

COPING STRATEGIES FOR PATIENTS WITH NEUROMUSCULAR DISORDERS

Bathing and Shampooing

- An empty half-gallon plastic cylindrical container makes a handy floating support for the head and neck to allow shampooing while the bather is reclined in a tub. Avoid overly hot water when bathing, since it causes fatigue.

Cleaning

- When bending is a problem in cleaning lower cabinets or appliances, they can be reached with a good spray cleaner. An O'Cedar Light N' Thirsty mop can be used to wipe the surface clean, after allowing the spray to set a few minutes.

Dressing

- Velcro closures make buttoning and donning shoes easier using buttons, snaps or shoestrings. Velcro buttons and strips are available at fabric stores. Velcro tabs can be sewn to shoes at a brace shop or shoe repair shop. Ready-made Velcro closure tennis shoes are usually found at discount department stores.
- A circular key ring can be attached to a zipper tab that has a hole in it, allowing fingers or thumb to easily grasp the tab and close the zipper. Sticky zippers will slide easily if rubbed with the lead from a lead pencil.
- If you have difficulty buttoning a shirt or blouse, get a larger size, keep it buttoned all the time and put it on as if it were a pullover shirt.

Eating and Swallowing

- Lightweight plastic bowls are easier to handle than glass or ceramic dishes. A rubber mesh mat will keep them from slipping on the counter or in the lap.
- Annoying phlegm can be decreased by limiting the ingestion of dairy foods, but be sure to get your daily calcium quotient in other ways. Citrus juice can "cut" thick saliva.
- Suck ice chips before eating if you have difficulty swallowing. It helps desensitize the gag reflex.
- Chewing licorice just before eating decreases the appetite because it dulls taste buds. Be careful not to overdo this. Too much licorice can decrease your serum potassium level.
- Where swallowing is difficult, a package of frozen peas placed on the front of the neck may prove of assistance by relaxing muscle spasm.
- When food gathers in the back of the mouth, tip the chin downward, not upward, to improve ingestion.

Exercises

- Balancing exercises are important because loss of balance can result in a fall with possible injury. Holding on to someone while standing on each foot alone is a simple way to improve balance.
- Simple breathing exercises can be performed by blowing through a straw, blowing up balloons or blowing a ping pong ball on a tabletop or other flat surface. Playing a harmonica, kazoo or other wind instrument is a pleasant way to exercise the lungs.



Heat Avoidance

- Excessive heat will increase symptoms in those with myasthenia gravis. Swimming in a cool pool is the best exercise for these patients. Cool foods and drink are also easier to swallow.

Keys

- To easily identify and retrieve a house key from a ring of keys, drill a second hole near the edge of the key so it will hang off center on the key ring or use a plastic key end cover, available at your hardware store.

Personal Care

- Use baby wipes instead of toilet tissue. They are easier to hold and you feel (and are) cleaner when you finish using them.

Sitting

- Because of its height, a bar stool is a good seat for the patient with weak hip and/or knee extensors. Look for one with a wide leg base. You might also want one with a back and armrests. When rising from a chair with arm covers, the covers can be kept from slipping by laying a sheet of art foam (Available at art supply stores) between the cover and the armrest of the chair. A terry cloth washcloth will also work.

Sleeping

- Friction is decreased for changing sleep position by using satin or nylon sheets and/or pajamas. But, be careful when sitting on the side of the bed as you will slip quite easily when trying to transfer to your wheelchair or commode.

Stress

- Emotional stress, even positive stress, increases weakness in this disease and should be avoided.

Traveling

- When traveling, an airline wheelchair can be rented for negotiating narrow doors and passageways.

Wheelchairs

- Radio waves can cause unintended motion of power wheelchairs or scooters. Take caution using CB radios or cellular phones when your wheelchair power is on. Also be aware of the location of radio transmitters such as radio or TV stations and two-way radios. Try to avoid driving near them.

Writing

- Pieces cut from a common kitchen sink foam sponge or even some rubber bands wrapped around a pencil/pen make it easier to grip. Many small pencil/pen grips are available at office warehouse stores. Inexpensive, too!

Courtesy Nerve and Muscle Center of Texas

