

**The Comfort of Home™ Multiple Sclerosis Edition:
An Illustrated Step-by-Step Guide for Multiple Sclerosis Caregivers
by Maria M. Meyer and Paula Derr, RN, BSN, CEN, CCRN
with the National Multiple Sclerosis Society**

326 pages

Trim: 7.5 x 9

Illustrations throughout; Resources; Glossary; Index

ISBN-10: 0-966476-76-X

ISBN-13: 978-0-966476-76-7

Price: \$24.95

**Published by CareTrust Publications, available via bookstores nationwide,
online bookstores, or by calling QP Distribution at 888-281-5170.**

Organizations please call 800-565-1533.

<http://www.comfortofhome.com>

Is Home Care For You?



Your Support System *↪* 5

Knowing What Level of Care Is Needed *↪* 5

Deciding Whether Home Care Is Possible *↪* 7

Home Care Considerations • Outside Help

Supportive Housing and Care Options *↪* 10

A Closer Look at the Options • Financing Options •
Points to Review Before Signing a Contract or Lease •
Things You Should Know About Facilities

Resources *↪* 20

Is Home Care for You?

The need to provide care for another person arises for many reasons. Often, the person who needs care does not realize it and family members must step in to help make decisions. One of those decisions involves who the caregiver will be and where care will be provided. The choices can be difficult unless you know what to consider.

When one member of the family becomes disabled, roles within the family often change. A person who took care of the family in the past or was the income provider may become dependent, while another person in the family takes on added, often unfamiliar responsibilities. For a single person, the changes may involve a new dependence on non-family members. Just the word “dependence” can cause unpleasant feelings. Being able to talk openly about fears, anxiety, frustration, and doubts can be very helpful in dealing well with these new facts of life.

Discuss chronic care needs with the person’s medical team to learn what treatments, adjustments and other changes may be necessary (see chapter 3). For some people, training to provide medical treatments, advice on coping with fatigue and occasional relapses, and some long-range financial planning will be enough. For others, in-home personal assistance is the best option. Sometimes a nursing home or assisted living center is the better choice for everyone involved.

In making the decision for home care, it is important to be realistic about what the person with MS needs, and what you, the caregiver, can provide in terms of time, kinds of care, and financial responsibility. For example, deciding to hire an in-home attendant may be necessary if the primary caregiver works full time. Before this happens, it’s important to look at the financial and emotional issues that go along with this decision.

Caregivers need to think about important issues such as independence, privacy, and the financial effect of hiring in-home help. Then the caregiver needs to talk to the person with MS and others living in the home about these issues. How will the family pay for in-home help and how will it find the right person(s) or agency?

Before a person can be hired, the family needs to look at what kind of care is needed: **medical** (symptom management, occupational or physical therapies, etc.), **personal care** (bathing, dressing, using the bathroom, etc.), **home-making** (shopping, errands, laundry, housecleaning), or **companionship** (social outlets, safety issues, etc.).

Your Support System

Sometimes children take on major household and personal care duties when a parent has disability due to MS. While it is positive for children to take on household jobs and tasks, their needs must be carefully balanced with the amount and level of caregiving they are expected to provide. Children are not equipped to handle the stress of being the main or primary caregiver. They should never be in charge of a parent's medical treatments or daily functions such as helping with the bathroom.

Family and friends can help. The first step is to let friends and family know that their help is needed and welcomed. Friends often worry that offering help might seem like meddling, especially when things seem to be going well.

Knowing What Level of Care Is Needed

Before you take on the demanding job of home care, decide what level of care you must provide. Do you need to give:





- minimum assistance?
- moderate assistance?
- maximum assistance?

In order to decide what level of care is needed, you must understand the person's condition and needs in the areas of daily care and health. Generally, these needs fall into two broad groups:

Activities of Daily Living (ADLs) such as eating, bathing, dressing, taking medicine, and going to the toilet.

Instrumental Activities of Daily Living (IADLs) are activities that are important to independence, such as cooking, shopping, housekeeping, getting to the doctor, paying bills, and managing money.

