



## PATIENT EDUCATION

### LIFE STRATEGIES FOR PATIENTS WITH NEUROMUSCULAR DISORDERS

*From Nerve and Muscle Center of Texas*

#### Bathing and Shampooing

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

#### 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.

#### Cleaning

- Bending can be challenging when cleaning lower cabinets, appliances, etc. Use a spray cleaner with strong pressure, spray the surface, and let it set for a few minutes, then wipe it with an O' Cedar Light N' Thirsty mop.

#### Dressing

- Replace buttons with Velcro. Velcro buttons and strips can be found at any fabric store. Velcro tabs can be sewn into shoes at brace or shoe repair shops. Ready-made Velcro closure tennis shoes can be found at most department stores.
- A circular key ring can be attached to a zipper tab with a hole in it, allowing fingers or thumb to grasp the tab and close it quickly.
- If you are struggling with a sticky zipper, rub it with a lead pencil to get it to slide.
- If you have difficulty buttoning a shirt or blouse, get a larger size, keep it buttoned, and put it on like a pullover shirt.

#### Eating and Swallowing

- Lightweight plastic bowls are easier to handle than glass or ceramic dishes.
- A rubber mesh mat will keep dishes, utensils, and cups from slipping off a table or counter.
- To decrease annoying phlegm, avoid dairy foods; just be sure to get your calcium in other ways.
- Consuming citrus juices can "cut" thick saliva.
- Suck on 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. Avoid overdoing it because licorice can reduce your serum potassium level.
- When swallowing is difficult, a package of frozen peas placed on the front of the neck may help to relax muscle spasms.
- When food gathers in the back of the mouth, tip the chin downward, not upward, to improve ingestion.



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### Exercise

- Balancing exercises are important because losing balance can result in falls and 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 surfaces. Playing the harmonica, kazoo, or other wind instruments 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 drinks are also easier to swallow.

### Keys

- To quickly 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, which can be found at most hardware stores.

### Sitting

- Because of its height, a bar stool is a good seat for a patient with weak hip and/or knee extensors. Look for one with a wide leg base, a back, and armrests.
- When rising from a chair with an armrest, keep the armrest covers from slipping by laying a sheet of art foam (Available at art supply stores) or a terry washcloth between the cover and the armrest of the chair.

### Sleeping

- To change sleeping positions easier and lessen friction, use silk, satin, or nylon sheets and/or pajamas. However, be cautious when wearing these fabrics, as you can slip quite easily off the side of the bed or 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

- Most airlines offer free wheelchair service, or wheelchairs can be rented at the airport.

### Wheelchairs

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

### Writing

- Pieces cut from a standard kitchen sink foam sponge or rubber bands wrapped around a pencil/pen make it easier to grip. Ready-made pencil/pen grips can also be found at office supply stores.