

A Guide for Caregivers



National
Multiple Sclerosis
Society

A Guide for Caregivers

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Foreword

Partners, family and friends can be drawn more closely together when they meet the challenges of caring for a loved one with a chronic illness. Providing loving care can be deeply satisfying, but also physically and emotionally exhausting especially for the primary caregiver (often a partner or spouse, but can also be a child, parent or friend).

There are a wide range of caregiving activities, just as there are a wide range of abilities and disabilities among people with MS. Someone giving care to a person who has relatively few functional difficulties may be helping with injections of a disease-modifying medication and offering support in dealing with the medical team. Someone caring for a person with a more severe level of disability may be involved in daily activities like toileting, dressing, transferring, and feeding, as well as medical treatments. This booklet provides an overview of the issues that caregivers in most kinds of situations might face.

Those caring for someone who is newly diagnosed or who has little disability may want to concentrate only on those sections relevant to their particular situation. The resource section at the end is a good starting place for those who want more in-depth information or specific kinds of support.

Throughout this booklet, the term **caregiver** is used to refer to the person primarily responsible for providing daily care to a person with MS. It may help to remember that the person giving care and the person receiving care are in this together.

Living with MS requires a team effort by the caregiver and the person with MS — a partnership that grows and evolves over time. This booklet sometimes refers to them as **carepartners**. MS doesn't change the fact that important relationships are always a two-way street. The person with disabilities may need a great deal of assistance, but the needs and concerns of **both** partners must be addressed if the relationship is to remain healthy.

The more you can each learn about MS, the better able both of you will be to deal with the challenges ahead. Don't be shy about asking your medical team for advice on sources of support and assistance, and reach out to the National MS Society. Being proactive early on will eliminate a lot of frustration down the road. Open communications between all parties is something that can't be emphasized enough.

Part I: Emotional Support

Providing emotional support and physical care to someone with MS is often deeply satisfying, but it is sometimes distressing, and — now and then — simply overwhelming. The strain of balancing employment, child-rearing, increased responsibilities in the home and the ongoing care of a loved one can lead to feelings of martyrdom, anger and guilt.

One of the biggest mistakes caregivers make is thinking that they can — and should — handle everything alone. The best way to avoid burnout is to have the practical and emotional support of other people. Sharing problems with others not only relieves stress, but can give new perspectives on problems.

“Why doesn’t anyone ask how I am?”

It is easy to feel invisible. Everyone’s attention goes to the person with MS and no one seems to understand what the caregiver is going through. Many caregivers say, “no one even asks.” Mental health experts say it’s not wise to let feelings of neglect build up. Caregivers need to speak up and tell other people what they need and how they feel.

If this seems like disloyalty to a partner or family member, or a caregiver fears being labeled a complainer, reach out to support groups, religious advisors, or mental health counselors to learn constructive communication techniques.

Self-help groups can provide an outlet for emotions and a source of much needed practical information. The National MS Society has affiliated self-help groups all around the country for people with MS, and many groups for caregivers exist as well. Religious and spiritual communities often provide support and guidance.

Many caregivers say it is difficult to find time to attend group meetings. They want to use their limited time for other things. The benefits of a group might be obtained through the internet. There are many useful online caregiver chat groups.

Effective ways to acknowledge feelings

Some people find that talking about carepartnership happens more easily when they schedule a regular time for conversation. Taking time out to sort out your feelings before bringing them up for discussion will make it easier to speak clearly and calmly. Ignoring a problem will not make it disappear. Anger, grief and fear are natural responses to challenges that can sometimes feel overwhelming. Talking about them can lead to productive and collaborative problem-solving. Trying to keep them under wraps may simply lead to guilt, numbness and resentment.

Two-way communication

Discuss concerns and fears openly; everyone needs emotional support. Although collaboration isn’t always easy or possible, working out long-term plans and goals together

will help both carepartners to feel more secure. Many emotional stresses are the result of poor communication.

The emotional and cognitive symptoms of MS are often more distressing than the physical changes. If memory loss, problems with problem solving, mood swings or depression are interfering with open communication or disrupting daily activities, consult a healthcare professional.

Taking care of the caregiver

Many caregivers focus so much attention on the needs of the person with MS that their own physical health is compromised. They ignore their ailments and neglect preventive health measures like exercise, diet and regular medical examinations.

Many caregivers do not get adequate rest or uninterrupted sleep. If sleep is regularly disrupted because the person with MS wakes in the night needing help with toileting or physical problems, discuss the problems with a healthcare professional.

The person with MS needs a healthy caregiver, and an effective care partnership depends on the physical and emotional wellbeing of both partners.

Outside activities

Researchers report that the emotional stress of caring has little to do with the physical condition of the person with MS or the length of time the person has been ill. Emotional stress seems more related to how “trapped” caregivers feel in their situation. This, in turn, seems to be closely related

to the satisfaction they have in their personal and social relationships, and the amount of time available to pursue their own interests and activities.

