FATIGUE MANAGEMENT

DOWNLOADABLE INFORMATION

SPECIFIC MANAGEMENT OF MS RELATED FATIGUE

Managing Fatigue in MS

Energy Saving Tools for MS

National MS Society Fatigue Management Guidelines
http://www.nationalmssociety.org/Brochures-FatigueMain.asp

Fatigue in MS: Current Understanding and Future Directions

Villamartelli Recommendations: Improved Fatigue Management  (Included in this handout)
http://villamartelli.com/P_FatigueMgmt.doc  or  http://villamartelli.com/P_FatigueMgmt.htm

SOME ASSISTIVE DEVICES AND ENERGY SAVING TOOLS

ABLEDATA
Information on assistive technology and rehabilitation equipment.
www.abledata.com

Disabled Online
Resources for the disabled community and their families and friends, including news stories, message boards, disabled topics and chat rooms
www.disabledonline.com

The Home Wheelchair Ramp Project
Manual of design and construction for modular wheelchair ramps
www.wheelchairramp.org

Project Link
"Your connection to assistive devices."
www.phhp.ufl.edu/ot/projectlink

Villamartelli Links: Accessibility/ Assistive Devices
http://villamartelli.com/#ACC
RECOMMENDATIONS FOR IMPROVED FATIGUE MANAGEMENT

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Specific Habit Training Should Include the Following General Goal Directed Strategic Interventions:

„ **Pacing** (as a general relaxation procedure and a pain prophylactic), including enhanced discrimination and proactive management of fatigue via segmenting activities into steps and taking frequent brief relaxation breaks.

„ **Energy Conservation** Strategies that emphasize early discrimination of fatigue (e.g., irritability, frustration, decreasing strength, speed or endurance, decreased cognitive efficiency), modifying activity and schedule to promote rest breaks before fatigue progresses, with gradual increases in length of activities to maximize energy level and peak performance on functional activities and vocational or educational pursuits.

„ **Task Analyses** and other Organization Strategies that not only enhance automatic performance, but significantly decrease energy requirements for task performance. Task Analysis involve breaking tasks into single, logically sequenced steps and recording the steps in a Checklist that can be followed and checked off as completed. Task analyses always make task initiation, completion and follow through easier. They also greatly improve ability to perform tasks in persons with limitations in energy, initiative, ability to sustain performance, memory, organization, etc. Task Analyses/Checklists are extremely useful in minimizing fatigue by reducing the demand for, and fatigue produced by reasoning and problem solving associated with planning, organizing. Most importantly, with repeated completion, they allow retraining of efficiency habits.

„ **Time Management** Strategies
Chronic Progressive Disorders

Developmental and Reactive Stresses

Generalized Declines in Control and Coping Resources
- Declines in Physical Ability
- Declines in Activity
- Declining Independence
- Decreased Self-Esteem and Self-Confidence and Sense of Purpose secondary to decreased involvement in activities & pursuits that allow fulfillment of needs to feel useful, productive & worthwhile
- Declining Friends and Social Outlets and enjoyments
- Decreases in Cognitive Abilities
- Declining Energy & Endurance / Increasing Fatigue

Developmental Factors that Increase Functional Decline
- Fatigue related decreases in physical, cognitive, emotional & social functioning
- Cognitive & Social Understimulation related increases in cognitive deficits, rustiness, atrophy, depression, etc.
- Depression related reductions in physical, cognitive & social functioning, and motivation
- Misunderstanding of symptoms by others (e.g., laziness, selective memory, manipulation, etc.)
- Beating-up on Self (Guilt, Frustration, Anger --> SelfAbuse)
- Learned Helplessness (i.e., difficulty making continued effort given past failures/expectation of future failures / belief that efforts will not work / over-reliance on others & external help)

Interventions For primary problems of Decreased Initiation/Endurance/Energy (i.e., fatigue), Decreased Physical Capacity, Depression, Declines in Cognition and Problem Solving, and Social Isolation

