



A Do-It-Yourself Owner's
Guide

101 Hints to “Help-with-Ease” for Patients with Neuromuscular Disease

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**101 HINTS
TO
“HELP-WITH-EASE,”
FOR PATIENTS
WITH
NEUROMUSCULAR DISEASE
(A DO-IT-YOURSELF OWNER’S GUIDE)**

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This little booklet was written to assist patients with neuromuscular disease in handling their tasks of daily living. All the hints it contains have been field-tested and proven useful. Most were suggested by patients or their families. Only a few have been gleaned from the literature. In this sense, the pamphlet, like the Heloise books, is truly a do-it-yourself owner's manual. Usually, "Help-With-Ease" hints don't require any special tools or equipment. Most of the gadgets described can be easily made with materials at hand in the ordinary household or purchased at a grocery, hardware or fabric store or ordered from readily available self-help catalogs.

We hope these hints will help you and your caregivers tend to your daily tasks of eating, grooming, dressing, sitting, transferring, communicating, getting around, using the toilet, working, recreating, traveling, shopping and sleeping. If you or yours have a suggestion you would like us to include in a future edition of our "Help-With-Ease" hints, send it on and we'll make it 102, 103, or even 110 or more hints next time.

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CONTENTS

Dressing	6
Communicating.....	10
Sitting, Transferring and Mobility	12
Recreating	14
Housekeeping.....	17
Sleeping or Resting	18
Grooming	20
Toileting	22
Eating	24
Exercising and Managing Contractures.....	27

DRESSING



1.

Velcro closures make buttoning and donning shoes easier than 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.

2.

Large bib overalls are excellent garb for young people in wheelchairs. They slip off easily to facilitate using the toilet. A front opening is available in some styles for use with male urinals. Elastic-waisted exercise clothing (i.e., sweat pants and running suits) is easier to push down and pull up. A 22-inch zipper can be sewn into the front seam and extended down the leg to allow plenty of room for the use of a urinal.

3.

A double bias tape loop (one attached to a belt loop, the other encircling the wrist) makes it easier to lift and lower a pair of trousers when at least one-hand support is needed to stand after using the toilet.

4.

Ventilation under plastic braces is improved by wearing fish-net panty hose. This practical apparel is especially useful in the summer.

5.

A simple pushing or pulling aid to help bring clothing closer to you from the bed, dresser drawer or closet, without reaching, can be made from a wire coat hanger custom bent at either or both ends. Be careful with a sharp end. Wrap the ends with masking tape or slip a soft pencil eraser on the end to help avoid tearing clothing and to provide a better grip.

6.

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.

7.

Buttoning can be eased by using elastic loops for buttonholes and sewing buttons on with elastic thread. The center of each button (front and back) can be touched with clear nail polish to seal the threads and make the button stay on longer. This works especially well with buttons on cuffs. Buttons can also be fastened to buttonholes for appearance and velcro patches placed on the back for closure.

8.

Although a gentleman's pre-knotted necktie can be adapted with an elastic band, a plastic or metal clip glued or sewn on the back of the knot might be easier to place on a buttoned collar.

9.

Tube socks (socks without heels that stretch to fit the foot) are easy for a child or adult to put on. Socks with a little Orlon in them are also easier to put on for winter wear than socks made of 100 percent wool.

10.

A foot that stiffens downward so much that it's hard to get a shoe on can be more easily slipped into a shoe if the back of the shoe is cut vertically and loosely laced. A tennis shoe can be adapted by sewing a zipper down the side. Any shoe repair shop can modify a pair of shoes in this fashion.

11.

When a child has difficulty telling the right shoe from the left, draw half an animal on each so the two halves make a whole animal when placed side by side.

12.

For the little girl who often puts her dress on backwards, provide a reminder to help her do it right, such as pinning a colorful bow to the front of the dress.

13.