Successful caregivers keep up enjoyable activities. Many organizations have respite care programs. Other family members are often willing — even pleased — to spend time with the person with MS. It may be possible to arrange respite care on a regular basis. Keep a list of people to ask on an occasional basis as well.

It is important for both the person with MS and the caregiver to stay involved in activities that have meaning for them and to make time for regular physical exercise.

Handling unpredictability

Living with MS means expecting the unexpected, making backup plans, and focusing on what can be done rather than what can't. The unpredictability of MS can be very stressful, but it can be managed.

If you are making plans for outings, for example, always include extra time for travel. Calling ahead to check out bathroom facilities and entrance-ways is wise. Buildings are not always accessible, even when they say they are. Don't make plans too complicated. And when plans fall through, have an alternative ready. If the night out is impossible, order in pizza.

A list of backup people who can be contacted for help at short notice is also useful.

Sex and intimacy

Carepartners who are also spouses or partners usually face changes in their sexual relationship. These changes can have physical or emotional causes. MS can interfere with both sex drive and function. Problems can include decreased vaginal lubrication, numbness or painful sensations, decreased libido, erectile dysfunction, or problems reaching orgasm.

MS fatigue can interfere with sexual activity. Spasticity or incontinence problems can negatively affect sexual desire. Most of these symptoms can be managed, so it is a good idea to seek the help of a healthcare professional.

In addition to MS-related functional problems, changes in roles may change the sexual relationship. Caregivers feel that they are performing a parental role, rather than being a lover or spouse, and this can dampen intimacy.

Sexuality does not have to disappear. Partners might begin by discussing what they find most rewarding about their intimate relationship. Many preconceived ideas of what sex should be prevent the satisfaction of actual needs and pleasures. Discussion could lead to the discovery of more imaginative sexual behaviors.

Open and honest communication about sexual needs and pleasures without fear of ridicule or embarrassment is the crucial first step. Counseling with a sex therapist can be helpful in this process.

Dependency and isolation

Concerns about dependency and isolation are common in the families of the chronically ill. The person with MS is increasingly dependent on the carepartner, and the carepartner needs others for respite and support. Many caregivers feel shame about being dependent on others. As a result, many don't ask for the help that they need. Anxieties are greatly reduced for carepartners who are able to develop personal and social support.

Anger

The situation feels — and MS is — unfair. Sometimes anger and frustration can build until it begins to seep out in hurtful words or actions. Talking about feelings with each other and with a counselor or religious advisor is an effective way to keep feelings from becoming overwhelming or spinning out of control. Physical exercise, meditation, and other self-care activities are also healthy outlets for anger and frustration.

Avoiding abuse

As carepartners, it is critical for both people to care for each other's emotional and physical well-being. While circumstances that produce frustration and anger are often unavoidable, an emotionally damaging or physically aggressive response is not okay. Tensions can mount in the most loving of families and both carepartners may struggle with strong emotions, but abusive behavior is never acceptable. If tensions are mounting, call for a time-out, and call for help.

Physical abuse usually begins in the context of giving or getting personal help — the caregiver might be too rough during dressing or grooming. The person with MS might scratch a carepartner during a transfer. Once anger and frustration reach this level, abuse by either partner may become frequent.

The dangers of physical abuse are obvious, but emotional abuse is also unhealthy and damaging. Continued humiliation, harsh criticism, or manipulative behaviors can undermine the self-esteem of either partner.

The majority of carepartners never experience such levels of distress or become abusive. Family and social groups may provide support and counsel. Therapists and marriage counselors can help partners work out problems. Sometimes having another person (a counselor) facilitate conversations around the real challenges in MS for the person with MS and the caregiver can help both people understand each other better. If the relationship is no longer sustainable, a counselor may also assist with the difficult choices regarding divorce or long-term care options. The National MS Society can offer local referrals.

Part II: Caring at Home

Adapting for safety, accessibility and comfort

Adaptations can increase safety, accessibility and comfort for everyone. But before deciding to make major home renovations, ask a doctor for a referral to an occupational therapist (OT) and physical therapist (PT) for a home visit. These therapists can suggest ways to keep the person with MS as independent as possible, ensure safety and reduce the physical strain on the caregiver. Ramps, widened doorways, and renovations in the kitchen and bath can often solve accessibility problems. New or existing equipment such as walkers, wheelchairs, etc. need to be addressed both for the home and work environment. The needs for each of these settings may be different. There are home remodelers and architects who can be consulted to make the necessary changes. These changes may need to comply with various regulations and/or Americans with Disabilities Act (ADA) requirements. Not all changes involve major expense. The National MS Society has information about practical, low-cost modifications and can provide referrals to appropriate resources.

Flexible roles

MS is extremely changeable and unpredictable. People experience attacks and remissions, loss and recovery or partial recovery of abilities. One day a person with MS can

dress alone, the next day the person can't. The caregiver has to take and then give back responsibility for tasks all the time.

Caregivers will need to rethink tasks and family schedules in order to ensure the smooth running of the household.

