



MS Fatigue Management

Hosted by

BC & Yukon Division

Thursday, November 3, 2016

6:00-7:30 pm (PST)





The MS Society, BC & Yukon Division gratefully acknowledges the educational grant received from Biogen which makes possible the **MS Fatigue Management** session. The MS Society does not approve, endorse or recommend any specific product or therapy but provides information to assist individuals in making their own decisions.

Identification of needs, determination of objectives, selection of content and speakers, educational methods and materials are the sole responsibility of MS Society staff and advisors.





MS Society of Canada

- **Mission Statement:** To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.



DENISE KENDRICK

- A Graduate of the Master of Occupational Therapy program from the Department of Occupational Science & Occupational Therapy at UBC.
- Began her career working in acute care and took on roles throughout this time to support the practice of other Occupational Therapists. This is where she developed her interest in teaching and program development and strived to provide improved Occupational Therapy services.
- Took on the role of developing student-led Occupational Therapy services in the UBC MS Clinic in 2014 and saw this as an opportunity to deliver evidence-based programs to address the impact of common symptoms of MS on daily function.
- Denise and her students build their programs upon the principles of self-efficacy to provide clients with the tools and strategies needed to effectively self-manage. Presently, programs to address fatigue, hand function, tremor and cognitive impairment are in development to minimize the impact these symptoms have on clients' daily function.
- Considers herself lucky to have the opportunity to learn something new from her clients every day.



Managing your fatigue

Denise Kendrick

Occupational Therapist

UBC MS/NMO Clinic, Vancouver





Outline

- ▶ What is fatigue?
 - Definition
 - Fatigue facts
 - Types of fatigue
- ▶ Your fatigue management team
- ▶ Assessment of fatigue
- ▶ Managing fatigue
 - Maximizing energy
 - Using energy conservation
- ▶ Questions



What is fatigue?

“ A subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with usual or desired activities.” *



How people describe their fatigue:

“It reminds me of falling into quicksand/a swamp - it’s a viscous, heavy, pulling feeling, but if I try to fight it, it hurts like hell and robs me of breath.”

“Fatigue feels like being weighed down, as if you are trying to walk up to your neck in a deep, muddy river in heavy, wet clothes carrying shopping bags full of rocks.”

“Fatigue leaves me feeling dulled and tired. I find it hard to concentrate and to absorb new ideas, and I’m often confused, searching for the right word, and forgetting things.”

Quotes taken from the MS Trust book [Living with fatigue](#)



Fatigue Facts

- ▶ 75-95% of people with MS experience fatigue
- ▶ 50-60% report fatigue as one of their worst problems
- ▶ Fatigue affects people differently
- ▶ Fatigue severity unrelated to disease process (e.g. lesion burden, EDSS)
- ▶ Fatigue may worsen other symptoms



Fatigue Facts

- ▶ a major reason for unemployment
- ▶ usually multifactorial
- ▶ out of proportion to the activity
- ▶ an “invisible” symptom
- ▶ changing and can fluctuate



Your Fatigue Team

- ▶ Neurologist
- ▶ Family physician
- ▶ Nurse
- ▶ Occupational Therapist
- ▶ Physiotherapist
- ▶ Social Worker
- ▶ Support network (i.e. family and friends)
- ▶ Employer



Fatigue Assessment

- ▶ Description of fatigue
 - Consider using a tracking tool
- ▶ Measures: CFAB-MS, MFIS, FSS, mobility screen, sleep questionnaire, mood screen
- ▶ Identify
 - Other medical conditions
 - Medications
 - Sleep, depression
 - Mobility



Sample Tracking Tool

6:00-7:00	4	Woke up, ate breakfast	Home	Alone
7:00-8:00				
8:00-9:00				
9:00-10:00				
10:00-11:00				
11:00-12:00				
12:00—1:00				
1:00-2:00				
2:00-3:00...				