Use Compensatory Strategies as Equalizers:
- Patience, Persistence, Coaxing and Self-Cuing of memories and efforts (promotes exercise & adaptation vs atrophy); successive approximations
- Self Pacing & Activity Planning to control fatigue (see self-control procedures)
- Internal & External Attention, Memory & Organization Strategies (see cognitive rehabilitation outline, related chapters)
  - Internal Aids (e.g., "Who, what, when, where & why?"; "Three-peat", "Bottom Line" or "One Thing at a Time" etc.)
  - External Aids (e.g., well designed memory log, outline strategies; alarm watch; etc.)
- Task Analyses to Counter Fatigue & Decreases in Organization & Energy (and memory, etc.) - breaking a chore or task into single, logically sequenced steps and recording the steps in a Checklist that allows checking off when completed, always makes the task easier
- Assertiveness: educating others; requesting accommodations (e.g., extra time, breaks, etc.); expressing thoughts, desires
- Set incremental, step-wise goals, build self up for what can be accomplished despite obstacles, and celebrate each tiny step of progress (Nurse it, don’t curse it; build yourself up instead of beating yourself up)
- Adjust Standards & Expectancies to Fit Limitations (make accurate comparisons vs inaccurate ones to healthy others, premorbid self)
- Set Modest, Incremental Goals to Allow Control & Minimize Interference Caused by Symptoms
- Employ Accurate Self-Expectancy, Self-Monitoring & Self-Evaluation and, finally
- Appropriately Self-Reinforce for Accomplishment Despite Odds, Obstacles
- Identify & Engage in alternative activities that allow feeling worthwhile & useful (including social activities & involvements)
- Dispute Myths:
  1. "Why me...? (vs "What contract did I sign that said this would never happen to me?")
  2. Grass is always greener
  3. Use "5 Commandments of Rehab", "Caregiver Rules", "Rules of Conflict", "Ideas to Help You Function" & Other Self-Help Tools, for patient, family, staff
Task Analysis (TA) Protocol

TA involves breaking any task, chore or complex procedure into single, logically sequenced steps & recording the steps in a Checklist. The list can be checked off as completed. TA’s always make task initiation, completion & follow through much easier. Performing a TA and generating a checklist can greatly improve ability to perform tasks in persons with limitations in memory, attention, energy, initiative, ability to sustain performance, organization, etc.

Task Analysis Checklists are also extremely useful in minimizing fatigue by reducing energy demands required by memory, planning, organization, prioritizing and deciding the sequences for a task. Task analyses are useful for both basic and complex behaviors. Once completed, task analyses allow performance of tasks or routines without assistance from others. Most importantly, through repetition and relearning, they re-establishing the efficient routines that make up normal everyday human activity. When the procedures assisted by Task Analyses are repeated consistently, they eventually become automatic [habits] and become as automatic and effortless as tying a shoe.

The ingredients for rebuilding these automatic habits are the 3 Ps: Plan, Practice, Promotional Attitude. The result is rehabilitation, or replacing obstacles with efficient habits that increase independence.

Several samples of different types of activities (tasks, cleaning routines, daily schedules) follow:

**TA Samples: Single Tasks**

*Weekly Shopping Checklist*

- MILK
- PAPER PLATES/CUPS
- HAND LOTION
- CHEESE
- NAPKINS
- CHAP STICK
- BUTTER
- PAPER TOWELS
- SHAMPOO
- EGGS
- PLASTIC WRAP
- AFTER SHAVE
- FRUIT
- TRASH BAGS

*‘Making A Bed’ Cheatlist*

1. Strip sheets, blankets and pillow cases
2. Put blankets and pillows on table
3. Take break
4. Get sheets and pillow cases from closet
5. Put on fitted sheet
6. Put on top sheet, evening it out
7. Put blankets and tuck in corners
8. Put pillow cases on pillow
9. Put comforter on bed

**Vacuum Cleaning Task Analysis**

1. Remove Cleaner and Parts From the Closet
   - canister
   - handle
   - floor brush
   - hand brush
   - crevice
2. Unwind Power cord
3. Decide task
   - carpets
   - wood/vinyl floors
   - hand dusting
   - change dust bag
4. For Carpets
   - attach power handle
   - adjust carpet level on canister
   - turn on power
   - vacuum first in main traffic paths and then to the sides
5. For Hard Floors
   - attach long handle brush
   - turn on power
   - vacuum from the center outward
   - turn off power
   - remove handle
   - clean brush head with vacuum power
6. For Hand Dusting
   - attach brush head to hand grip
   - turn on power
   - carefully dust all surfaces
   - turn off power
   - remove brush and clean it with vacuum handle
7. Change Dust Bag
   - when red light on canister comes on, or check monthly
   - when bag supply is low, purchase more at Sears. Bring code# to store.
   - open canister, carefully pull bag off attachment.
   - place dirty bag carefully into the trash
   - put new bag following reverse procedure
8. After Cleaning
   - recoil power cord into canister
   - store all parts in the closet

