At Home with MS

ADAPTING YOUR ENVIRONMENT

MANAGING MAJOR CHANGES

National
Multiple Sclerosis
Society

Martha (front cover), diagnosed in 1973.

At Home with MS

ADAPTING YOUR ENVIRONMENT

BY: JANE E. HARMON, OTR

Jane E. Harmon, OTR, is a registered occupational therapist who has lived with MS for more than twenty-five years.

The editors wish to acknowledge Donna M. Jensen, OTR, of Fairview MS Center for her assistance.

This publication is supported by contributions to the National MS Society from its members and friends.

Reviewed by members of the Client Education Committee of the National Multiple Sclerosis Society's Clinical Advisory Board.

© 2011 NATIONAL MS SOCIETY. ALL RIGHTS RESERVED.

Designing your approach to life with MS

Since you are reading this booklet, you or someone in your home probably has multiple sclerosis. That means the whole household is living with MS. You all go to bed with it at night and get up with it in the morning. You and your family are at home with MS.

To be truly at home with MS, there are some qualities you can foster in yourself. MS often brings the prospect of major lifestyle changes. It is easy to be defeated before you begin. The first battlefield is your attitude.

Although you don't have control over what has happened to you, you do have control over how you choose to respond to your changing circumstances.

You may eventually be surprised at the creative ways you can find to make your life easier if you decide to learn and grow rather than wither as a result of your experiences.

- **Make a game of living life to the fullest.** Plan strategies against your opponent, just as you would in checkers or chess. Relish your victories whenever you win something back that MS has stolen.
- **Make a hobby of life improvement.** You need not become an efficiency or design expert to develop an interest in making life easier. The self-help craze has filled our world with books, articles, radio programs, television shows, and Web sites, on living with disabilities, general household hints, getting organized, work simplification, interior design, home remodeling, and home repair. The resources can be found. Look forward to enriching your life through what you can learn.

Designing your environment

When you moved into your home, you arranged your things to meet your needs. After a few years, you probably rearranged or redesigned because your needs changed.

Most homes and the things in them are designed for standard-size humans with standard physical and mental abilities. But not everyone is standard. New parents "baby-proof" the house and buy baby furniture. If a horse moved in, the modifications you'd need would be different.

Whether the MS with which you live is a baby or a horse, your first thought when it moved in was probably not to remodel or redecorate. But making changes to your home is part of the game of adapting.

Energy conservation and work simplification

Fatigue affects everybody, but especially people with MS. Look at all the things you have in your home, one by one. Ask yourself to answer honestly. Do you need it? Do you really want it?

If "yes", keep it. Otherwise, pack it away, give it away, sell it, or throw it away. The uncluttered look is a definite plus for cutting down your workload. It also makes it easier to find what you're looking for if you have a visual impairment.

Next, think through your activities at home. Ask who, what, where, when, why, and how about everything you do. Who can help with what specific jobs? What jobs can you eliminate? Or simplify? Would you be more comfortable doing the job somewhere else? Can you make the location more pleasant? Plan in terms of **work centers** where you can sit for each of your activities, with everything you need handy. Ask for input from everyone in the family. This process can and should take time.

Almost any equipment or installation required by a disability can be tax deductible, within IRS rules and guidelines. There may be other resources you can tap as well. See pages 16–19. But not all changes, as you will note, are costly.

Accessibility

Determine how many levels of living space there are inside and outside your home. Identify any potential access problems. Mobility aids need a certain amount of open space to maneuver. Canes, crutches, and walkers need ample turning space. Wheelchairs and scooters have a considerably wider turning radius, which varies with the design. (Consider this factor when selecting an aid. The turning radius is usually specified in the product literature.) Improving access fights fatigue, even if you do not use an aid.

If you decide that access to a storage shed, an attic, basement, or even your second floor is not important or feasible, make sure there is nothing stored in those locations to which you need access.