Treating Fatigue

Two-pronged approach =

1. Maximizing energy
2. Using energy efficiently (energy conservation)

National Institute for Health and Care Excellence (NICE) Guideline for the Management of MS fatigue (2014) :

- ✓ Assess and treat anxiety, depression, difficulty sleeping and any medical problem (i.e. anemia or thyroid disease)
- ✓ Offer amantadine
- ✓ Consider mindfulness-based training, cognitive behavioural therapy or fatigue management
- ✓ Advise people that aerobic, balance and stretching including yoga may be helpful



Types of Fatigue

- ▶ Acute vs chronic fatigue
- ▶ Primary vs secondary fatigue
- ▶ Physical, cognitive and emotional fatigue



Acute vs Chronic Fatigue

- ▶ Acute fatigue = new or noticeably worse fatigue, in the last 6 weeks
- ▶ Chronic fatigue = lasts for longer than 6 weeks, more than 50% of days, during some part of the day



Primary vs Secondary Fatigue

- ▶ Primary (MS-related) fatigue = due to the disease process itself, diagnosis of elimination
- ▶ Secondary (non-MS related) fatigue = fatigue arising from secondary factors:
 - Poor sleep
 - Mobility problems
 - Depression and anxiety
 - Stress
 - Inadequate nutrition
 - Lack of physical activity
 - Heat
 - Medications



Prevalence Factors Contributing to Fatigue

	<u>n (%)</u> ¹	<u>n (%)</u> ²
Non-MS fatigue-ACUTE	4 (8%) -	
Non-MS fatigue-CHRONIC	36 (72%)	945 (74%)
◦ Sleep problems	29 (58%)	313 (25%)
◦ Depression	20 (40%)	567 (44%)
◦ Medications	10 (20%)	105 (8%)
◦ Deconditioning	10 (20%) -	
◦ Significant chronic stressors	3 (6%)	255 (20%)
◦ Concomitant medical problems	2 (4%)	181 (14%)
Secondary MS fatigue	26 (52%)	282 (22%)
◦ Unmanaged mobility impairment	26 (52%)	282 (22%)
◦ Respiratory problems	2 (4%) -	
Primary MS fatigue	14 (28%)	335 (26%)

Forwell et al (2008)¹; Stewart et al (2007)²



Types of MS-related Fatigue

1. Physical/motor fatigue – central vs peripheral neuromuscular fatigue from ‘short-circuiting’ in nerve messages to muscles
2. Cognitive fatigue –ability to think becomes difficult as cognitively demanding tasks progress; “brain fog”
3. Emotional fatigue – can manifest as frustration, decreased motivation, loss of pleasure



Maximizing Energy - Treating Secondary Factors

- ▶ Initial treatment of fatigue involves treating:
 - Poor sleep
 - Low mood, depression or anxiety
 - Inadequate nutrition
 - Lack of physical activity
 - Heat
 - Pain
 - Medications



Sleep Issues in MS

- ▶ Restless leg syndrome
 - ▶ Sleep disordered breathing
 - ▶ Insomnia due to:
 - Pain
 - Spasticity
 - Depression
 - Anxiety
 - Nocturia
 - Medication effects
- ** address these with your MS nurse or physician



Managing Sleep

- ▶ Keep regular sleep hours
- ▶ Avoid being over-tired
- ▶ Avoid activities other than sleep and intimacy in the bedroom
- ▶ Stay active, but avoid exercise in evening
- ▶ Prior to bed, avoid:
 - × Stimulants (caffeine and nicotine)
 - × Excessive alcohol
 - × Large meals
 - × Mentally taxing activities
 - × Computer/smartphone
- ▶ Develop a bedtime routine, take a bath, read etc.
- ▶ Reduce noise and light in bedroom
- ▶ Use relaxation exercises



Making the Most of a Nap

- ▶ Naps are helpful only if they don't interfere with nighttime sleep
- ▶ **Where:** a sofa, recliner, a bed
- ▶ **How often:** one to three times per day
- ▶ **How long:** 10–30 minutes
- ▶ ***HELPFUL HINTS:***
 - Loosen tight clothes
 - Turn TV and music off
 - Dim the lights
 - Close curtains or blinds