**TA Sample: Daily Habits & Routines**

*AT’s Initiative/Energy Retrainer*

**MORNING**

- Wash Face
- Shave
- Apply medication to face if needed
- Brush Teeth
- Comb Hair
- Dress before “morning” nap
- Check finger nails & toe nails; trim when needed
- Check hair length and get a haircut as needed
- Shower and wash hair
- Perform an Activity/Chore (Choose from Menu)
- Check Schedule (e.g., M,W,F=Y; Tues=RedX)
- Check your appearance before leaving the house

**AFTERNOON**

- Fill Out Chart (Behavioral Activity Monitor & Points)
- Eat Lunch
- Perform Relaxation Nap (PRN; Use Tape)
- Perform Activity or Chore (Choose from Menu)

**EVENING**

- Eat Dinner
- PRN (PowerRelaxationNap; Use Tape)
- Engage in Evening Activity
TA Samples: Cleaning Routines

TB's Bachelor Pad Cheat Sheet

1) CLEAN APARTMENT:
   A. KITCHEN:
      z CLEAN COUNTERTOPS DAILY
      z SWEEP FLOOR DAILY
      z ORGANIZE CABINETS & WIPE OFF ICE BOX
      z EVERY WEDS MOP FLOOR & WIPE WALLS
   B. BEDROOM
      z FOLD CLOTHES OR HANG THEM UP AND STORE WHERE APPROPRIATE DAILY
      z SWEEP AND VACUUM FLOORS WHEN APPROPRIATE OR PRN
      z ORGANIZE COMPUTER AREA
      z EMPTY CAT BOX DAILY
      z MOP FLOORS WHEN APPROPRIATE PRN
   C. DEN:
      z SWEEP FLOOR
      z VACUUM DAILY
      z DUST DAILY
      z STRAIGHTEN UP DAILY
      z VACUUM UP
   D. LIVING ROOM
      z DUST DAILY
      z STRAIGHTEN UP DAILY
      z SWEEP DAILY
      z VACUUM ONCE A WEEK
      z MOP ONCE A WEEK
   2) SET A CLEANING SCHEDULE:
      z A: DAILY DUTIES DUST, SWEEP, STRAIGHTEN UP EACH ROOM
      z B: EVERY WED MOP ALL ROOMS AFTER A IS COMPLETE

Single Doctor Chores Cheat List

BATHROOM
   z Dust around the mirror and light and window, including the tops of the light and mirrors and window sills.
   z Dust, with a damp cloth, around the windowsills, on the front of the blinds and the back (reverse sides by adjusting slats up and down), and along the tile division.
   z Wipe down the bathtub walls, going to the ceiling.
   z Use a rag to get the floor behind the toilet. Be sure to get in all the nooks and crannies along the edges of the floor, near the tub, etc.
   z Use a rag to get the floor behind the toilet. Be sure to get in all the nooks and crannies along the edges of the floor, near the tub, etc.
   z Tub and Toilet
      z Use soapy brush to quickly wash and rinse the inside of the shower curtain.
      z Use soapy brush to quickly wash and rinse the inside of the shower curtain.
      z With a soapy disinfectant, clean the toilet top, seat, behind the seat, and under the seat, along the walls to the floor
      z Fold all tiles neatly on the tile racks
      z Sweep the floor, including behind the toilet.
      z Take out the rug and shake it off of the porch vigorously to remove dirt and dust.
      z Remove and empty the garbage can.
      z Mop the floor, using ammonia or Clorox and be sure to get behind the toilet.
      z Use soapy brush to quickly wash and rinse the inside of the shower curtain.
      z With a soapy disinfectant, clean the toilet top, seat, behind the seat, and under the seat, along the walls to the floor
      z Fold all tiles neatly on the tile racks
      z Sweep the floor, including behind the toilet.
      z Take out the rug and shake it off of the porch vigorously to remove dirt and dust.
      z Remove and empty the garbage can.
      z Mop the floor, using ammonia or Clorox and be sure to get behind the toilet.
      z Use a rag to get the floor behind the toilet. Be sure to get in all the nooks and crannies along the edges of the floor, near the tub, etc.
   z Living Room
      z Dust Furniture, including all shelves
      z Use broom/duster to dust along all baseboards, window sills, ceiling molding & fireplace mantle
      z Sweep and Vacuum Under Rugs
      z Sweep and Vacuum Floors
      z Vacuum the couch, love seat, and chair
   z Kitchen
      z Empty Trash Can
      z Clean Top of Refrigerator and Microwave (Wet Soapy Cloth)
      z Clean Inside Refrigerator and Microwave
      z Wash Any Dishes and Clean Sink with Cleanser
      z Clean Sink and Surrounding Countertop
      z Sweep, and then Mop Floor
   z Study/Office
   z Dining Room
   z Bedroom
      z Dust dresser tops, around doors and windows, and along baseboard and ceiling molding
   z Laundry
      z Get Dressed
      z Comb Hair
      z Make and eat breakfast
      z Clear, rinse, stack breakfast dishes (for pm wash)
      z Make counter, table stovetop if needed
      z Feed animals
      z Brush teeth
      z Gather items to take for the day
      z Leave house at 7:00; go to Grandma's House
      z Leave house at 7:30-8:00; go to Grandma's House
      z Arrive between 7:30-8:00; go to Grandma's House
      z Leave for Grandma's between 3:30-4:00
      z Dinner at Grandma's & take medication
      z Take Medication
      z Make Bed
      z Shower
      z Get Dressed
      z Take Medication
      z Wake 6:00 AM to the Alarm Clock
      z Raise between 7:30-8:00 Am by van
      z Follow Morning Schedule (In Rehab SchedBook)
      z Lunch at 11:30, Take medication
      z Follow Afternoon schedule
      z Leave for Grandma's between 3:30-4:00
      z DInner at Grandma's & take medication
      z Home between 6:00-7:00 PM
      z Get mail, read & sort; put bills on microwave
      z Get Mail, read & sort; put bills on microwave
      z LAUNDRY
      z Get Dressed
      z Comb Hair
      z Make and eat breakfast
      z Clear, rinse, stack breakfast dishes (for pm wash)
      z Make counter, table stovetop if needed
      z Feed animals
      z Brush teeth
      z Gather items to take for the day
      z Leave house at 7:00; go to Grandma's House
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      z Home between 6:00-7:00 PM
      z Get mail, read & sort; put bills on microwave
      z Get Mail, read & sort; put bills on microwave
      z EVENING: PREPARE FOR THE NEXT DAY
      z Laundry if needed (clothes, sheets, bath/kit Towels)
      z separate colors and whites
      z set water level
      z put soap in
      z put clothes in
      z turn on
      z put clothes in dryer - set timer for 45min
      z Listen for Buzzer - fold when dry

