

How To Fight MG Fatigue

Here's a guide to help patients preserve their strength:

Around the House:

- Don't stand when you can sit.
- Plan your activities and assemble everything before you start.
- Schedule daily tasks so you do a little each day, allot time for rest periods
- Get your family involved: ask your children or other family to help.
- Schedule regular rest periods each day.
- Use a cart, wagon, basket to carry things from one part of the house to another to eliminate retracing your steps.
- Move things you use often to low easily accessible shelves.
- Use power tools and labor saving electrical appliances (i.e. electric can openers, etc.)

During Personal Grooming:

- Sit on a stool in the bathroom while shaving or applying make-up. Prop your elbows on the counter top if you can, or install additional towel bars to prop your arm.
- Allow enough time to complete personal grooming in "phases" allowing for frequent rests periods and avoiding the stress of rushing.
- Take short showers or tub baths using warm (not hot) water.
- Prolonged bathing in warm water may worsen muscle fatigue, and you may have difficulty getting out of the tub without assistance. The hotter the water, the more exaggerated your muscle fatigue may be.

When Taking Your Medicines:

- If you feel extremely weak in the morning, keep one dose of the drug and some water at your bedside ready to take when you wake up. Or, discuss with your physician the possibility of taking long acting pyridostigmine bromide (Mestinon Timespan®) tablets at bedtime.
- Use a watch or cell phone with an alarm to remind you to take the next dose.
- If you have a daily medicine routine, tape your schedule to the bottle. A printed schedule is especially important at times when you are unable to medicate yourself or unable to tell someone else when your next dose is due.
- Perform strenuous activities only at peak drug times. Remember Mestinon® begins to work within the first 15-20 minutes, and is out of your system in 3-4 hours.
- If you find that you are weaker or more short of breath than usual and have more difficulty swallowing, call your physician, go to his office, or go to the hospital. Your MG drug dosage may need to be adjusted.
- If you have no trouble swallowing, take your medicine with food to reduce stomach upset and diarrhea. If you do have trouble swallowing, some medicines are available as liquids and others may be crushed and added to small amounts of liquids, applesauce or pudding.
- Keep several doses of medicine in your car, at your work place, and in your wallet or purse. You should also keep a copy of your medication list with you at all times.

- Do not take new drugs, especially over-the-counter remedies, without first checking with your physician or nurse.
- Avoid any drugs that have ever worsened your MG symptoms.

While Shopping:

- Get a handicapped parking sticker. Your local department of motor vehicles has the form that your physician will need to fill out.
- Shop when your drug effects are at their peak.
- Shop by yourself only when you need a few items, let other family members do the major weekly shopping.
- When shopping alone, ask the grocery clerk to help you carry the groceries to your car.
- If you arrive home tired, unload only the perishables. A family member/friend can unload the rest.
- Shop by phone whenever possible.
- Avoid peak shopping/traffic hours.

When You Have Problems With Vision:

- Have your eyes checked regularly in case you need glasses or a new prescription.
- If you have double vision, wear an eye patch while reading or watching TV. Alternate the patch from one eye to the other to avoid eyestrain.
- If you have visual disturbances, rest for 30 minutes with your eyes closed before you go out. Remember to take along an eye patch.
- If reading is a problem, your local library or bookstore may have books available on audiotape.
- Temporary use of a cooling eye mask may also help.

When You Have Difficulty Eating:

- Grind meals to make them easier to swallow.
- Begin meals with cold beverages; hot foods tend to promote muscle weakness/swallowing difficulties.
- Try semi-solid foods. You may find them easier to handle than either solids or liquids.
- Ask a nurse or dietician to help you plan your meals.
- If you take steroids, avoid salty foods and notify your physician if you gain weight suddenly, or if your vision begins to cloud, unlike blurred vision, which improves with rest, persistent cloudy vision may be a sign of steroid induced cataract formation.
- Keep nutritious snacks handy. Try milkshakes, eggnog or pudding, as well as fresh seasonal fruits.

Avoid Irritants that Make Your Symptoms Worse:

- Very hot or very cold weather may affect the amount of weakness you are experiencing.
- Many aerosol pesticides and cleaners contain neuromuscular paralyzing agents and may make symptoms worse.
- Alcoholic drinks, tonic water (because it contains quinine), and cigarette smoke may cause further muscle weakness.
- Avoid stressful situations as much as possible. Most important of all, safeguard your health by educating yourself about your disease and medications. **Wear a medical identification bracelet**, and carry a personal medical identification sheet in your wallet with a list of your current medications and doctors and their phone numbers.