Things to look for in deciding the overall level of care needed are the person's—

- ability to get from bed to wheelchair without help
- ability to move without help in wheelchair or walker
- ability to manage bladder and bowel
- ability to carry out the basic activities of daily living
- ability to call for help
- degree of sight and hearing impairment
- degree of confusion

Also, consider emotional conditions that might require advanced or special levels of care:

- depression
- a need to be with other people or to have privacy
- homesickness

After giving some thought to the level of care that might be needed and the person's condition, abilities, and emo-

tional state, try to place the person you might care for in one of these categories:

Minimum Assistance—This person is basically independent, can handle most household chores and personal care, and needs help with only one or two activities of daily living.

Moderate Assistance—This person needs help with three or more activities of daily living, such as bathing, cooking, or shopping.

Maximum Assistance—This person is unable to care for himself or herself, requires total assistance, and must be placed in a nursing home if no skilled caregiver is available in the home. Care is often provided by professionals, either in the home through home service agencies or in foster care homes, assisted living facilities, or nursing homes. At this level, serious problems are a real possibility.

Deciding Whether Home Care Is Possible

When a person has a chronic condition like multiple sclerosis, daily long-term skilled help with health and personal needs may be in order. Whatever level of care is needed, it can take place in three settings:

- the person's own home
- your home
- residential care facilities, such as a foster care home, assisted living, or a skilled nursing facility

Home Care Considerations


Whether care will take place in your home or in the home of the person who needs care, the following factors must be considered:





- Is there enough room for both the person and items such as a wheelchair, walker, bedside toilet, and lift?
- How accessible is the home if walkers or wheelchairs are used?
- Is a doctor, nurse, or specialist available to supervise care when needed?
- Is there a hospital emergency unit close by?
- Is the home environment safe and supportive and does it allow for some independence?
- Is money available to hire additional help?
- Is the person in question willing to have a caregiver in the home?
- Can the caregiver manage this role along with other family and personal responsibilities?

Things That Must Be Provided

- medication
- meals
- personal care
- housecleaning
- shopping
- transportation
- companionship
- accessibility (wheelchair ramps, support railings, and changes to the bath and shower stall) ( See *Preparing the Home*, p. 97)

Benefits of Home Care

- When a caregiver's spouse is supportive, the experience can strengthen the marriage.
- The relationship between the caregiver and the person in care can grow stronger.

- A great deal of money can be saved on health care costs.

Why Home Care May Not Be Possible

- financial reasons (inadequate health insurance to cover the cost of home nursing)
- family limits (lack of time or money)
- the caregiver's lack of physical and emotional strength
- the person's complex medical condition
- the home's physical layout
- the person's desire to live independently of family

Possible Hazards of Home Care

- Possible lack of freedom for the caregiver.
- Caregiver duties may affect the caregiver's job, career, hobbies, and personal life.
- There may be less time for family members, and the caregiver's family relationships may suffer.
- Children in the home may need to be quieter.
- There may be less time for religious services and volunteer work.
- Friends and family may criticize the caregiver's efforts and offer unwelcome advice.
- The caregiver may often be awakened during the night.
- The caregiver may feel unable to control life's events and may suffer from depression, worry, anger, regrets, guilt, and stress.
- Instead of being grateful, the person receiving care may display unpleasant changes in attitude.
- He or she may react to constant daily irritations by lashing out at the caregiver.






- The caregiver may begin to fear the time when he or she may be dependent on someone for care.
- The caregiver may feel obliged to spend personal funds on caregiving.
- The caregiver may become physically ill and emotionally drained.

Outside Help

One of the biggest pitfalls in caregiving is trying to do it all yourself. But other help is available and should be called on whenever possible. That help includes:

- support groups
- day care and respite care, which provide relief for the caregiver
- organizations providing respite care
- pastoral counseling services
- parish nurses
- medical services provided by professionals, such as nurses and therapists
- personal services for the person in your care, such as grooming or dressing, provided by home health aides
- community home health services on a fee basis, such as Visiting Nurse Associations ( See *Getting In-Home Help*, p. 45)

Supportive Housing and Care Options

If you believe that home care is not practical for you, many other options exist. Good programs foster independence, dignity, privacy, a very high level of functioning, and connections with the community. However, people who have lived independently all their lives may not be