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**PUT CLOTHES AWAY: Drawers/Closets**

**Kitchen**
- wash dishes
- wipe off countertops, stovetop;
- rinse out sink
- sweep floor; mop if needed
- Change or empty cat litter if needed
- Vacuum Carpet/Rugs if needed
- Dust Furniture if needed

**Bathroom** if needed
- clean sink, tub, countertop
- put toilet cleaner in toilet
- wash toilet inside and out
- change towels, mat, washcloths
- WATER PLANTS ON FRIDAY IF SOIL DRY
- CHECK OFF THINGS NEEDED ON LISTS WRITE OUT LIST WHEN GOING SHOPPING - KEEP LIST ON KITCHEN COUNTER
- PICK & LAY OUT CLOTHES TO WEAR FOR THE NEXT DAY

**Relax/Free Time**

**Prepare for Bed**
- Floss/Brush Teeth
- Wash Face
- Shave
- Set Alarm for 6:00AM

**DG’s Daily Checklist**

**Morning**

- Wake 5:30 AM to the Alarm Clock
- Take a shower - Wash and condition hair
- Shave
- Put Cologne On
- Comb Hair
- Put Deodorant On
- Brush Teeth
- Get Dressed
- Make Bed
- At 6:00 AM Take Medication
- Make and Eat Breakfast
- Clear, Rinse, Stack Breakfast Dishes to Prepare for PM Washing
- Wipe, Rinse, Stack Breakfast Dishes to Prepare for PM Washing
- Gather Items to Take for Day - including medication
- At 7:00 AM Leave House & Go to Pick-up Point

**For Sheltering Arms**

**Lock Door**

**Rehab Center**

- Arrive 8:00-8:30 AM by the Van
- Follow Morning Schedule
- Lunch at 11:30, Take Medication
- Follow Afternoon Schedule
- Leave Between 3:30-4:00 PM to Go to the Pick-up Point

**Late Afternoon**

- Take Medication at 6:00 PM
- Get Mail, Read & Sort, Put Bills in Appt Book
- To Give to My Sec.
- Business Related Activities
- Check for Messages
- Return Calls
- Make Dinner

**Evening: Prepare for the Next Day Kitchen**

- Wash dishes
- Wipe off countertops, stovetop;
- Rinse out sink
- Sweep floor; mop if needed
- Change / Empty Trash Can - If Needed
- Laundry - If Needed (Clothes, Sheets, Bathroom & Kitchen Towels)

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Kevin’s Daily Task Initiatives