Next, consider accessibility to high and low storage spaces, furniture, work spaces, and controls. You will need to measure heights.

The easy-reach zone, for most wheelchair users, begins about 15" or 16" from the floor and ends about 51" or 52" from the floor. Standing, the zone begins at knee level and ends a few inches higher than **your height**, not your outstretched arms.

- Put the things you use most often within your easy-reach zone. In each work or storage area (kitchen, bathroom, garage, study center), measure out that zone and figure out how to use it as completely as possible, leaving those areas outside your easy reach zone for storage of things you almost never need. Your storage adaptations may include hanging baskets, rolling storage carts, peg boards, hooks, and more.
- People with limited balance or vision tend to avoid open spaces, preferring to keep in contact with walls and furniture. Check walls for low-hanging mirrors or pictures. Make sure furniture is stable.
- Furniture helps define simple or complicated paths of travel through an area. It can be an obstacle or provide assistance. Plan improved furniture locations on graph paper first. Be sure to allow easy access to light switches, electric outlets, windows, window coverings, and controls such as thermostats.
- Place the bed away from the walls; bed making is much easier. You'll need four-and-a-half feet on one side for access by most wheelchairs.
- Handrails need not look institutional. Some are designed to be almost invisible, giving the impression of a chair rail or wall design feature.
- All outside doors should be 36" wide. All inside doors should be at least 32", including bathroom and closet doors. Most doors can be widened a couple of inches by replacing standard hinges with offset hinges. Some doors can simply be removed. The door frame can also be removed to provide more width. Some doors can be replaced with curtains if privacy is an issue. A sliding door or a pocket door, which slides into the wall, may be an option. Folding doors are another alternative if there is no room for a door to swing open, but they **narrow** the doorway by several inches.

  If the door cannot be modified, a crank device can be added to a folding manual wheelchair which can briefly narrow the width of the chair.
- Install grab bars in the bathroom, bedroom, and anywhere else they would be helpful to you. Placement is critical for safety and usefulness. You will need to consult an experienced rehabilitation or occupational therapist. In many locales, wall-mounted grab bars **must** be installed by a licensed plumber. Grab bars are available in colors. They don't have to be ugly to work.
- Beds, chairs, and toilet seats are easier to rise from if they are high. There are several ways to elevate a toilet seat. The 3-in-1 commode can be used as a bedside commode, a shower chair, or placed over the toilet as an elevated toilet seat. Other options include a variety of permanent or portable elevated seats, with or without arms or backs and of different heights.

  Avoid low chairs, especially if the seats slant back and down. If you transfer to and from a wheelchair, try to have all your other seats **at the same level**, so you can slide easily from one to the other using a sliding board. This is easier than standing up, turning, and sitting again.
- Hi-lo hospital beds are a big investment but have important advantages. Some are available that don't look like institutional furniture.

  These beds can be raised to change the bedclothes, or to permit a person to "stand down" from the bed when rising. The bed can be lowered to reduce the risk of injury from falls during occupancy, to allow access to nightstands, or to make for smooth transfers. When selecting a bed, be sure to check maximum and minimum heights and ease of operation.

