

Lifestyle Tips for MG Patients

The following document was adapted from the Australian Myasthenia Association in New South Wales with permission. To learn more about the organization, please visit: <https://www.myasthenia.org.au/>

The first step to managing your condition is to accept that you have it. From then on you can move forward. Below, we have listed below some helpful hints on day-to- day living with MG.

BATHROOM

- Install grab bars in the shower, near the bath and near the toilet. If showering is tiring, use a chair in the shower and in the bathroom in general so that you are not standing while shaving, brushing your teeth, etc.
- Consider installing shower heads with flexible hose. You can then bring the shower head closer to your body, allowing faster rinsing.
- Replace old fashioned handles with a new one that has one handle that turns water on and off and controls temperature with the one easy movement.
- If possible, have the shower stall separate from the bathtub - climbing out of a slippery bathtub could be challenging and dangerous if you have difficult swinging your legs over the edge. Do's and Don'ts It is important that MG patients learn to accept the disease in order to know how to better live with it and, at the same time, try to arrange their lives so that they avoid situations leading to distress, anxiety, emotional crises, etc.

Do's & Don'ts

DO's

- Do adopt a positive attitude, and remain cheerful.
- Do visit your doctor at regular intervals. It is in the nature of MG to cycle a little.
- Do have a system for remembering to take your drugs.
- Do take a warm drink, crackers or a snack with your medication.
- Do cut down on alcohol and tobacco. Both can exacerbate the disease.
- Do eat sensibly and drink plenty of water.
- Do get plenty of rest.
- Do remain within your capabilities, pace yourself, learn to accept your limitations, and when you're tired, REST.
- Do use any labor saving devices you can get.
- Be sure that any doctor from whom you seek treatment for any illness fully understands your condition and the medications you are taking.
- Do use eye drops and eye gels to relieve your eyes from becoming dry. Failure to close the eyes completely, sometimes leading to poor blinking, can result in the loss of the "windshield-wiper

effect". Dust and dirt, therefore, are allowed to accumulate in the eye. If the eyes do not close completely during sleep, the cornea (the clear membrane in front of the eye) dries out and the 2 eyes become red, crusted and painful. Use eye gels to lubricate the eye, and patch the eye in the closed position before sleep.

- Do carry an identity card or medical alert device. Remember symptoms vary in kind and severity from day to day. We are adversely affected by weather changes and extremes of heat or cold. We can also be adversely affected by extremes of emotion. Ideally one should live an utterly placid life in a permanent temperate climate, but as we are all human beings, we have to make the best of what life can offer us.

DON'TS

- Don't be determined "not to be a nuisance". If you can't manage something, swallow your pride and ask for help.
- Don't rush. If it looks like you're going to miss the bus or train, go ahead and miss the bus. There'll be another.
- Don't try to exercise affected muscles beyond normal usage because this leads to needless exhaustion.
- Don't take any medication unless you have checked with your doctor first.
- Don't get into highly stressful or emotionally charged situations. Live as placid a life as possible.
- Don't get too hot or cold. Temperature extremes are weakening.
- Don't have very hot baths. If you can, take a shower.
- Don't try to eat huge, heavy meals. Little and often is easier and more sensible.
- Don't let yourself go. Remain neat and well groomed.
- Don't forget that even athletes get tired, so REST.
- Don't fret if your MG takes a dip. Myasthenics have their ups and downs just like everybody else. If you feel down, call your doctor.

MEDICATIONS (non-MG related)

You should always check with your doctor before taking any medication that is not related to your MG as certain drugs will make your MG worse. Neuromuscular blocking drugs are obviously drugs that myasthenics should be cautious of, but even the simple over-the-counter common cold medicines can have adverse effects on MG. In some cases, these drugs can even unmask the condition in an undiagnosed myasthenic by exaggerating MG symptoms.

You can find a comprehensive list of drugs to be wary of at mgakc.org.