Heavy fishing line pulled through zipper tabs and tied in a loop (the knot can be sealed by melting it with the heat from a lighted match) makes it easier to pull the zipper closed. This idea works especially well on men's or women's slacks. The loop is invisible and also washes well.

14.

A gastrostomy tube can be covered easily with body-size stockinette tubing. This will protect clothing from getting soiled by the tube. A 10- to 12-inch-wide piece is cut and slipped over the head and arms. Ask your clinic orthotist to give you some.

15.

Leaving your leg braces in the shoes provides an instant shoe horn which may help when slipping the shoes and braces onto your feet.

16.

Don't try to trim plastic braces by yourself. Even using a sharp tool to carve the plastic can cause it to weaken.

17.

Always use shoes that have the same heel height as those worn when your leg braces were fitted. If you don't your feet and ankles may be tilted up or down, which will throw you off balance. Also check the sole on tennis shoes. Some brands have soft cushion bubbles on the soles that can make you unsteady. Look for firm, flat soles.

18.

If one side of the body is weaker, it takes less effort to dress this side first. For example, put the weaker arm into the shirt sleeve first, the stronger arm next. Whenever possible, sit while dressing so you can safely rest as needed.

19.

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.

COMMUNICATING



20.

When speaking is a problem, a doodle board can be used. Some types are the Magna Doodle, Etch-A-Sketch and Magic Slate. These handy devices make it unnecessary to carry a pencil and pad. Small electronic models are also available. Look for memory organizers with simple functions that will write out a word, phrase or sentence on the screen. These instruments are relatively legible, portable and inexpensive.

21.

Large felt tip pens are more easily handled than the average ball-point model. Large-diameter ball-point pens are available at office supply stores, at checkout counters in many drug stores, discount stores, etc.

22.

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 pen/pencil grips are available at office warehouse stores. Inexpensive, too!

23.

A small rubber ball can be punctured so a pencil can be forced through. This makes an excellent grip for a pencil or other writing implement. A small lazy Susan turntable on the desk top for pens, tape, paper clips, etc., makes them easier to reach.

24.

Many children with poor hand control can learn to write well on a typewriter or computer keyboard. The youngster who is clever with numbers can do many accounting tasks on a small calculator.

25.

When hands are too weak to turn the pages of a book but neck strength and control remain, an excellent head-centered turner can be fashioned by attaching a pencil-thin wooden dowel, approximately 18 inches long, to the center of the brim of a tightly fitting cap or sunshade. A soft pencil eraser slipped over the end of the dowel can provide friction for turning the page. Mouthsticks and commercial pointers are also available if this doesn't work.

SITTING, TRANSFERRING AND MOBILITY



26.

An effective transfer board can be fashioned from a length of hardwood which is sanded, waxed and highly polished. Both ends should be beveled. This is a project for someone at your house who likes to work with wood.

27.

Transfers and gait can be assisted by using a wide, securely buckled belt around the patient's waist, which is then grasped to support him/her during transfer or steady him/her while walking. However, special gait belts are often inexpensive, usually under \$10 at a medical supply store.

28.

A king-size satin pillow case is an excellent aid to use as a drawsheet for transfer or turning in bed.

29.

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 arm rest of the chair. A terry cloth washcloth will also work.

30.

Leverage can be increased when moving in bed by using arm elevators constructed with lightweight, wide-based wooded blocks to which dowel handles have been fixed.

31.

Football receiver gloves afford a better grip on the handrail when climbing or descending stairs. Baseball or biking gloves are not quite as good.

32.

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

33.

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.

34.

A heavy rope, knotted at 12-inch intervals and slung from a secure tree branch, can be used for support to help a child with weak legs practice walking outside in the back yard.

35.

Low-cut pile carpeting without padding is safer to walk on than heavy shag or throw rugs and makes wheelchair mobility at home easier to manage.

36.

