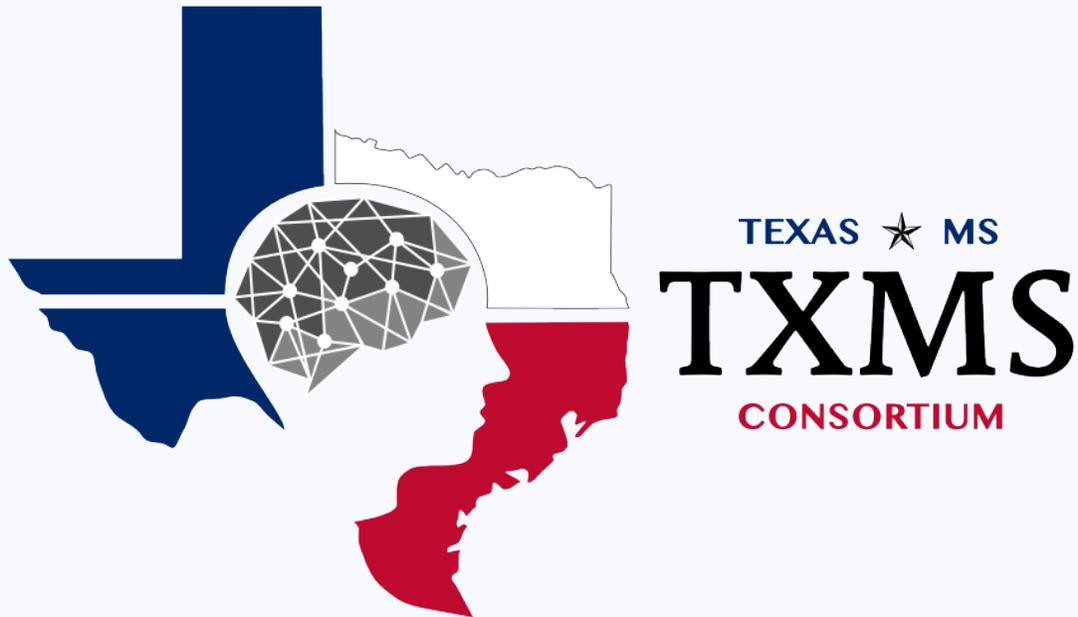
Building a Healthcare Team You Can Trust

From Diagnosis to Daily Life

CAN DO
MULTIPLE SCLEROSIS

WEBINAR 
WEDNESDAYS

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 **NOVARTIS**

UPCOMING PROGRAMS

Thursday, August 7

CARE PARTNER MEETUP

Defining Help: Finding Common Ground

Tuesday, August 12

SPECIAL WEBINAR

Hormonal Health and MS:

A Guide for Both Men and Women

Wednesday, August 13

WEBINAR

Addressing MS Discomfort from
Numbness to Pain

Tuesday, August 19

NEWLY DIAGNOSED MEETUP

Daily Life with MS



CANDO-MS.ORG

How to Ask Questions During the Webinar

Type in your questions
using the Questions Box



Provide comments and engage
with the speakers and audience
using the **Chat Box**

NEW! Closed captioning

YOUR SPEAKERS



Katherine Rivas, MD
Neurologist

Lubbock, TX



Maggie Rodriguez, NP
Nurse Practitioner

McAllen, TX

A Team and Treatment Plan that Works for You



Building Your Medical Team

- Who do you need on your team to help support your needs and goals?

The Basics of MS Medications and Treatments

- Understanding how your needs influence treatment decisions

Shared Decision Making

- How should you communicate this to your care team? What is important to you? What are your goals?

Advocating For Yourself

Evaluating & Finding Trustworthy Resources

POLLING QUESTION

What medical team members have you seen?

- a) **Neurology** (Physician, Nurse Practitioner, or Physicians Assistant)
- b) **Primary Care Provider**
- c) **Mental Health** – Psychologist, Social Worker, Therapist, Coach
- d) **Rehab Medicine** – Physical Therapy, Occupational Therapy, Psychiatrist
- e) **Cognition** – Speech Pathology, Neuropsychologist
- f) **Other Specialist** – Urology, GI, Dietician, Pharmacist, Integrative Medicine, etc.
- g) **Someone else** – write it in the chat!

Core Members of the MS Care Team



Neurologist

- Primary specialist for diagnosis & disease modification
- Diagnosis
- DMT Management
- Monitoring & Relapse Management



Advance Practice Providers

- PA's and NP's provide direct clinical management
- Symptom control and medication management



Ophthalmologist

- Manages visual complications
- Optic neuritis diagnosis and treatment
- Visual rehabilitation coordination



Pharmacist

- Optimizes medication regimens and safety
- DMT adherence support
- Regimen optimization
- Adverse event management

Building Your MS Medical Team



Why Do We Need To Treat MS?