Checklist **The Ideal Caregiver**

The ideal caregiver is—

- ✓ *emotionally and physically capable of handling the work*
- ✓ *able to share duties and responsibilities with other willing family members*
- ✓ *able to plan solutions and solve problems instead of withdrawing under stress*
- ✓ *able to speak in a simple and clear way*
- ✓ *comfortable giving and receiving help*
- ✓ *trained for the level of care required*
- ✓ *able to handle unpleasant tasks such as changing diapers, bathing, or cleaning bed sores*
- ✓ *in good health and has energy, skill, and the ability to adapt*
- ✓ *able to cope with anger and frustration*
- ✓ *able to afford respite (back-up) care when necessary*
- ✓ *able to speak to and understand the care receiver*
- ✓ *able to make this person feel useful and needed*
- ✓ *valued by other family members*
- ✓ *able to adjust to the future needs and wishes of the person in care*
- ✓ *aware of other care options and willing to explore them*

If you have most of these traits, you may be a good candidate to provide home care. However, consider the list called “Possible Hazards of Home Care” and be honest with yourself about your ability to cope.





suited to live in groups, and those who are mentally alert or are younger may be very unhappy living with people who suffer from dementia.

Keep the above factors in mind when you check out the following:

- **Independent Living Options**—apartment buildings, condos, retirement communities, and single-family homes
- **Semi-independent Living Options**—places that offer the same benefits as independent living but also include meal service and housekeeping as part of the monthly fee, provide help with personal care, keep track of health and medications, and provide special diets. These options are frequently offered in assisted living facilities and group homes.
- **Skilled Care Facilities**—nursing homes

NOTE

States use different names for care facilities. The services can also vary, so it is important to check with the facility and each state's licensing agency to confirm exactly which services are offered. For example, in Wyoming, assisted living allows people who are unrelated to share a room. In some other places, living spaces are not shared, except by personal choice.

A Closer Look at the Options

House Sharing—for people who are fully independent

- Two or more unrelated people live together, each with a private bedroom.
- All living areas are shared.
- Chores and expenses are shared.
- Personal-assistant services may be shared.

Group Homes or Adult Foster Care Homes—homes in residential neighborhoods for people whose needs vary, from assistance with individual services to dependent residents with increased nursing services

- Care is given to small groups of people in the primary caregiver's home or with a live-in resident manager/caregiver.
- The home is privately run and provides private or shared rooms with meals, housekeeping, personal care (such as bathing and dressing), keeping track of medication, safety supervision, and some transportation.
- Rates vary according to individual care needs, and Medicaid funding is often available for repayment to those who qualify.
- Staff are qualified and facilities are licensed according to the level of services offered, which can include housekeeping, laundry, personal care assistance, bathing, dressing, grooming, and management of medication and other medical needs, such as injections or inability to control bladder and bowel.

NOTE

Some states do not license, inspect, or keep watch over adult foster care homes. Before selecting one, call your local Area Agency on Aging or the state or county Department of Health to see if any complaints have been filed against the home you are considering.

Assisted Living Facilities—for moderate assistance to those who are frail and usually require assistance with activities of daily living

- Each person lives in his or her own apartment.
- An emergency staff is available 24 hours a day.
- Monthly charges are based on the level of service needed.





- Activities such as games, hobbies, crafts, and music are offered.
- Meals, housekeeping, medication management, and nursing assessment are provided.
- Transportation and access to medical services can be arranged.

NOTE

There is no national control over these facilities but there is state licensing and regulation. For information on a specific facility, call the ombudsman in your state or the state agency that licenses the facility. (An ombudsman is someone who looks into complaints made by individuals.)

Continuing Care Retirement Communities—for people who want a range of services from independent living to nursing home care

- These facilities provide a lifetime contract for care.
- They provide or offer meals and can handle special diets.
- They offer housekeeping, scheduled transportation, emergency help, personal care, and activities for fun and learning.
- Many retirement communities require entrance fees that can vary quite a bit.
- They also have monthly fees ranging from several hundred to several thousand dollars.
- Some provide home health care and nursing home care without extra fees.
- Some charge extra for nursing unit residents.