A lightweight bicycle helmet is comfortable as head protection for children prone to falling. A homemade head protector made of cloth strips filled with closed-cell foam padding sewn to circle and cross the top of the head is also effective.

RECREATING



37.

Many libraries will deliver or mail books to your home. Check with your local library for information.

38.

Gardening can be aided by using a length of plastic tubing as a conduit to plant seeds when seated in a wheelchair.

39.

The dimples on a rubber thimble provide friction to help turn the pages of a book or magazine.

40.

For fishermen who have difficulty retrieving a line, several devices are available, including a vest with a lightweight harness which holds the fishing rod in an aluminum tube with a locking feature. Also obtainable is an electronic fishing reel featuring a four-speed control with two manual and two electronic settings.

41.

A spring-loaded billiard cue is available for billiards or pool players who lack strength enough to handle the standard cue.

42.

If you want to play a stringed instrument (guitar, banjo, ukulele, etc.) but have weak hands and wrists, a soft glove can be modified by gluing individual plastic picks onto the fingers, adding a Velcro strap (for quick sizing) at the wrist and opening the thumb area for easy removal. The glove facilitates plucking and strumming stringed instruments by moving the fingers in a clawing manner, either separately or together.

43.

For those who sew, a small magnet glued to the end of a yardstick makes an effective “retriever” for dropped pins and needles.

44.

The Department of Transportation, Office of Consumer Affairs, 400 7th Street, SW, Washington, DC, 20590 (202/366-2220) distributes an excellent booklet, “New Horizons: Information for the Air Traveler with a Disability,” which details one’s rights as a disabled person. It is free on request.

45.

“Paddle-minton” is a badminton-like game using a short paddle which is easy to handle from a wheelchair. The game’s birdie is modified so as not to fly fast or high. The birdie’s speed can be adjusted by tying the feathers together for faster play or spreading them apart to slow its flight.

46.

The “Quad-Bee” frisbee has two adaptive thumb clips allowing someone with upper extremity weakness to hold and throw the device.

47.

Hand control in children can be developed with games utilizing rings placed around pegs. Pegs can be made from an old broomstick or other small dowels nailed or glued to a flat board. Rings can be fabricated from the plastic holders found on soda pop or beer cans or cardboard rings can be cut from a cylindrical oatmeal box or a paper towel tube.

48.

Wheelchair archery is made easier for persons with weak arms by using a straight arm splint on the arm that holds the bow and a hook fashioned to the other hand to pull the bowstring. Archery may help correct spinal curvature. The arm pulling the string should be on the side that has the more prominent curve of the spine.

49.

A secure seat for a small child's use on a seesaw can be fashioned from half of a plastic bucket or a section of an automobile tire. Tape the edges with duct tape for safety.

50.

A thick board can be slotted to hold a hand of playing cards for those whose grasp is weak. Ask your handy woodworking friend to make this simple but useful gadget for you.

HOUSEKEEPING



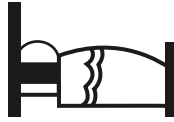
51.

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 Cloth mop can be used to wipe the surface clean, after allowing the spray to set a few minutes.

52.

When fingers are too weak to grasp a broom or mop handle firmly, a leather or cloth loop can be placed over the handle and pulled with the forearm.

SLEEPING OR RESTING



53.

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.

54.

A heavy belt or strap tied to the bedposts or a bed frame is a simple way to gain leverage to turn yourself from side to side.

55.

For the couple who want a double bed where only one requires a hospital bed, an extra long (80") twin bed can be attached side by side to an electric hospital bed. Order an electric hospital bed that has no headboard (80"), then a king-size headboard can be attached to both beds.

56.

Washable synthetic sheepskin padding or commercial egg-crate foam can be placed under a fitted sheet for more comfort when lying down. Any of a variety of inflatable camping mattresses serve the same purpose.

57.

A U-shaped travel neck pillow can be used to support the neck while lying flat or reclining in bed or in a lounge chair.

