
Managing Fatigue

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Objectives

- Provide a brief overview of what we know about MS fatigue
- Outline the common approaches to managing fatigue
- Discuss research on energy management education, a non-pharmacological approach to managing fatigue
- Share a few energy management tips

What is Fatigue?

- “a subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with usual and desired activities” MS Council (1998)
- Described several ways:
 - As physical or cognitive
 - By severity and frequency
 - Based on impact on daily life

Descriptions of fatigue from people with MS

- “debilitating, frustrating, scary” “invisible” “overwhelming” “relentless”
- “Constant tiredness. I wake up tired, I go to bed tired. I’m tired all of the time”
- “I can’t wrap my head around complex topics; it’s mysterious, it’s a time waster”
- “Heaviness, like walking in cement”
- “Like hitting a brick wall”

What do we know about fatigue?

- Fatigue is one of the most common symptoms of MS
 - Up to 90% of people with MS experience it
 - In comparison, 20-25% of the general population indicate that they are “always tired”
 - As many as 50% of people with MS describe it as their worst symptom
 - Influences all aspects of life
 - Self-care, family activities, leisure and social, work

Impact on everyday life

- “I’ve given up golfing. I loved to golf and walk the holes. Using a cart just isn’t the same. I just gave it up.”
 - (George, 45, self-employed)
- “I go out less after work now, my social network is smaller. I’m cautious about who I go out with too – some people don’t understand”
 - (Marjorie, 40, a lawyer)
- “I used to love shopping and wandering around. Now I just go for exactly what I need. Nothing else.”
 - (Nancy, 55, retired)

What do we know about fatigue?

- Different than “normal” fatigue
 - Takes longer to recover
 - Comes on quickly
 - Not always related to activity, and therefore difficult to predict
 - Has both physical and cognitive aspects
 - Tends to worsen in high temperatures
 - Is chronic (lasts more than 6 weeks)

What do we know about fatigue?

- Can make other MS symptoms worse
- Only weakly related to level of disability and disease course
- Not related to:
 - age,
 - gender, or
 - length of time with the disease

Types of Fatigue

- Primary fatigue
 - Due to the disease itself
- Exact mechanism unclear. Current ideas:
 - Damage & inflammation in the nervous system may mean that more energy is needed to perform activities
 - Number of lesions may influence brain function and body's response to activity

Types of Fatigue

- Secondary fatigue
 - Not a direct result of the disease process
- Key contributors to secondary fatigue
 - Sleep problems (3x more common in MS)
 - Medication side-effects
 - Physical deconditioning
 - Temperature
 - Other health issues

Steps to Manage Fatigue

- Acknowledge the impact of fatigue and importance of addressing it
- Recognize and address the other factors that may contribute to fatigue in your life
- Learn about and apply energy management strategies
- Consider asking your doctor about medication options

Acknowledge the Impact

- Fatigue is important
 - Leads to focus on obligatory tasks
 - Can lead to decreases in participation in leisure and social activities
 - Can contribute to difficulties performing tasks
 - Potential safety issues
 - May initiate an emotional roller coaster, feelings of anger and hopelessness
- Fatigue is not okay – it can be addressed

Other Factors: Sleep

- Establish good sleeping habits:
 - Have regular times to go to bed and to get up
 - Ensure that your sleeping environment is dark, quiet, cool and comfortable
 - Have a wind-down routine for bedtime
 - Avoid caffeinated drinks later in the day
 - Avoid hard/intense exercise late in the evening



Other Factors: Medications

- Many medications have fatigue as a side-effect
 - Learn about your medications
 - Ask your doctor or pharmacist
 - Make sure that you tell your doctor about the medications you are taking so potential interactions and side-effects can be considered
 - Including over-the-counter and natural products



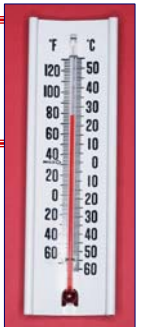
Other Factors: Physical Deconditioning

- Physical deconditioning can start a negative spiral
 - Tired, so less active – leads to more tired
- Talk to doctor about activity restrictions
- Ask for referral to a physical therapist who is knowledgeable about MS
- Start slow, and build up over time