- MS can lead to disability
- Once lesions occur, we don't have a good way to repair myelin
- Prevention is key!

- Disease modifying therapies reduce the number of new and active lesions and may decrease progression as well as reduce the frequency and severity of relapses.

Disease Treatment & Management

Two Buckets:

- **Disease Modifying Therapies (DMTs)** – aim to control the disease
- **Symptom Management** – help to improve or manage symptoms

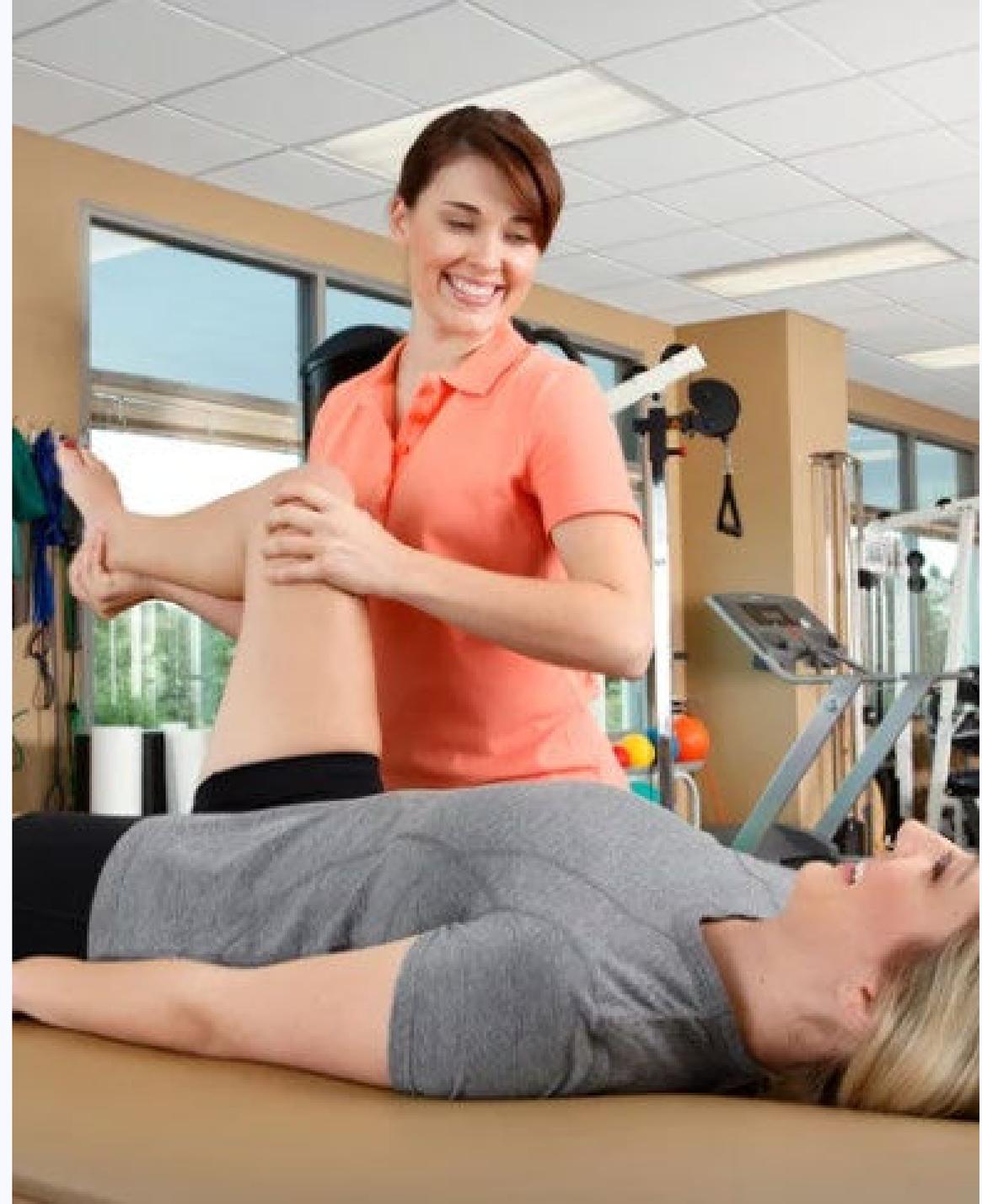
DMT Considerations:

- How they work (mechanism of action)
- How you take the medicine (route of administration)
- High efficacy vs. Low efficacy
- Side effects

Disease Treatment & Management

Symptom Management

- Medication / Devices:
 - Mobility/walking
 - Mood/pseudobulbar affect
 - Bladder/bowel
 - Fatigue/sleep
 - Cognition changes
 - Muscle pain/nerve pain
 - Vertigo/migraines
 - Heat intolerance



Best Practices for MS Care



The optimal MS care team is **multidisciplinary, integrated, and patient-centered.**

- Integrated Care Models
- Shared Decision Making
- Addressing Access Barriers

Shared Decision Making



A process that brings together:

The clinician's expertise and experience with potential treatments including

- Options
- Research
- Risks
- And Benefits

with the patient's preferences, personal circumstances, goals, values, and beliefs...to choose the best course of action for their individual situation.

Your Individual Needs, Goals, and Values are Key!



Low risk & minimal side effects



Weighing the benefits: risk profile of highly effective medication



Family Planning



Lifestyle modifications or non-pharmacologic interventions



How treatment fits into your daily life



A holistic approach that includes complimentary and alternative medications

Examples of Shared Decision Making

- Sharing your goals for the medical visit with your doctor:
 - I would like my questions answered before I leave
 - I do not want to feel rushed
- Knowing what type of medication works for your life – example: how medication is administered
- Feeling confident to speak up when you don't agree with the treatment plan



Why Self Advocacy Matters

Effective self-advocacy empowers you to:

- Access appropriate treatments and support services
- Maintain control over your healthcare decisions
- Improve your overall quality of life



Key Self-Advocacy Strategies

Educate Yourself

- Become an expert on your condition, treatment options, and latest research developments
- Utilize resources from advocacy organizations
- Track symptoms with specialized apps and journals
- Join education programs and conferences

Communicate Effectively

- Develop skills to clearly express your needs with healthcare providers
- Prepare questions and symptom lists before appointments
- Use “I” statements to describe your experiences
- Seek second opinions or MS specialists when needed

Know Your Rights

- Understand the legal protections available to you
- ADA protections against workplace discrimination
- Reasonable accommodation requirements
- SSDI benefits eligibility if MS impacts your ability to work

Building Your Support Network

Support Groups

- Connect with others who understand your journey through support groups and programs. These provide emotional support and practical advice from those with lived experience

Family and Friends

- Educate your loved ones about MS so they can advocate alongside you. Clear communication about your needs helps them provide appropriate support without overstepping.

Professional Advocates

- Patient advocates, social workers, and case managers can help navigate complex healthcare and insurance systems when you need additional support.

Financial & Insurance Advocacy



Insurance Strategies

- Appeal insurance denials with documentation from your healthcare team
- Understand ACA protections for pre-existing conditions
- Review policies annually to ensure appropriate coverage