58.

Fiberfill or down comforters are lighter and warmer than wool or acrylic blankets. It's easier to move underneath or to lift them.

59.

Covers tented over a straight-back chair at the end of the bed will free your feet and legs while keeping you warm. Using bed corner garters to secure the blanket edges to the mattress is an inexpensive way of keeping them securely tucked. They can be found in the bedding department of discount stores.

60.

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 keyring or use a plastic key end cover, available at your hardware store.

61.

Long body pillows can be used to prop the back for side lying, preventing you from rolling backward. They can also be placed between your knees to decrease pressure and propped to reduce hip contracture.

GROOMING



62.

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.

63.

For a “dry shampoo,” sprinkle cornstarch or baby powder lightly on oily hair and brush it out. Pull a nylon stocking over the brush bristles and brush vigorously to remove more dirt and restore the sheen to your hair.

64.

Cylindrical foam can be purchased in yard lengths and attached or wrapped for extending or enlarging the handle of a razor, comb, toothbrush or other grooming tool. One end of a flat wooden coat hanger can be drilled to accept a pick-type comb. This device provides a light and easily handled comb extension.

65.

Liquid soap containers are convenient to use when attached to the bathroom or shower wall. You don't have to handle a slippery bar of soap or bottle of shampoo or hair conditioner. Make a slit and pocket in a thick sponge to hold a flat bar of soap. When you wash just squeeze the sponge to get the suds.

66.

A toothbrush can be adapted for use by weak hands/wrists by cutting the middle rows of bristles down to half their height. With this modification the front and back of the teeth are brushed by the high front and back bristles while the tops are cleaned by the shortened middle bristles. Such a toothbrush can also be purchased through an appliance catalog, as can an electric-powered model suitable for those lacking the strength or agility to brush their teeth. Look for one with a rotary brush. It's easier to hold in front of your mouth.

67.

A washcloth mitten is easier for some folks to use than a regular washcloth for washing oneself or the dishes.

68.

A nail clipper and file combination can be mounted on a sturdy board, eliminating the need for thumb or pinch strength when using these implements.

TOILETING



69.

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

70.

Serenity Security Pads worn at night can decrease the number of times you have to use the bathroom. They can also be worn on long car trips.

71.

A piece of semi-flexible plastic (like that used to make small pocket rulers) can be employed to fold toilet tissue for use. The tissue is wrapped around two-thirds of the length of the plastic (no sharp edges please), and the remainder used as an extension handle. Another way to provide an extension for cleaning yourself with toilet paper is to wrap the tissue around the working end of a pair of ordinary kitchen tongs.

72.

Easy access to and egress from a bathroom can be provided by removing the door (and even part of the door-frame) and hanging an opaque shower curtain instead. This ends the difficulty of opening and closing the door without sacrificing privacy. Offset hinges can also be used to widen the doorway without removing the door.

73.

A Texas condom catheter for men or boys who can't control their urine or are in situations where it's inconvenient to use the toilet can be prescribed by your physician. It's attached with double-sided adhesive tape to avoid leaking and fastened to a leg bag for urine collection. The long connection hose (for the leg bag) can be clamped at the end and placed over a urinal or toilet edge, thus eliminating the need for a leg bag. The condom can be reused if carefully washed in plain soap and water.

EATING



74.

A moistened paper towel placed under your plate will keep it from slipping on a formica tabletop.

75.

The diameter of eating utensil handles can be increased with cylindrical foam (available as pipe insulation at the hardware store).

76.

Wide-handled plastic mugs are easier to lift when all four fingers can be placed inside the handle. This way a firm grasp isn't needed to hold and tip the cup toward the mouth. An inexpensive sip-a-mug can be purchased at most drugstores or supermarkets. This is a light plastic mug with a contoured handle which also serves as a straw.

77.

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.

78.

A sport-type plastic drink container often has a hole containing a straw in its cover which eases/allows access to its contents.

