

# Chapter 2

# Saving Energy



## BATTLING FATIGUE

**E**nergy conservation depends on the elimination of unnecessary steps in an activity. In ALS, muscle fatigue becomes a problem any time you make greater demands than your muscles can handle. By understanding the cause of your fatigue, and incorporating energy-conservation techniques into daily life, you'll be able to live more independently and do more for yourself with less fatigue.

But you also should be aware that frequent fatigue, headaches and lethargy may indicate weakness of breathing muscles. See Chapter 5 of this guide for more information about respiratory issues and ALS. Fatigue also can have emotional roots; depression symptoms or stress are common in ALS. Help is available for these challenges, so don't hesitate to talk to your doctor about these issues.

The following are tips for avoiding fatigue, and modifying or streamlining simple tasks so that you can conserve energy.

## PRINCIPLES OF ENERGY CONSERVATION

---

### Avoid Rushing

- Preplan your work, and schedule rest periods.
- Spread heavy and light tasks throughout the day.
- Set priorities and eliminate unnecessary tasks.

### Avoid Unnecessary Motion

- Sit instead of standing for any task that may last longer than 5 minutes.
- Avoid holding or lifting heavy objects by sliding or using a wheeled cart.
- Avoid reaching and bending by arranging your work area within normal reach.
- Apply for a "disabled" parking permit early in the disease process.



### Arrange Your Work Center

- Place supplies and equipment at the point of first use.
- Live simply, avoiding unnecessary cluttering of items.
- Use modern labor-saving equipment. For example, use a food processor for chopping or cutting.
- Use good posture to prevent fatigue by keeping your trunk muscles in their best biomechanical position for function.



### Use Proper Working Conditions

- Adjust work areas to a proper height.
- Use adequate ventilation.
- Use good lighting.
- Work in a relaxed manner, for example, with music.
- Wear comfortable clothing.

## EVERYDAY ACTIVITIES

---

Household tasks, errands and other routine activities comprise a large part of daily life. As fatigue becomes more of a problem, modification of ordinary tasks is necessary. By prioritizing and simplifying

routine tasks you can conserve your energy for more enjoyable activities.

## Cooking and Meal Preparation

- Plan menus in advance.
- Use menus that require short preparation time and little effort, such as frozen or microwaveable foods and ready mixes.
- Plan preparation so that you can save trips around your kitchen and dining area. For example, use a wheeled cart to gather all necessary items (such as meal ingredients or plates and silverware) and transport them to the work area or dining table, sink, etc.
- Slide or use a utility cart to transport items to the cooking area or storage (for example, slide pots, don't lift).



- Sit at a table or counter of correct, comfortable height to mix ingredients, chop and slice vegetables, etc.



- After a meal, sit on a high stool at the sink when washing dishes. Use a cart to transport them to the storage area.



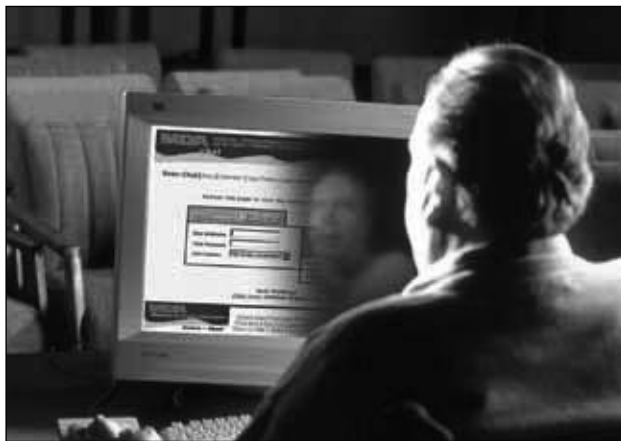
- Open lower cupboard doors to allow more leg room at the sink or counter while sitting on a stool.
- Use a cutting board that fits over the sink.
- Avoid items that require constant stirring and attention.
- Use lightweight dishes, and double-handled pots and pans.
- To eliminate or reduce scrubbing pots and pans, use vegetable spray prior to cooking.
- Urge other family members to do their share of physical chores, or to do the most demanding ones.
- Look for special tools with built-up handles that make kitchen chores easier.



## Errands

- Consider online or catalog shopping and direct shipping for items such as toys or gifts.
- Plan menus to avoid unnecessary trips to the market.
- Save your activities for the time of day when you feel your best.

- Keep a list of grocery items you need, and then organize the list to correspond with the layout of the store. Use an electric scooter if one is provided by the store.
- Shop at stores where employees will unload your cart and deliver items to your car.
- Put heavier items near the handles of the shopping cart for better leverage.
- Shop by phone or Internet with grocery stores that deliver.



- Get help, such as a service dog, a personal attendant or a housekeeper. Also, contact public service organizations in your community. Many have



programs whose members must fulfill community service hours by doing things like lawn care, dog walking and grocery shopping.

- Organize your schedule by placing the most important tasks at the top of your to-do list and doing those tasks first.
- Use bathroom aids to your advantage. Grab bars, shower chairs, raised toilet seats and handheld showers offer the aid you need without the struggle.
- Don't hesitate to ask friends and neighbors for assistance with errands.

## Cleaning & Housework

- For easier bed making, place the bed where both sides are open, not one against the wall. Make one trip only around the bed.
- Use a mop with a long handle to clean your bathtub.
- Use cleaning products that don't require you to scrub.
- Get help, such as a service dog, a personal assistant or a housekeeper.
- Contact public service organizations in your community for help.