MORNING
- 6:00am - Rise to Alarm
- Go To Bathroom - Toilet and Wash Hands
- Prepare Breakfast
- 6:30am - Eat
- Put Dishes in Sink and Clean Counter
- 7:00am - Dress
- Brush Teeth
- Brush Hair
- Pack Book bag - Lunch Tickets, Keys, Schedule
- 8:00am, Get Ready to Catch Bus

CIVITAN
- 8:30 - Bathroom - Toilet, Wash Hands
- 9:00 - Check Productivity
- 10:30 - Check Productivity
- 12:00 - Bathroom - Toilet, Wash Hands
- 12:30 - Eat Lunch
- 1:00 - Clean Up
- 2:00 - Bathroom - Toilet, Wash Hands
- 2:30 - Break
- 3:00 - Check Productivity
- 4:00 - Get Ready for Bus

EVENING
- 4:30 - Bathroom - Toilet, Wash Hands
- 4:45 - Prepare Dinner
- 5:00 - Eat Dinner
- 5:30 - Clean Table
- Prepare Lunch for Next Day
- Clean Dishes in Sink
- Clean Counter
- Bathroom - Shower and Clean Tub
- Dress
- Pick up Bedroom - Put Clean Clothes in Drawer/ Dirty Clothes in Basket
- Make Bed
- Free Time
- 9:30 - Prepare for Bed - Toilet, Wash Hands, Brush Teeth & SET ALARM
- 10:00 - In Bed - Sleep

Kevin’s Special Duties

Automatic Habit/Energy/Initiative Retrainer

ONCE PER WEEK:
DAY/Time: ____________________________
- Change Bed
- Vacuum Floor
- Dust
- Wash Kitchen Floor
- Wash Bathroom Floor
- Scrub Bath Tub
- Scrub Bathroom Sink
- Scrub Kitchen Sink

THREE WASH LOADS PER WEEK
DAYS/Time: ____________________________
- Gather Clothes
- Take to Basement
- Sort Clothes
- Load Washer and Start
- Load Dryer
- Fold Clothes (with help)
- Take Clothes Upstairs (with help)
- Put Clothes in Drawer (with help)

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**Strategies for Energy Conservation**

When considering ways to conserve energy, remember to prioritize, delegate, pace yourself, and plan high-energy activities at times of peak energy.

**Activities of Daily Living**
- Sit down to bathe and dry off. Wear a terry robe instead of drying off.
- Use a shower/bath organizer to decrease leaning and reaching.
- Install grab rails in the bathroom.
- Use extension handles on sponges and brushes.
- Use an elevated toilet seat.

**Organize time to avoid rushing**
- Lay out clothes and toiletries before dressing.
- Minimize leaning over to put on clothes and shoes.
- Bring your foot to your knee to apply socks and shoes. Fasten bra in front then turn to back.
- Modify the home environment to maximize efficient use of energy. Example: Place chairs to allow rest stops (e.g. along a long hallway).
- Wear comfortable clothes and low-heeled, slip on shoes. Wear button front shirts rather than pull-overs.

**Housekeeping**
- Schedule household tasks throughout the week.
- Do housework sitting down when possible. Use long-handled dusters, dust mops, etc. Use a wheeled cart or carpenter's apron to carry supplies.
- Delegate heavy housework, shopping, laundry, and child care when possible.
- Drag or slide objects rather than lifting. Use proper body mechanics. Use your leg muscles not your back when working.
- Sit when ironing and take rest periods.
- Stop working before becoming tired.

**Shopping**
- Organize list by aisle.
- Use a grocery cart for support.
- Shop at less-busy times.
- Request assistance in getting to the car.
- Purchase clothing that doesn't require ironing.

**Meal Preparation**
- Use convenience foods/easy-to-prepare foods.
- Use small appliances (they take less effort to use).
- Arrange the preparation environment for easy access to frequently used items.
- Prepare meals sitting down.
- Soak dishes instead of scrubbing and let dishes air dry.
- Prepare double portions and freeze half.

**Child Care**
- Plan activities to allow for sitting down (e.g., drawing, pictures, playing games, reading, computer games).
- Teach children to climb up on the lap or into the highchair instead of being lifted.
- Make a game of the household chores so that children will want to help.
- Delegate childcare when possible.

**Workplace**
- Plan workload to take advantage of peak energy times. Alternate physically demanding tasks with sedatory tasks.
- Arrange work environment for easy access to commonly used equipment and supplies.

**Leisure**
- Do activities with a companion.
• Select activities that match energy level.
• Balance activity and rest (don't get overtired).