- Remove the doors and perhaps the cabinets under the sink in the kitchen. Leaving the cabinet base in place can provide a footrest if you use a scooter with a swivel seat. Cover exposed pipes with insulating material to prevent bumps and burns. If you remodel, consider a **wall-mounted** sink.
- Kitchen countertops usually need to be lowered for wheelchair users. This major carpentry job should be carefully planned. Even if you don't use a wheelchair, consider installing at least one low section, so you can sit while doing kitchen work.
- Raising a desk or table can improve sitting posture and provide a surface on which to stabilize your arms to improve your coordination and reduce tremor. It is often necessary to raise tables and desks to allow access to a wheelchair or scooter. Desks, tables, chairs, and beds can be raised by adding wheels. This improves their mobility but greatly decreases their stability, depending on the wheels and the braking system. Decide which trade-off is best for you.
- Desks, tables, chairs, and beds can also be raised by putting them on blocks. Blocks are commercially available. If you construct your own, be sure the legs sit well down **into** the top of the block, at least one third of its depth, so they can't slip. Blocks can be made of wood or from coffee cans partially filled with concrete and painted to match the decor. Adaptive equipment suppliers and catalogs carry leg extenders which fit some tables and chairs.
- High doorsills, the edges of carpets or rugs, and other changes in the floor covering can impede access. Doorsills can often be removed. Special little ramps are available in catalogs for unavoidably high doorsills.
- The thicker the carpet, the more difficult it is to pick up heavy feet or propel a wheeled mobility device. Smooth non-skid floors are always best for anyone with mobility problems. All rugs and mats should be firmly secured to the floor with double-sided carpet tape, non-slip backing or matting, and/or metal or other edging. Any worn rugs, mats, or carpet should be removed.
- Stairs can be circumvented by ramps, electric stairchairs, or elevators. Ramps and outdoor grades should not rise more than one inch per foot, for safety. Ramps should be 30" to 40" wide. Stairs and long ramps need sturdy handrails on both sides.
- For bathtub access, remove tub doors and replace them with shower curtains.
- Permanent or portable transfer lifts can pick you up, move you, and put you down almost anywhere. Mounted on ceilings, walls or wheels, they provide access to the pool or tub, to your vehicles, or from bed to chair. Some can be operated independently.
- Make gardens accessible and less fatiguing to care for by building narrow raised beds along sidewalks and driveways. Look for books on container gardening methods.

Ease of use

- Consider the location of wall switches and electric outlets. If you have the luxury of designing your rooms, outlets can be placed in whatever location is best for you. If you do not, extensions can be placed on existing switches and electric outlets to bring them into your easy-reach zone. Plan enough electric outlets so you don't have to unplug to plug in another appliance.

- If a door is difficult to open or close, try changing the hardware. Lever-style handles are usually easier to use than round doorknobs. Temporary metal or rubber handles, found in adaptive equipment catalogs, are useful if you travel or live in a rental property. The more expensive options are electric or hydraulic door openers.
- If you have poor vision or balance, get your family members in the habit of leaving doors either opened or closed **all the way**, so you don't run into or reach for unstable partially opened doors.
- If you purchase a new stove, choose one with controls at the front or center of the cooktop so you don't have to reach around hot pans. Smooth cooktops are easiest to clean.
- Short strings or control rods on blinds or drapes can be replaced with longer ones. They can also be operated by remote controls.
- Make sure the remote controls for your home electronic equipment actually work with all the features you expect to use. The more expensive model may be a wise investment.
- Access to the telephone is essential for safety, as well as for social and business reasons.
  - Carry a portable telephone to eliminate travel. Some models clip on to the belt and have small headphones in place of a receiver. Cellular phones are more expensive but they operate even if phone or power lines are down.
  - Install telephone jacks wherever you need them, even if it is unconventional. Include the bathroom and all your usual work areas. Portable jacks plug into any electric outlet.
  - Consider which special features provided by your phone company might make use easier.
  - Phone directories can be visually and physically difficult; so can dialing. Disability exemptions are provided by most local and some long-distance carriers. This eliminates charges for directory assistance and operator-assisted calls. You can also preprogram numbers into some phones so you only have to press one button. Ask your telephone company.
- Consider placing a half-size refrigerator, hot plate, toaster oven, or microwave in the room or rooms where you spend most of your time.
- If you are constructing or remodeling a bathroom with a tub, consider centering the faucets in the middle of the long wall of the tub rather than at one end. An 18" tile-covered seat at one or both ends of the tub, and level with the tub, facilitates transfers and storage. The ideal bathroom would have a tub and a roll-in shower.
- Consider the weight of your tools, containers, and hand appliances. Light weight tools and containers help with weakness and fatigue but heavier objects give more sensory input (both touch and pressure). Weight may help some tremor and coordination problems. Some objects can be weighted, perhaps with sand or lead pellets.
- Environmental control units (ECUs) can provide bedside or chairside control of many electrical functions. With an ECU you can operate lights, fans and other small appliances, heat, air conditioning, the telephone, the hospital bed, and audiovisual equipment. You can open and close drapes, answer the door and admit visitors. ECUs can be operated by voice, computer, push buttons, your breath — even by eye movement. The simplest systems, providing push button or computer control, are "X-10 Powerhouse" compatible. These are inexpensive, expandable, and available at major retailers.