EATING & SWALLOWING

It is important for the myasthenic to maintain a healthy, nutritional diet. At times, the myasthenic could experience chewing and swallowing difficulties. It is important to see your doctor or a dietician in the management of your diet when you are experiencing swallowing difficulties. They will recommend food types and consistencies.

- Large meals tend to cause fatigue, so eat more, smaller meals.
- Eat warm rather than hot meals as heat aggravates MG and could affect your ability to swallow.
- Sip a cold drink during a hot or warm meal.
- Meat should be ground or cut into small pieces to make chewing and swallowing easier. Cook meat well to allow for easier breakdown while chewing.
- Avoid foods that require a lot of chewing (e.g. tough meats).
- If chewing is difficult, replace fruit and vegetables with fresh juice drinks so that nutrition is retained. Mash vegetables. Thick soups are easy to manage.
- Rest your jaw between mouthfuls.
- Avoid dry foods that easily crumble into fine particles - the particles may get into the windpipe causing choking. Add liquids such as gravy to keep foods moist.
- Avoid hot, spicy foods.
- If you do find yourself with a mouthful of food and unable to swallow, then spit the food out (even if you are in public). Sometimes, supporting the neck while swallowing assists in getting the food down - apply pressure to the top of your neck by holding your index finger and thumb at either side of the base of your jaw.
- Alcohol could aggravate MG, so it is best avoided or at least kept to a minimum (especially with meals).
- Try soft boiled eggs as a soft yolk is easier to swallow than a harder, crumbly yolk.
- There could be times when swallowing is dangerous and tube feeding is preferred. This will be determined by your doctor.
- Some foods, such as lemons and tonic water (because it contains quinine), will aggravate MG and should be avoided.

EDUCATION

Knowledge eliminates the mystique of MG. Many myasthenics suffer the condition for years before being successfully diagnosed. The prize for diagnosis should be education - this way you have the chance to be informed on treatment choices. Sources of information include:

- Your neurologist
- Myasthenia Gravis Associations (they are usually listed in the white pages, or with government health organizations)
- The internet - a world of information!
- Reference books

EMERGENCIES

Educate family and friends on difficulties that you may encounter in a crisis - you might wish to provide a list of symptoms so that they have a checklist of questions to ask during the crisis (e.g. trouble breathing, unable to swallow, choking, unable to talk, etc). Then develop a system of communication if you are unable to talk (e.g. using telephone receiver: 1 click for "yes" and 2 clicks for "no").

Also available for crisis situations are electronic call devices which are monitored by third parties. You wear the device around your neck and in an emergency you simply press the button on the device. This communicates with a box in your house which automatically sets off an alarm at the monitoring center. The monitoring center will then contact your nominated party to alert them to the situation.

Wear a medical alert bracelet detailing your condition, the medications you are taking and carry an MG information sheet with you in case you suffer a crisis outside of your home. This will save doctors valuable time when treating you. Take the information sheet to the hospital with you as hospital staff may not be familiar with MG or the medications that will make your MG worse. Make sure that you hand over the information sheet to the doctor or nurse looking after you. If you are able to talk, provide as much information as possible on what it is you are experiencing (e.g. difficulty swallowing, difficulty breathing, tightness of chest), your limitations, and what previous treatments you received in a similar crisis. If you are unable to talk, write down the problem on a note pad or have family describe the problem. It is crucial that the symptoms be thoroughly explained to hospital staff.

EXERCISE

Exercise is important to keep muscles and bones in shape. So exercise if you can, but take it easy.

- Some steroid based medications are prone to causing weight gain and exercise might help in controlling weight.
- Whether your choice of activity is walking, swimming, cycling, bowling, going to the gym, or playing tennis, do not over-do it.
- Take medication if required prior to the session, ensure that your body is adequately hydrated, and remember to not over-exert yourself.
- It is probably best to avoid outdoors when there are extremes in weather temperature - they play havoc with a myasthenic's muscles.
- Listen to your body - if you start suffering fatigue of limb or have difficulty breathing, then stop and rest.
- Do not expend energy on exercise unless you feel that you are up to it. Do not be embarrassed to say "no" to well-meaning friends.