79.

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.

80.

Suck ice chips before eating if you have difficulty swallowing. It helps desensitize the gag reflex.

81.

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.

82.

When swallowing is difficult, a package of frozen peas placed on the front of the neck may prove of assistance by relaxing muscle spasm.

83.

When food gathers in the back of the mouth, tip the chin downward, not upward, to improve ingestion.

84.

A little Oscar's meat tenderizer (MSG) on the back of the tongue will help to break up thick saliva and aid swallowing.

85.

A damp dish towel wrapped around the base of a bowl will keep it from slipping on a smooth counter.

86.

A simple portable aid to help get the hand to the mouth can be made with any forearm support such as a flat length of wood or even split bamboo (with several slips of velcro tacked on to secure the arm) and attached in the middle on both sides with a pin to two large dowels which are fixed to a heavy wooden base. This forearm prop can be placed on a table where it acts like a seesaw, lifting the hand to the mouth when the elbow is dropped.

87.

A disposable plastic cup with a space cut out along the rim to fit about a child's nose will allow the youngster to drink in a better, more controlled position with his chin forward, rather than having to bend his head back.

88.

A child having trouble controlling a cup with one hand can often do better if it's fitted with two handles. This adapted cup is listed at low cost in ADL catalogs or you can ask a local potter to make one for you if a ceramic mug will not be too heavy to lift.

89.

An "octopus" soap holder which has multiple suction supports makes an effective plate, glass or cup stabilizer. This gadget can be purchased in most grocery stores.

90.

An extra-long plastic straw can be used to eliminate the need to lift a glass when drinking.

EXERCISING AND MANAGING CONTRACTURES



91.

Tight heel cords can be treated while a young child rides a rocking horse by fitting the horse with stirrups so that the feet will be stretched up to a more normal position as he/she rocks.

92.

Contractures can be measured by folding a piece of paper to match the angle of the joint, tracing the folded edge onto a second sheet and measuring it with a protractor. By keeping a record of the degree of contracture, the caregiver can see progress and is more likely to keep working hard at stretching exercises to correct the contractures.

93.

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.

94.

A foot board (one-half- to three-quarter-inch plywood padded with a blanket will do) for support at the foot of the bed to keep the feet propped at the ankles during sleep, helps prevent ankle contractures. Of course, this means you must be able to sleep on your back with both feet against the board. You could, however, be side-lying with at least one foot against the board for some effect.

95.

If your heels feel sore while you're lying on your back, place a small pillow under your calves to relieve heel pressure. This same technique can be used during the day when you prop up your feet to reduce swelling. Tender heels can be toughened by patting them with a moist teabag at night. When the tea dries, the tannic acid it contains will act to harden (and slightly discolor) the skin. Passive stretching of the knee can be accomplished by placing the calves on a pillow supported by a hassock or kitchen chair. In this way, your heels aren't resting on the supporting surface and there is no heel pressure that might reduce local vascular circulation.

96.

Hand exercises can be fun. Try learning sign language and playing "shadow puppets." Or squeeze the poles of a toy that makes an articulated animal go loop-de-loop. Fingers are exercised comfortably by squeezing a washcloth or sponge in a basin of warm water.

97.

Exercising with your child can be made entertaining by strapping a small bell or flag to the arm or leg so that it will ring or flap when the child moves.

98.

The easiest way to stretch heel cord contractures is to stand at arm's length from a wall and place your hands on the wall. Lean toward the wall, bending your elbows, while keeping the heels flat on the floor and the knees straight, and attempt to touch the wall with your chest. If this is too hard you can start with your feet closer to the wall, or bend one knee at a time.

99.

When a child is seated, his feet should always be supported. A box or large book will do. Dangling feet are more prone to develop contractures.

100.

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.

101.

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. Emotional stress, even positive stress, increases weakness in this disease and should be avoided. That's right, you can have too much fun!