Adapting to low vision

- Assess the lighting throughout your home. Avoid abrupt changes, such as going from a dark hallway to a bright bathroom full of shiny surfaces. The use of nightlights can soften the changes inexpensively.
- Sensitivity to light does not necessarily call for less light. Explore properly placed, properly shaded, indirect light sources.
- Minimize shiny reflective surfaces by removing, covering, or refinishing them.
- Stove controls, thermostats, and other dials can be marked. Use contrasting materials (dark on light or light on dark) if you rely more on your vision. Try "invisible" markers if you can use touch or don't wish to mar the appearance of the item. Clear nail polish dots or puff paint works on hard surfaces. Clear raised stick-on dots that don't obstruct the view of sighted users are available commercially. Or try gluing various lengths of toothpick on the dials.
- Identify steps, stairs, drop-offs, and edges by using a bright color paint and texture provided by sand additives. Paint the edge of each step, the top and bottom of ramps, and the edges of walkways. The edges of doorways and windows can be identified by having the molding done in a dark color if the walls are light, or in white if the walls are bright colors.
- Maximize contrast wherever you work. Use light-colored containers and cutting boards when preparing dark food. A dark non-skid mat or towel under a container often helps you see what you're doing.
- Clutter and busy background patterns on floors, walls, tables, and dinnerware can make it harder to see accurately.
- Use a large-print calendar, address book, calculator, and telephone dial.

Safety

While everyone should consider the safety of their home, it is especially important to plan for emergencies if your MS causes cognitive, mobility, or vision problems. Crime, fire, and accident prevention should be your first goal, so emergency measures will never actually be needed.

Remember that a fire or other crisis is very stressful, so plan with that in mind. Make sure you can get to and operate the phone, essential doors and locks, window latches, and your mobility aids — **when you are at your worst**.

- Ask your police and fire departments for a safety inspection. Some fire departments will place a special decal on the bedroom window of a resident with a disability, if you wish.
- Plan emergency exit routes.
- Install wide-angle peep holes in solid doors at your eye level. Install two if you sometimes answer the door from your chair or scooter. When answering the door, call out, "I'll get it, Henry," even if you are alone. Never open the door to a stranger. If he or she claims to be a police or utility officer, ask for a badge and a verifying number to call. Then do so.

- Look at your residence from the outside to be sure you aren't advertising that someone with a disability lives there. Camouflage ramps with landscape plants, no more than waist high. Keep your car with wheelchair carrier or handicapped plates in a closed garage. Choose a removable handicapped vehicle placard or hangtag if your state gives you the option.
- Don't invite salespeople over or place classified ads which require people to come to your home unless someone is with you.
- Never let strangers on the phone know you are alone or disabled. It may be tempting to use your disability as an excuse to put off telemarketers or to strike up a conversation if you are lonely, but it can be dangerous.
- Electric door lock and intercom systems may be well worth the investment. You can talk with a visitor without opening the door, and be assured that the door will lock automatically behind guests as they leave. Some designs also function as an intercom throughout the house.
- Choose a visual reminder at the table where you eat to ask yourself if you turned off the stove. If you need an actual note to yourself, use it. Or use something which is always there, like the salt and pepper shakers, to remind you.
- Be sure your fire extinguisher is accessible and that you know how to use it.
- Choose a day of the week on which to test your smoke alarms. Change their batteries when you reset the clocks for daylight saving time changes. Or get the new ten-year batteries.
- Keep electric cords and computer cables controlled, out of traffic patterns, and not hanging over counter edges.