FAMILY, FRIENDS, & PEERS

Understanding of your condition by family and friends is important in the management of MG. You may look fine to all, but at the same time feel terrible. Educate those around you by providing literature on the subject or referring them to our website, mgakc.org. You could even take them along to your local MG Support Group meeting. Depending on the nature of your job, it may help to tell your manager and/or co-workers.

If your condition is particularly bad and you are often alone, arrange a roster where family and friends check on you regularly. Myasthenics must learn to accept assistance. There are going to be times when a helping hand will come in very useful.

HOUSE WORK

- Forget the big Saturday cleans. Break up house work into manageable smaller tasks, with plenty of rest between tasks.
- Ask family and friends for assistance, and learn to accept assistance when offered.
- Plan your routine so that you avoid unnecessary repetitions.
- Use a cart or basket on wheels to carry things from one part of the house to the other.
- Use energy saving devices - electric appliances and power tools over manual appliances.
- Avoid chemicals around the house where possible - some products may contain agents that adversely affect myasthenics, others cause allergies to flare up. There are now many chemical free, environment-friendly products on the market - good for you and good for the planet!

INFORMATION SHEET

If you are susceptible to a myasthenic crisis, it is a good idea to carry some information on MG. If you collapse in the street, with talking and breathing difficulties, the information sheet provides those around you with immediate means of assistance. The information sheet can include the following details:

- The name of your condition
- MG symptoms
- Names of your neurologist and Primary Care Physician
- Names of all medications you are currently taking
- Symptoms of Mestinon overdose
- List drugs or treatments which worsen MG (see section on Drugs (non MG related above)
- Telephone numbers of two friends or relatives

KITCHEN

The aim in the kitchen is to minimize effort. To achieve this, you can:

- Enlist the help of family or friends to assist in general house work, including cleaning of the kitchen.
- Use labor saving devices and products (electric blenders and mixers over manual, vacuum over the broom, ready-made over start-from-scratch).
- Use a tap mixer rather than the old-fashioned tap spindles - a tap mixer can control quantity of water flow and temperature in one easy movement.
- Place often used utensils, pots, pans and dinner wear in easy to get to locations so that you are not moving other things to get to them.
- Use smaller, easy to manage storage containers (heavy containers could deplete your energy).
- Avoid screw-tops.
- Break up housework into smaller activities - do a little each day rather than one monumental effort that will leave you bed ridden for the next two days!
- Ensure all of your cabinets, drawers and windows are easy to open and close.

MEDICATIONS FOR MG

- If the medication upsets your stomach, take it with food. If you have difficulty swallowing, try liquid forms. If the medication is making you feel terrible consult your doctor about alternative treatments.
- Take medications at regular intervals. Use an alarm to remind you. It is also handy to keep a schedule of your medication regime beside your medicines - it will help in times when you are unable to communicate.
- If you are on Mestinon and feel weak upon waking up, try Mestinon Timespan before going to bed - the tablet takes longer to break down and could offer relief first thing in the morning. Alternatively, keep your medication by your bedside for consumption upon awakening.
- Keep your eye on the use-by date of all of your medication - dispose of any medication that passes the use-by date (medicines lose effectiveness in time and old medicines could be dangerous).
- Only alter medication doses after consultation with your doctor.
- Keep some medication in your handbag (or wallet) and at work.
- Do not take other drugs without consulting your doctor as some drugs may aggravate MG, or could be dangerous to mix with your MG medication. Even over-the-counter medicines could prove harmful (e.g. cough medicines contain relaxants).

NEUROLOGIST

It is important to find the right MG knowledgeable neurologist for you. The right doctor could be somebody who:

- is experienced in the treatment of MG
- is happy to answer all of your questions
- listens to your experiences and your concerns
- discusses various treatment options with you

Usually, the myasthenic's first visit to the neurologist is to either diagnose the condition or to confirm the suspicions of their Primary Care Physician. To assist the Neurologist, take a list of all of your SYMPTOMS with you, as well as any medical records that you believe may be relevant.