Nursing Homes—for people who require continuous and ongoing nursing assistance or monitoring

Nursing homes typically offer three levels of care:

- **Custodial**—minimal nursing, but help with hygiene, meals, dressing, etc.
- **Intermediate**—help for those who cannot live alone but do not need 24-hour skilled nursing care
- **Skilled Nursing**—intensive 24-hour skilled nursing care

Hospice care is available in all settings as a covered benefit under Medicare. It is also covered for those who receive Medicaid in states that offer hospice coverage under their Medicaid program.

Financing Options

The choice of the right housing option may depend on financing available:

- **Personal Resources** are the most common way to pay.
- **Private Insurance** is helpful, but some policies limit the length and type of benefits and have waiting periods or other limits.
- **Medicare** is for those 65 and older or for people who have been declared disabled by the Social Security Administration. Medicare partially pays for up to 100 days in a skilled nursing care facility after a qualifying related hospitalization of more than three days in a row (not including the day the person leaves the hospital). The financing of hospice care is a separate benefit under Medicare.
- **Medicaid** partially pays for services, including assisted living services in some states, to those who are aged, blind, or have disabilities and have limited financial resources. It is also a major payer for nursing home care.



Checklist **Review Before Deciding on a Facility**

- ✓ *Is a trial period allowed to be sure a person is happy with the facility?*
- ✓ *Will the facility refund deposits or entrance fees if the resident dies, chooses to leave, or is asked to leave?*
- ✓ *Can a resident choose his or her own apartment? Can personal furniture be used?*
- ✓ *Are there younger residents at the facility?*
- ✓ *If the person must be away for a short time (even for a hospital stay), will the same apartment be available when he or she returns? Is there a reduced rate during long absences?*
- ✓ *If the person marries, can the couple live in the same apartment?*
- ✓ *Can the staff handle special diets? Are meal menus posted?*
- ✓ *Is transportation provided?*
- ✓ *How many people are on staff and how much training have they had?*
- ✓ *How often and for what reasons can staff enter the apartment?*
- ✓ *Can the resident see his or her own doctor? Who gives out the medications?*
- ✓ *Is physical therapy available within the facility?*
- ✓ *Is the facility licensed to deal with a resident whose health gets worse or must the person leave if, for example, he or she can no longer walk or begins arguing or fighting with others?*
- ✓ *How are decisions made when a person must be moved to another part of the facility?*
- ✓ *Is there a 30-day-notice provision for ending the agreement?*
- ✓ *Does the facility take Medicare?*
- ✓ *Will the facility let a resident “spend down” his or her assets and go on Medicaid?*

- **Medigap** policies cover gaps in coverage and may be in place to pay Medicare coinsurance.

( See *Financial Management*, p. 71.)

Points to Review Before Signing a Contract or Lease

Although it is hard to know what problems may arise in a care setting, it is extremely important to take the following steps before signing any legal papers:

- Find out who owns the facility and review the owner's financial status.
- Ask for a copy of the contract and review it with an attorney or financial advisor.
- Do not rely on spoken promises. Make sure the contract is geared to the resident's needs.
- Read the state inspection report on the facility.
- Read all the rules and policies of the facility that are not in the contract.
- Ask to see the facility's license.

Things You Should Know About Facilities

Residents' Rights

General Rights—Residents maintain all their rights guaranteed under the U.S. Constitution, including the right to vote. In addition, they can receive visitors, voice their concerns, form resident councils, and enjoy informed consent, privacy, and freedom of choice.

Privacy—In some cases, a resident may have a roommate. However, residents' rooms are considered private and staff must knock before entering. Also, residents can have private visits with spouses.





Restraints—Only the resident’s doctor may order a restraint as part of a care plan and must state the specific restraint’s use and period of use. (Use of restraints is strongly discouraged, although not prohibited.)

Lifestyle Choices—Residents do not have as many choices as they would have at home regarding meal times, menu choices, and times for sleep. However, most facilities try to satisfy residents’ needs as much as possible.

Ability to Effect Change—Issues can be brought up to the resident council or the long-term-care ombudsman.

Freedom to Leave—A person chooses to enter a facility and has the right to leave at any time regardless of what the family thinks or safety concerns.