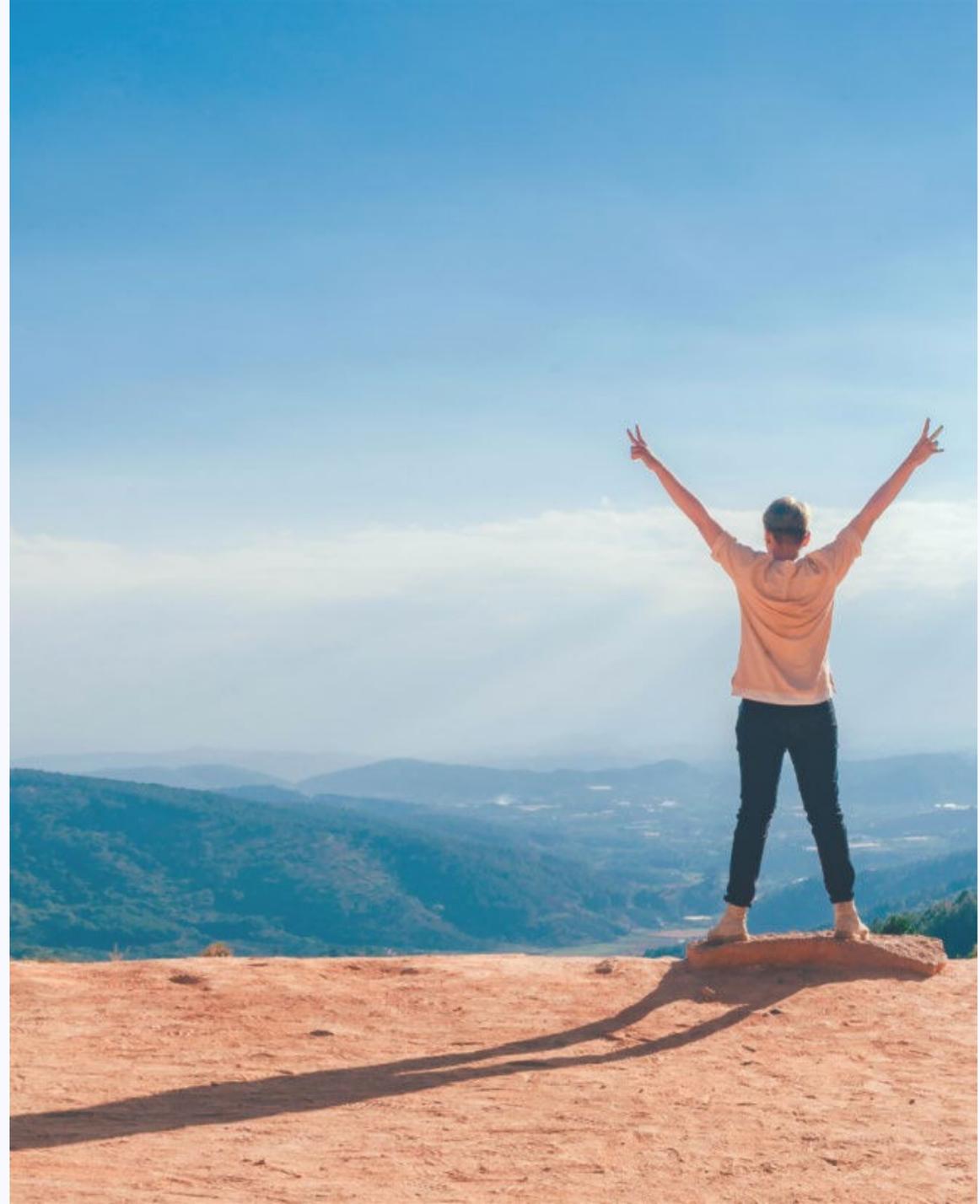
Financial Resources

- Explore pharmaceutical copay assistance programs
- Investigate MS-specific financial aid foundations
- Consider consulting with a financial advisor who specializes in chronic conditions



Remember:

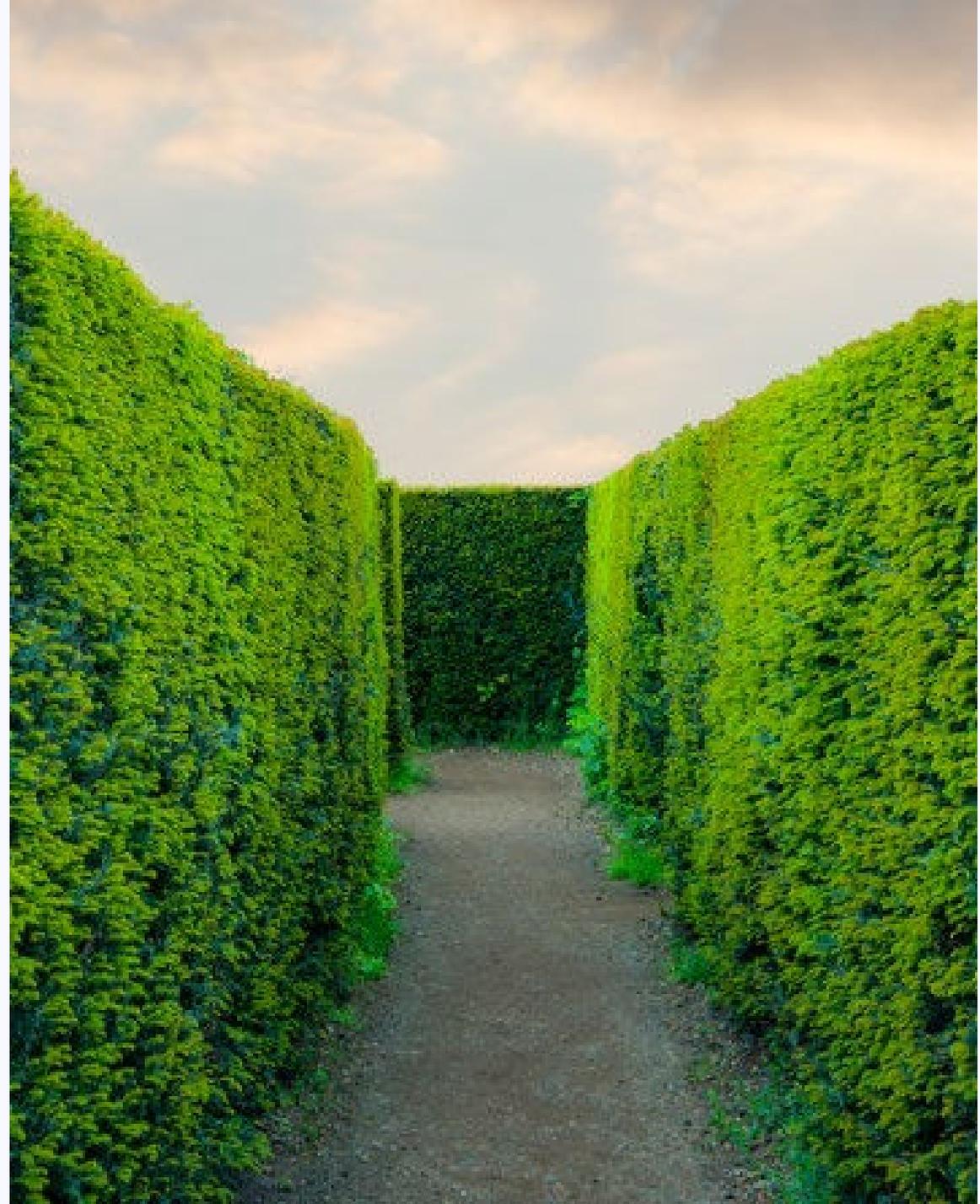
Self-advocacy is an ongoing journey. Be patient with yourself, celebrate small victories, and remember that you are your most important advocate. The orange MS awareness ribbon symbolizes hope and the fight for better treatments and support.