After positive diagnosis for MG, the Neurologist will:

- explain the condition
- explain treatment options
- recommend a treatment strategy

Many people's reaction to being told they have Myasthenia Gravis is "I have WHAT??" It is not a common condition, so ask questions. If it helps to remember what you are being told, make notes or ask your doctor to make notes.

As MG symptoms differ from person to person, reaction to treatment can also differ. If you are not sure about your treatment, talk to other myasthenics about their treatments and their experiences. Better still - tell your neurologist (they do wonderful things, but they cannot read minds). If you find a particular

treatment is not working, or is not suitable to your situation, then talk to your neurologist about alternate treatments. Talk to your neurologist if your condition worsens.

If you are unhappy with your Neurologist, ask your Primary Care Physician or local MG chapter/association to recommend somebody else.

PERSONAL HYGIENE

- For females, opt for a low maintenance hair style (something that does not require a lot of blow-drying and brushing). If high maintenance is a must, then consider regular visits to your hairdresser or enlist the help of family and friends to help with your 'do.
- If washing your hair causes fatigue in your arms, have somebody help you (it would be handy to have a shower head with flexible hose for this purpose).
- Try an electric toothbrush.
- Try an electric shaver. If shaving causes fatigue in the arms, have somebody help you.
- Avoid hot baths. Keep showers short and warm (not hot as heat aggravates MG).
- Sit to brush teeth, blow dry hair, shave, etc. if you are tiring easily.

SHOPPING

Shopping can be a daunting task. To minimize its impact:

- Wear comfortable clothes and comfortable shoes - you don't want to be fussing with your clothing as well as your muscles!
- If the shopping trip is to be a long one, ensure that you take medication beforehand and that you have medication with you. Make sure that you have a good rest before you leave the house
- If you expect to be carrying heavy items such as when grocery shopping, then it is probably best to take somebody with you to carry the groceries or push the cart. At home, unload the light items and leave the heavy items for others to deal with. If you do not have anybody to help you with groceries, consider using a lightweight personal shopping cart (they were popular with the elderly years ago, but are a fantastic (and environment-friendly) alternative to plastic shopping bags).
- If you can, use private transport - the use of public transport can be a battle in itself (particularly climbing onto buses).
- If you are not able to venture outside, consider internet shopping. There are now a number of stores and services that bring groceries right to your kitchen.
- Air conditioned shopping centers are more comfortable and convenient than strip shops - they provide for plenty of resting spots and most have a concierge service to assist if you get into difficulties (e.g arranging taxis, and wheel chairs may be available if you have difficulties walking).
- Obtain a handicapped parking sticker if you suffer from walking or other difficulties.
- If it will help, use a walking aid (or those neat scooters to get to get around).

SUPPORT GROUPS

Support groups and associations are beneficial in that:

- Members normally can empathize with your experiences.
- You will realize that you are not alone in your battle with MG.
- You have the opportunity to share experiences and ask questions.
- You have the opportunity to help others and make new friends. • Hear interesting, MG related topics.

VISUAL DIFFICULTIES

- If double vision is a problem, DO NOT DRIVE. If droopy eyelids also affect your vision, then you should also avoid driving.
- Use an eye patch while reading or watching TV to relieve double vision. Alternate the eye patch from one eye to the other to avoid eye strain.
- Rest your eyes before leaving the house.
- Outdoors, use sunglasses and sun visors to keep glare away from your eyes.
- Some myasthenics suffer from dry eye as they are unable to fully close their eyelids when sleeping. To alleviate the problem, use eye lubricant before going to bed and tape your eyes closed.
- If you are having difficulty keeping your eyelids up, then tape them open (probably not the best look outside of the home!).
- Have your eyes tested at regular intervals. Inform your optometrist of your condition (so they can hold up your eyelid during eye examinations). This is especially important for myasthenics on steroid-based medication to assist in the early detection of glaucoma.
- MG does cause blurred vision, so be aware of this when having eyes checked.

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