NOTE

The following describes general guidelines regarding a resident's rights. To obtain specific rules for a particular state, contact the state agency responsible for licensing the facility.

The Resident's Rights When Leaving a Facility

Depending on the admission agreement, a resident must be given written notice 30 days before being moved. If there is a medical emergency, no written notice is required. Generally, a resident may be moved from a facility for the following reasons:

- The person wants to be moved.
- The person must be moved for his or her own good.
- The person must be moved for the good of other residents.

- The facility is not being paid. (However, someone who runs out of money cannot be moved if Medicaid will pay.)
- The person came into the facility for special care and that care is completed.
- The facility is being closed.

If the person does not want to leave the facility, IMMEDIATELY contact the state agency responsible for licensing the facility and/or Medicaid certification.

If you have questions, call the following:

- the Center for Medicare-Medicaid Services
- the local Senior and Disabled Services Division of the Department of Health and Human Resources
- the long-term-care ombudsman
- the Federal Health Care Financing Administration
- the local Area Agency on Aging

What Family Members and Friends Should Do

- Visit whenever possible.
- Send cards or letters between visits.
- Bring small gifts and treats.
- If allowed, walk around with the person when visiting to provide exercise.
- Listen to the resident's complaints.
- Build a good relationship with the staff.
- Plan off-site outings if appropriate.





RESOURCES▶

AARP

601 E Street, NW
Washington, DC 20049
(800) 424-3410
www.aarp.org

Web site provides information on housing and other senior issues.

National Council on Independent Living

1916 Wilson Boulevard, Suite 209
Arlington, VA 22201
(703) 525-3406 (voice)
(703) 525-4153 (tty)
ncil@ncil.org
www.ncil.org

Refers callers to local independent-living centers. Offers publications and advice related to disability issues. Advocates for policy changes.

Assisted Living Facilities and Nursing Homes

American Association of Homes and Services for the Aging

2519 Connecticut Avenue, NW
Washington, DC 20008
(202) 783-2255
(800) 508-9442
www.aahsa.org

Provides information on not-for-profit nursing homes, senior housing facilities, assisted living, and community services. Call for free consumer information brochure.

American Health Care Association/National Center for Assisted Living

1201 L Street, NW
Washington, DC 20005
(202) 842-4444
www.ahca.org

Provides consumer information on services, financing, public policy, nursing facilities, assisted living, and subacute care. Represents more than 10,000 providers of assisted living, nursing care, and subacute care.

Assisted Living Federation of America

11200 Waples Mill Road, Suite 150
Fairfax, VA 22030
(703) 691-8100
www.alfa.org

Offers referrals to local facilities listed by state. Provides free 15-page consumer guide to assisted living.

The Center for Medicare and Medicaid Services has detailed information about the past performance of every Medicare- and Medicaid-certified nursing home in the country. For more information, go to www.medicare.gov, click on Search Tools at the top of the page, and then click on Compare Nursing Homes in Your Area. For a list of **Medicare-certified nursing homes**, call the local office or department on aging.

Respite Services

ARCH National Respite Locator Service

800 Eastowne Drive, Suite 105
Chapel Hill, NC 27514-2204
(919) 490-5577
www.respitelocator.org

Provides caregivers with contact information on respite services in their area.





Eldercare Locator

National Association of Area Agencies on Aging
1730 Rhode Island Avenue, NW, Suite 1200
Washington, DC 20036
(800) 677-1116

www.eldercare.gov

www.aoa.dhhs.gov

Supplies information about many eldercare issues, including respite care. Provides referrals to local respite programs and local Area Agency on Aging.

Books

Creative Caregiving by James Sherman, PhD

Available from National Multiple Sclerosis Society (800) FIGHT-MS (800-344-4867) or www.nationalmssociety.org

Brochures

Brochures designed and published by the National Multiple Sclerosis Society are available at your local chapter. Call (800) FIGHT-MS (800-344-4867) to locate the nearest chapter. Some are available online at www.nationalmssociety.org

A Guide for Caregivers by Tanya Radford

If you don't have access to the Internet, ask your local library to help you locate a Web site.