Sleep Resources

National Sleep Foundation

www.sleepfoundation.org

Canadian Sleep Society

www.css-scs.ca



Mood

- ▶ Low mood or depression can increase fatigue
- ▶ Up to 54% of people with MS experience depression
- ▶ Depression can be a symptom of MS, or a reaction to an illness
- ▶ When depression is treated, fatigue decreases by 50%
- ▶ Seek help from your family physician to address your mood
- ▶ To address low mood:
 - Exercise regularly
 - Spend time with positive people
 - Address your worries as they arise
 - Seek support from family/friend or professional



Nutrition

- ▶ Avoid sugary foods
- ▶ Add protein
- ▶ Never go longer than 4 hours without food
- ▶ Shrink meals to eat more often; avoid large portions
- ▶ Avoid too much caffeine
- ▶ Stay hydrated



Nutrition Resources

- National MS Society Food for Thought
- MS Society Healthy Eating: A Guide for People with MS
- Canada's Food Guide
- Ontario 1-877-510-5102
- British Columbia 8-1-1
- Manitoba 1-877-830-2892



Food Preparation Tips

- ✓ Organize the kitchen so things are within reach
- ✓ Keep kitchen cool
- ✓ Cook when energy is high
- ✓ Sit rather than stand
- ✓ Get all ingredients together before starting
- ✓ Use appliances such as mixers
- ✓ Use ready prepared foods
- ✓ Keep heavy items in fridge within easy reach
- ✓ Soak dishes to avoid scrubbing



Benefits of Exercise

- ▶ No single “right exercise”
- ▶ Improves daily activity performance
- ▶ Improves mood, self-esteem and self-efficacy
- ▶ Ignore “no pain, no gain”
- ▶ Manage heat
- ▶ Pace yourself
- ▶ Use everyday activities as exercise
- ▶ Ask about discount at community centres
- ▶ Research for:
 - Vestibular training
 - Treadmill training
 - Elliptical exercise



Canadian Physical Activity Guidelines

FOR ADULTS WITH MULTIPLE SCLEROSIS

Guidelines

To achieve important fitness benefits, adults aged 18-64 years with multiple sclerosis who have mild to moderate disability need at least:



- 30 minutes of moderate intensity aerobic activity, 2 times per week, AND



- Strength training exercises for major muscle groups, 2 times per week.



Meeting these guidelines may also reduce fatigue, improve mobility and enhance elements of health-related quality of life.

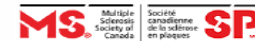
Who are the Guidelines for?

- These guidelines are appropriate for adults (aged 18-64 years) with minimal to moderate disability resulting from either relapsing remitting or progressive forms of multiple sclerosis

Getting Started

- You may wish to speak to a health professional to find out what types and amounts of physical activity are appropriate for you.
- A health professional might include a doctor, a physiotherapist, or a qualified exercise professional.
- If you are physically inactive, activities performed at a lower intensity, frequency, and duration than recommended may bring some benefit.
- Gradually increase duration, frequency, and intensity as a progression towards meeting the guidelines.

Now is the time. Walk, run, or wheel, and embrace life.





Exercise Resources

- MS GetFit Toolkit: MS Society of Canada
- Exercises for people with MS: MS Trust





Mobility

- ▶ Use of gait aids, such as bilateral walking poles reduce energy needed to walk
- ▶ Physiotherapists assess whether inefficient mobility is contributing to fatigue and recommend appropriate gait aids
- ▶ Consider using a parking permit for persons with disabilities



Managing Heat

- ▶ Hot showers, weather, drinks or meals can trigger fatigue
- ▶ Keep core body temperature from rising by:
 - ✓ Drinking cool liquids and stay hydrated
 - ✓ Avoiding outdoor exercise in hot climate
 - ✓ Using cooling equipment