Evaluating & Finding Trustworthy Resources

Navigating the information maze with confidence can be challenging when living with multiple sclerosis.

Why is it important to trust resources in MS information?



Identifying Trustworthy MS Resources

Credible Organizations

Look for information from established medical institutions, MS societies, universities, and government health agencies like the NIH or CDC.

These organizations have rigorous review processes and provide evidence-based information.

Up-to-date Content

MS research evolves rapidly. Check publication or "last updated" dates—information older than 2-3 years may no longer reflect current best practices.

Clear Authorship

Trustworthy sources clearly identify authors and their credentials. Medical professionals with MS expertise or researchers with relevant qualifications should be creating the content.

Citations & References

Quality resources cite their sources and link to peer-reviewed studies, allowing you to verify claims and dig deeper if needed.

Red Flags & Signs of Unreliable Resources



Miracle cures or guarantees

- Claims of revolutionary breakthroughs or treatments that sound too good to be true

Missing author information

- Anonymous content or vague attribution like “staff writer” may indicate lack of expertise

Primarily product focused

- Content that pushes products rather than education often has commercial rather than health interests at heart

Smart Search Strategies



- Use specific search terms: "MS fatigue management techniques" instead of "MS help"
- Add site filters in search engines: "site:.edu" or "site:.gov" for academic or government resources
- Include "evidence-based" or "clinical trial" in your search terms
- Create a folder of bookmarked trusted websites for quick reference
- Check multiple sources to verify information

Trusted Resources & Professional Guidance



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MS A-Z | Exercise | Prog

Can Do helps families with MS thrive

Our free programs and resources help people living with multiple sclerosis and their care partners make each day the best it can be. Learn how MS can impact your life, find motivation and personalized guidance to overcome challenges, and build a positive support network.

A large amount of new information can be overwhelming. Try starting here if you're unsure.

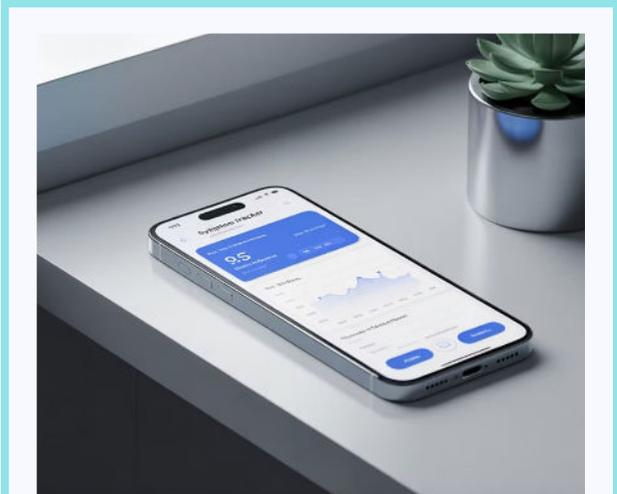
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