Style

Decide on a decorating style or overall tone that makes you most comfortable. A sleek look is the easiest to clean and maintain. It is possible for a home to look warm and full of favorite things while promoting work simplification and energy conservation. For example, keeping collections under glass reduces cleaning.

A Sense of Comfort

Comfort has direct effects on you physically, emotionally, and socially. You provide yourself, your family, and your guests with a comfortable home through the physical senses. Consider all of them when planning your home.

Lighting can make your home appear warm and cozy or bright and cheery. Good lighting improves safety and reduces some types of fatigue. Light can come from natural or artificial sources.

Colors and visual texture can influence moods and enhance safety as well as beautify your home. Look at your home with the eyes of a newcomer, a decorator, or photographer. What can you do to enhance your views? Get in the habit of appreciating your best views. Surround yourself and your family with emotionally important objects.

Music, environmental sound tapes, wind chimes, and some clocks provide pleasing background sounds. So do pets such as canaries, finches or other birds, a bubbling aquarium, or a purring cat, all of which need daily care.

These pleasant sounds can drown out unpleasant noises. So can "white noise" machines. Inside walls can be soundproofed if noise levels are causing you stress.

Temperature, humidity, and ventilation affect your comfort and influence how things feel. Moreover, your MS may make you sensitive to temperature extremes — 68°F is considered the ideal temperature for working indoors.

Different textures have inherent temperatures; metals, ceramics, and smooth surfaces feel cool; fabrics, carpets, and textured surfaces are perceived as warm.

Common sources of pleasant scents are flowers and plants, candles, potpourri, cooking aromas, cleaning products, fabric softeners, air fresheners, and perfume. But don't overwhelm your environment. A little goes a long way.

Resources

There are several sources to explore for technical and financial help.

- Your National MS Society chapter has information on equipment discounts, entitlement programs, local resources, and emergency equipment loans.
- Every state has a department of vocational rehabilitation. Some have independent living programs which provide evaluation and advice on structural modification or equipment to allow people with disabilities to live successfully at home.
- Many cities have independent living centers (ILCs). These are nonprofit consumer organizations with extensive information and referral services on living at home with a disability.
- Any adaptation or renovation to help you cope with MS may be tax deductible.
- If you meet low-income requirements, state and local departments of human resources may have programs which provide housekeeping and/or attendant care and financial assistance for adapted equipment and structural modifications.
- Look for sources of donated goods and services. Explore your connections to your family, friends, neighborhood, church or temple, school, employer, and social, professional, and special-interest groups. Lions Clubs specialize in helping people with visual problems. Scout troops earn badges for service to people with disabilities. High school vocational departments may give credit for building projects.

- Most states have a service agency for the blind. Anyone with a visual impairment is generally eligible for their services.

Information and Referral Services

- **National Rehabilitation Information Center for Independence**
  8201 Corporate Drive, Ste 600, Landover, MD 20785
  Tel: 800-346-2742
  Web site: **www.naric.com**
  E-mail: **naricinfo@heitechservices.com**
  (One-stop shopping for referrals, information and equipment sources. Fees charged for some services.)
- **AbleData**
  8630 Fenton Street, Suite 930, Silver Springs, MD 20910
  Tel: 800-227-0216
  Web site: **www.abledata.com**
  E-mail: **abledata@macrointernational.com**
  (This independent organization provides information on assistive technology and rehabilitation equipment with a database of over 29,000 products that can be searched by type or topic.)
- **The Independent Living Research Utilization at TIRR**
  2323 S. Shepherd, Suite 1000, Houston, TX 77019
  Tel: 713-520-0232
  Web site: **www.ilru.org**
  E-mail: **ilru@ilru.org**
  (A national center for information, training, research and technical assistance in independent living.)