Pain

- As high as 65% of people with MS experience pain
- Pain interferes with sleep
- Pain is exhausting
- Management of pain leads to improved quality of life and productivity

Resources:

Pain BC

Canadian Pain Coalition



Medications



- ▶ Discuss all medications with neurologist, family physician or pharmacist, including:
 - Prescription medications
 - Vitamins and supplements
 - Recreational drugs
 - Alcohol consumption
- ▶ Side effects of some medications used to treat MS symptoms can cause fatigue (e.g. medications for spasticity, nerve pain)



Benefits of Relaxation Techniques

- ✓ Slows heart rate
- ✓ Lowers blood pressure
- ✓ Slows rate of breathing
- ✓ Reduces stress hormones
- ✓ Increases blood flow to major muscles
- ✓ Reduces muscle tension and chronic pain
- ✓ Improves concentration and mood
- ✓ Reduces fatigue
- ✓ Promotes good sleep
- ✓ Reduces anger and frustration
- ✓ Boosts confidence to handle problems



Relaxation Techniques

- ▶ Meditation
- ▶ Body awareness
- ▶ Deep breathing
- ▶ Visualisation techniques
- ▶ Muscular relaxation
- ▶ Music or meditative sounds
- ▶ Massage
- ▶ Yoga, tai-chi and pilates





Time to Practice!

<https://www.dartmouth.edu/~healthed/relax/downloads.html#deep>





Medications

Generic Name	Brand Name	Use
amantadine	Symmetrel	Antiviral; alters dopamine levels
modafinil	Alertec	CNS stimulant; used to treat daytime sleepiness in Narcolepsy
methylphenidate	Ritalin	CNS stimulant; typically used to manage Attention Deficit Disorder in children
antidepressants	e.g. Wellbutrin	May help manage both depression and fatigue, which often occur together

Behavioural Approaches



“What if we don’t change at all ...
and something magical just happens?”



4P's

- ▶ **Planning**
- ▶ **Prioritizing**
- ▶ **Pacing**
- ▶ **Positioning**



Planning

- ▶ Think ahead
- ▶ Make friends with technology
- ▶ Plan for outings to avoid unnecessary stress
- ▶ Keep multiples of frequently used items to avoid trips
- ▶ Plan for meals and grocery shopping
- ▶ Cook larger meals to have leftovers
- ▶ Plan for higher energy activities at higher energy times of day
- ▶ Build in extra time between activities



There's an App for That!

- ▶ **Remember the Milk** – organizes your to-do lists so you can prioritize, set reminders etc.
- ▶ **Evernote** – takes notes, screenshots, records audio and indexes it
- ▶ **Cozi** – calendar feature that sync's family schedules and sends reminders for appointments

This Week's Menu

S		<i>Shopping List</i> _____ _____ _____ _____ _____ _____ _____ _____ _____ _____
M		
T		
W		
T		
F		
S		

Created by Sweet Bella Roos 2012. For Personal Use Only.
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Prioritizing

- ▶ Make a list of your activities, rank them, ask yourself...
 - What do I enjoy?
 - What has to be done today, or this week?
 - How often do these have to be done?
 - Do I have to do these myself?
 - Are my expectations of myself realistic?
 - What do others expect of me?

Never put off 'til tomorrow what you can delegate to someone else today.



someecards
user card

** Consider putting all items in categories of need to do, want to do and should do**



Prioritizing

- ▶ Remember, independence doesn't mean doing everything yourself:
 - Grocery delivery services
 - Online banking
 - Online shopping
 - Delegate household chores
 - Hire a housekeeper



Energy Analogies

Energy Bank Account



The Spoon Theory

Good morning! Here's to another brand new day!
In your hands are 15 spoons.
Each spoon represents the energy needed to complete a part of your daily routine.
Once you're out of spoons, you're out of energy. But don't worry,
Tomorrow always brings more spoons.