## At Work

- For desk jobs that involve extended computer use: Use technology



designed to save keystrokes and mouse clicks. For example, certain



software allows you to control your computer with voice commands, or use means other than your fingers and hands, such as a head mouse. (See Chapter 6.)

- Some computer software, such as word-processing programs, has built-in features to save keystrokes, like “word completion.” (See Chapter 6 for more information.)
- Investigate the possibility of telecommuting or completing your work from home.
- Discuss with your employer in advance the need to redefine your duties or put you in a position with fewer physical demands.
- Use a telephone that allows hands-free usage with a headset or speaker system.
- For better grip on pencils or pens, wrap them in a piece of foam sponge or in multiple rubber bands. Other innovative grips can be found at office supply stores.



- Look for large-diameter pens or use large, felt-tip pens that are generally easier to handle than the average pen.
- You can make a homemade page turner by slipping a rubber eraser over the tip of a dowel or pointer that is about 18 inches long. Then attach it to the brim of a hat or visor, and use the eraser end to grip the page. This is best used by someone with head and neck control, but weak hands and arms.



## PERSONAL CARE

Simple modification of daily self-care tasks can significantly reduce energy expenditure while helping you to maintain your independence.



Review the basic principles listed on page 31. The following techniques can help you save energy and can make assisting you more efficient and less tiring for your caregiver.

## Bathing & Showering

- Gather all necessary items and place them within easy reach at waist level.
- Sit to undress, bathe, dry and dress.
- Use water of moderate (not too hot or too cold) temperature.
- To avoid excessive reaching, use a long-handled sponge to wash your back while sitting on a tub bench.
- To avoid bending from the waist, use the cross-leg method to wash and dry feet.



## Dressing

- Gather all necessary items and place them within easy reach.
- Sit in a straight-backed chair to dress.
- Complete above-the-waist dressing first.
- Avoid reaching by choosing front-opening and/or loose-fitting garments. Fasten underclothes in front of the body.
- To avoid bending, use the cross-leg method to put on socks, underwear, trousers and shoes, in that order.
- Dress the weaker side first.
- Pull both underpants and trousers to your knees, then stand, pulling both to your waist, and fasten them.
- To avoid bending, gather all soiled clothes while seated.

- Consider using a grabbing device or reacher that allows you to pick up items such as shoes without having to bend over. Or store shoes on a raised shoe rack to avoid straining to pick them up each day.

### Getting Into Bed

Turn your back toward the bed and hold onto the headboard or side of the bed. Lower yourself and sit on the edge. Slide slowly back until sitting securely.

Place both arms toward the head of the bed and support your body weight. Slowly lie down onto your side while lifting your legs onto the bed.

### Getting Out of Bed

- Roll onto your side and bend your knees.
- Slowly push your body up with your arms while lowering your legs to the floor.
- Keep your back in a straight line and avoid twisting.
- If the bed has a siderail, use it to help you turn. (See page 26.)

### Other Helpful Hints

- Attach leather or webbed loops to drawer handles.
- Lower the clothes rods in closets to increase accessibility.
- Use an electric toothbrush.



## Spotlight on Care Circles

Care circles have made a big difference in the lives of many people affected by ALS. Described in the how-to book ***Share the Care*** by Cappy Capossela and Sheila Warnock, care circles are groups of volunteers organized to do daily, weekly or occasional tasks such as shopping, preparing meals, lawn mowing, making phone calls about insurance issues, or even something as simple as becoming an e-mail buddy.

At the heart of this concept is that a care circle is designed so that tasks are appropriate for the volunteer, and no volunteer takes on too much.

One of the hardest parts of a care circle is getting started, which means asking for help. A simple first step is to create a list of things you need help with, and a list of people or groups that you think might be willing to volunteer (beginning with those who've asked, "Is there anything I can do to help?"). See "Spotlight: Checklist for Getting Help."

MDA's *myMuscleTeam* is a free online service that helps MDA families receive strength from a personally created community — their "Muscle Team" of family and friends. Users create private, secure *myMuscleTeam* Web pages that enable them to post journal entries to keep friends and loved ones updated, and to utilize a "care coordination calendar" where they turn general offers of help into scheduled assistance.

To utilize *myMuscleTeam*, go to [www.mda.org/mymuscleteam](http://www.mda.org/mymuscleteam), or visit MDA's home page and click on the *myMuscleTeam* link on the top of the page.

# Spotlight: Checklist for Getting Help

## The Ways I/We Need Help

Item	Volunteer	Contact #
<b>Chores</b>		
Car Maintenance		
Minor Home Repairs		
Pet Care		
<b>Food</b>		
Grocery Shopping		
Meal Preparation		
<b>House</b>		
Cleaning		
Laundry		
Mow Lawn		
Water Lawn		
Weeding		
Yard Work		
<b>Miscellaneous</b>		
Child Care		
Just Visit		
Write Letters		
<b>Respite</b>		
During Week		
Evenings		
Weekends		
<b>Shopping</b>		
<b>Transportation</b>		
Church		
Entertainment		
Medical Appointments		
School		
<b>Other</b>		

### Whom to ask for help:

- Church/Sunday School class
- College organizations (nursing, occupational therapy, physical therapy)
- Co-workers
- Friends
- Family
- Mayor's Office for People with Disabilities
- MDA Health Care Service Coordinator for suggestions
- Neighborhood association
- Neighbors
- Scouts
- Students
- Support group leaders