Other Sources of Plans and Advice

- **AbilityHub** (Assistive technology for people who find operating a computer difficult.)
  Web site: **www.abilityhub.com**
- **Adaptive Environments Center Inc.**
  200 Portland Street, Boston, MA 02114
  Tel: 617-695-1225 (v/tty)
  Fax: 617-482-8099
  Web site: **www.adaptiveenvironments.org**
  E-mail: **info@HumanCenteredDesign.org**
- **"How to Build Ramps for Home Accessibility"**
  The Home Wheelchair Ramp Project
  Metropolitan Center for Independent Living, Inc. (MCIL)
  1600 University Avenue West, Suite 16
  St. Paul, MN 55104-3825
  Tel: 651-603-2029
  Web site: **www.wheelchairramp.org**
  E-mail: **jimwi@mcil-mn.org**
  (Web site contains complete instructions for building a ramp.)
- **Center for Universal Design**
  College of Design
  North Carolina State University
  Campus Box 8613, Raleigh, NC 27695-8613
  Tel: 800-647-6777
  Fax: 919-515-8951
  Web site: **www.design.ncsu.edu/cud**
  E-mail: **cud@ncsu.edu**

- **SpeciaLiving Magazine**
  Web site: **www.specialiving.com**
  (Better and easier living for mobility-challenged individuals.)
- **National Institute for Rehabilitation Engineering**
  P.O. Box T, Hewett, NJ 07421
  Tel: 800-736-2216/973-853-6585
  Web site: **www.angelfire.com/nj/nire2**
  E-mail: **nire@theoffice.net**
  (Provides custom-made devices and onsite training for people with severe and multiple disabilities. Services are offered on a sliding fee scale.)
- **Paralyzed Veterans of America**
  801 18th Street NW, Washington, DC 20006-3517
  Tel: 800-416-7645
  Web site: **www.pva.org**
  (Not just for veterans, not just for paralysis. Ask for the Architecture Program.)
- **World Institute on Disability**
  3075 Adeline Street, Ste 280, Berkeley, CA 94703
  Tel: 510-225-6400
  TTY: 510-225-0478
  Fax: 510-225-0477
  Web site: **www.wid.org**
  E-mail: **wid@wid.org**
- **Lighthouse**
  111 East 59th Street, New York, NY 10022-1202
  Tel: 800-829-0500
  Web site: **www.lighthouse.org**
  E-mail: **info@lighthouse.org**
  (Includes link to Vision Connection, an interactive resource for latest information on vision; with "Help Near You" function, to find resources in your area.)

The National Multiple Sclerosis Society is proud to be a source of information about multiple sclerosis. Our comments are based on professional advice, published experience and expert opinion, but do not represent individual therapeutic recommendations or prescriptions. For specific information and advice, consult your physician.

Early and ongoing treatment with an FDA-approved therapy can make a difference for people with multiple sclerosis. Learn about your options by talking to your health care professional and contacting the National MS Society at nationalMSsociety.org or 1-800-344-4867 (1-800-FIGHT-MS).

The Society publishes many other pamphlets and articles about various aspects of MS. Visit nationalMSsociety.org/brochures to download them, or call your chapter at 1-800-344-4867 to have copies mailed to you.

Some of our popular pamphlets include:

- Plaintalk: A Booklet About MS for Families
- A Guide for Caregivers
- So You Have Progressive MS?
- The Win-Win Approach to Reasonable Accommodations

MS STOPS PEOPLE FROM MOVING.

WE EXIST TO MAKE SURE IT DOESN'T.

JOIN THE MOVEMENT®

National
Multiple Sclerosis
Society

nationalMSsociety.org

For Information:
1 800 FIGHT MS (1 800 344 4867)

© 2011 National MS Society. All rights reserved.

ES6035 12/11