This is the spoon theory, an everyday reality
for those who live with a chronic illness.

Spoon Theory

UNDERSTANDING CHRONIC ILLNESS THROUGH THE

So, how would you like to use your spoons today?

  get out of bed	  take a shower	  visit your doctor	  grocery shopping
 call your parents	 manage meds	 walk your dog	 take kids to school
 get dressed	 make dinner	 socialize	 go to work

original 'Spoon Theory' written by Christine Miserandino
For more information please visit www.MollysFund.org



Molly's Fund
fighting lupus



Pacing

- ▶ Consider the “2 hour rule”
- ▶ Balance activities that are physically, cognitively and emotionally taxing
- ▶ Learn to recognize times of day that you are fatigued and plan for rest prior to these
- ▶ Plan for leisure activities
- ▶ Pace all activities
- ▶ Avoid doing several things at once
- ▶ Don't feel obligated to finish a task all at once



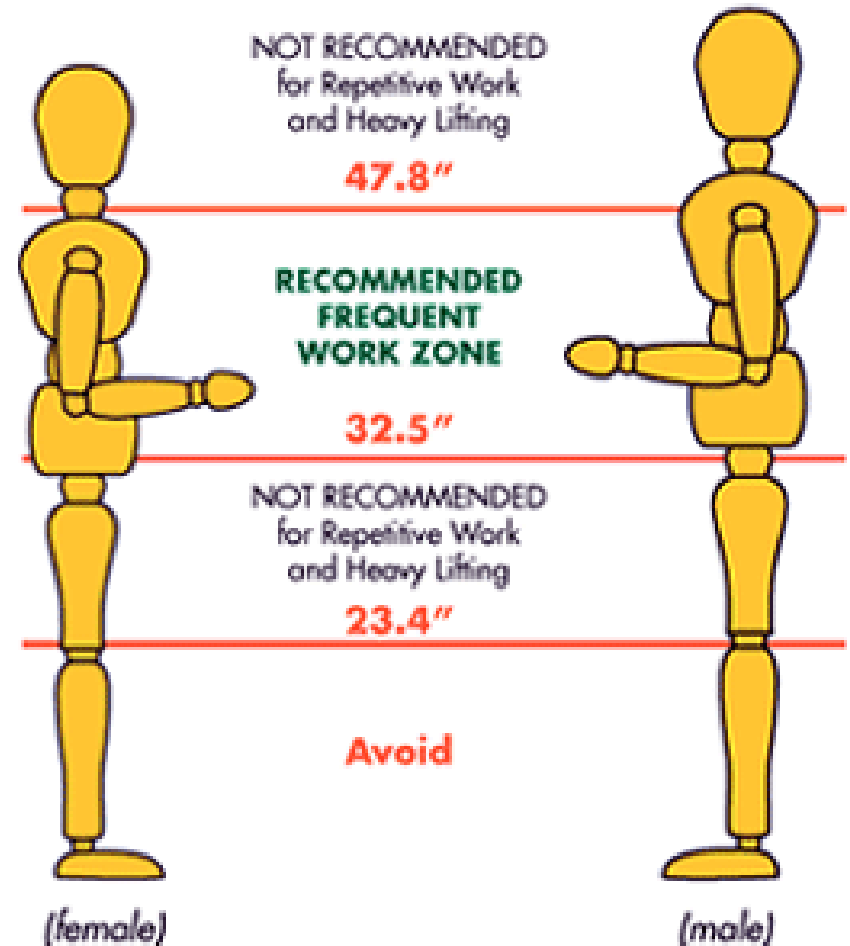
Positioning

- ▶ Use your physical energy in the most efficient way
- ▶ Consider body mechanics
 - Position self close to objects
 - Maintain vertical line of gravity
 - Use big muscles rather than small
 - Avoid frequent bending and turning
 - Know your limits and seek assistance

Examples:

- ✓ Use a shower chair
- ✓ Sit while doing meal prep
- ✓ Use a telephone headset

Vertical Reaches

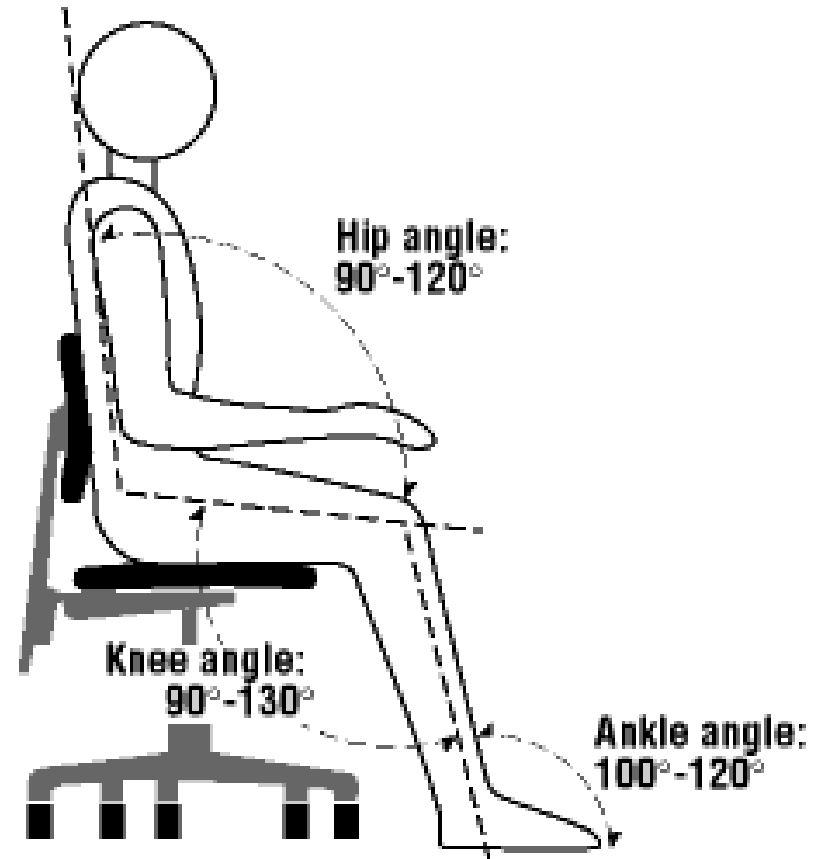




Managing Fatigue at Work

- ▶ Consider requesting an ergonomic assessment
- ▶ Request accommodations as needed, these may include:
 - A designated quiet space with recliner chair or couch
 - A modified work schedule
 - Taking shorter, more frequent breaks
 - Avoiding heavy duties
 - Using a headset
 - Working from home

Resources: MS Society of Canada:
MS in the Workplace; MS clinic
Social Worker/OT





Energy Management Programs

Fatigue: Take Control (Copperman & Hugos, 2005)

- Produced through the National MS Society
- Group leader & participant workbook
- Five 15-25 minute videos
 - Video One: Medical Management of Fatigue
 - Video Two: Activity Diary, Cognitive Fatigue, Heat Sensitivity, Efficient Diet and Meal Preparation, Goals and Priorities
 - Video Three: Exercise
 - Video Four: Changes at Home/Work, Gait and Mobility Issues
 - Video Five: Energy Conservation: Posture, Ergonomics, Analyzing and Modifying Activities



Energy Management Programs

Energy Management for Restoration and Renewal – MS (EMPIRE-MS) **pending research

- Developed by Dr. Susan Forwell
- Group leader & participant workbook
- Four 2-hour sessions
- Content includes:
 - Normal/abnormal fatigue
 - Energy expenditure self-analysis; rest:activity ratio self-analysis
 - Energy management strategies including: sleep hygiene, planning & prioritizing, ergonomic evaluation, naps vs daytime sleep, relaxation training, social life and communication, stress busters, exercise, equipment and technology, general health



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Questions?





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