Other: Temperature

- Avoid being out in high temperatures
- Avoid becoming overheated
 - Important when exercising
- Consider use of a cooling vest
 - Some evidence in the research that cooling vests can reduce fatigue
- Consider air conditioning in home and car



Other: Health Issues

- Other health issues can contribute to fatigue:

- Pain
- Depression
- Thyroid changes
- Heart or respiratory problems
- Poor diet



- Talk to doctor: Not all fatigue is MS
- Rule out or treat other causes

Energy Management

- A set of strategies focused on making the most use of the energy you have
 - Activity modifications
 - Strategic use of rest
 - Planning ahead
 - Using assistive technologies
 - Proper body mechanics
- Typically taught by occupational therapists, individually or in groups

Research on Energy Management

- Since the late 1990's, series of MS studies to determine if energy management education:
 - Reduces impact of fatigue on everyday life
 - Reduces severity of fatigue experienced
 - Improves quality of life
 - Improves confidence in ability to manage MS fatigue

Randomized Control Trial

- Funded by the NMSS (2002 & 2005)
- Tested an energy management education program
- Total of 169 participants
 - Average age = 48 years
 - Average of 10 years since diagnosis
 - 49% still working
 - 62% had relapsing remitting MS
 - Mild to moderate MS disability

Educational Course

- 6 weeks long, 2 hours per week
- Groups of 5 to 10 people with MS
- Lead by an occupational therapist
- Sessions included:
 - Teaching/lecture
 - Discussion and sharing strategies
 - Opportunities to practice new skills
- Homework to apply ideas

Evaluation of the Program

- Measured participants before and after the course, and then 6 months and 1 year later:
 - Fatigue impact and severity reduced
 - Quality of life improved
 - More confident about managing fatigue
- Most improvements maintained for one year
 - Some areas actually continued to improve over time
- Course was better than doing nothing (control)

Other Related Studies

- Self-study modules
 - Effective, but not as effective as group format
- Teleconference education
 - Pilot study supported effectiveness
 - Currently in a randomized trial
 - Results are promising

Energy Management: Tips to Take Home

Tip #1: Make Active Choices

- Remember: Energy is a resource.
 - Think about how you want to use yours
 - Analogy: banking and budgeting
- Make active choices
 - What activities are really important for you to do?
 - What activities give your life meaning and purpose?
 - Are you spending your energy on these important, meaningful activities?
- Use these answers to:
 - Set activity priorities, delegate, ask for help

Reflections from People with MS

- “When I sit down and prioritize and break things down into smaller steps, it is easier to manage. I learned that I have to stop trying to do everything at once.”
 - John, 42, relapsing/remitting MS
- “I must budget my energy so I can do important things. It helps to think this way.”
 - Margaret, 51, secondary progressive MS

Tip #2: Devices & Organization

- Devices and organization help to:
 - Simplify tasks & reduce energy use
 - Reduce number of steps in a task
 - Use your energy efficiently
- Examples of devices
 - Kitchen gadgets, power tools, cane, grab-bars
- Getting organized puts items in easy and efficient reach



Reflections from people with MS

- “I bought a little wheeled cart to move the laundry. It’s so much better now. I should have done this a long time ago”
 - Christine, 40 years, relapsing/remitting MS
- “I moved things around in my bathroom so the things I use everyday are on a convenient shelf. It’s so common sense, I’m not sure why I didn’t think of this before. It made real difference.”
 - Don, 52 years, progressive MS

Tip #3: Strategic Use of Rest

- Rest allows your body to recuperate
 - Also offers “back-up” energy for the times when you need it most
 - Many different forms of rest
- Rules for resting:
 - Rest before you are tired
 - Plan your rests, making them a habit
 - Alternate work and rest
 - Pace yourself



Reflections from People with MS

- “I had always felt guilty or like I was being lazy when I stopped to take a rest, but I realized it was a good thing. It’s not being lazy.”
 - Mike, 58 years, Relapsing/Remitting MS
- “Even though my life is a little hectic, the idea of planning days and scheduling rest periods is helpful.”
 - Maria, 38 years, type of MS unknown

Summary

- Fatigue is common and can be severe
 - Doesn’t mean that you shouldn’t address it
- Many factors contribute to fatigue
 - Not all of them are MS-related
- There are strategies to manage fatigue that have been shown to be effective
- Managing fatigue involves many components
 - Request referrals to obtain skilled input