For example:

- Household tasks such as general cleaning, shopping, cooking, laundry, child care and transportation.
- Care-related tasks such as dressing, bathing, eating, toileting, exercising, transportation, doctor visits and taking medication.
- Daily activities such as work, recreation, entertainment, exercise, hobbies, private time and religious activities.

Plan to re-evaluate schedules and task assignments as needs and circumstances change. And make sure to schedule personal time for everyone in the household.

Relationships change, particularly as people with more advanced MS lose their independence and caregivers have to take on more and more responsibilities. This shift can be a source of tremendous anxiety.

Inevitably, the caregiver and the person with MS will have different perspectives about the same issue — about adaptations, the severity of symptoms, the amount of assistance needed or whether hired help needs to be sought. MS affects everyone involved, but it affects everyone differently. Take the time to talk about it.

Helping with daily activities

If a task seems impossibly difficult or stressful, there is probably an easier way to do it. The medical team can provide tips and techniques for bathing, dressing, toileting and safe transfers. Other caregivers and the National MS Society are also good sources of advice and tips.

Roles and gender differences

Women and men who act as caregivers face the same day-to-day responsibilities, frustrations and satisfactions. However, women caregivers may feel more comfortable than men caregivers, since caregiving has traditionally been viewed as a more feminine role.

Studies have found that many men who are caregivers report difficulty in discussing their problems and are more likely to suppress emotional reactions. They find it more difficult to ask for help and many do not use the resources available to caregivers. On the other hand, men may be more willing to participate in social and recreational activities that contribute to their overall well-being.

Women are often better at expressing their feelings and accessing supportive networks. But women caregivers are more likely to neglect their own health, and their need for outside activities. They tend to report more physical and emotional ailments than their male counterparts.

Family and friends

Family and friends can be crucial members in a network of assistance but caregivers often report that it's hard to actually get their help. The first step is to tell friends and family that their help is needed and welcomed. Friends often worry that offering help might seem intrusive, especially when it looks as if things are being handled well.

Keep a list of projects, errands and services that friends could do. Then, the next time someone offers to help in some way, it will be easy to oblige them. Give people specific, time-limited tasks. Asking a friend or relative to come by on Saturday for three hours in the afternoon so the caregiver can run errands is going to be more successful than asking them to stop by when they have a moment.

Medical issues

Management of MS and its symptoms will be easier if everyone involved learns as much about the disease as possible. For general information, contact the National MS Society. To get the best information about an individual, caregivers should rely first on the person with MS and that person's medical professionals.

The healthcare team and symptom management

Many MS symptoms can be controlled by medications, management techniques and rehabilitative therapies. Once a person with MS has given permission for the healthcare team to talk with his or her carepartner, the healthcare

team can offer symptom management tips and strategies, including those that can help with the bowel and bladder issues or sleep problems that can be particularly challenging for carepartners. Although MS cannot yet be cured, symptoms can be managed.

For some people, the most frightening aspect of giving care to someone with a chronic disease is being responsible for treatments. This may involve keeping track of medications, administering injectable drugs, or performing intermittent urinary catheterization.

Caregivers can and should make appointments with healthcare professionals to get information, advice and training. Treatment plans can fail if the caregiver does not know the medical staff, does not understand why and how a procedure is done, or instructions are given that seem impossible to carry out. If there are problems with carrying out a medical or treatment procedure, contact the healthcare team and arrange for a follow-up training session. With proper training and a little experience, most caregivers end up feeling confident about this part of their role.

It isn't always MS

Both the person with MS and the caregiver need to remember that having MS doesn't protect anyone from the normal ills that can affect us. This is especially important for people with MS who see a neurologist for their medical care. Specialists may not suggest routine, preventive health exams like Pap smears or prostate exams. Type "Preventive Care Recommendations for Adults with MS" in the search

box on the Society's Web site at nationalMSSociety.org, or call 1-800-344-4867 to receive a printed copy of this important document.

When a child is a caregiver

Sometimes children assume major household and personal care responsibilities when a parent has disability due to MS. This is more likely to occur in single-parent households. While it is positive for children to take on household responsibilities, their needs must be carefully balanced with the amount and level of caregiving they are expected to do.

Children are not equipped to handle the stress of being a primary caregiver. They should never be responsible for a parent's medical treatments or daily functions such as toileting. Children under 10 can certainly handle some household chores. Young teenagers can take on more responsibility, but they also need to spend some time with their peers. Older teenagers and young adults may be competent caregivers, but they should not be expected to undertake long-term primary care. They have their own futures to attend to.

When a parent is a caregiver

The return of an adult child to the home can be stressful for both the parents and the adult child. Often, this homecoming resurfaces the earlier struggles that occurred before the child became independent. Parents probably have house rules that they want to have respected. But the

adult child needs to be treated as an adult, and some house rules may presume the wrong kind of dependence.

As parents age, providing care often becomes more difficult. In time, one or both parents may become ill and require care themselves. Alternative care plans and living arrangements should be discussed with the adult child well before such a crisis occurs.

Safety and security

Leaving a person with significant disabilities home alone can be a frightening proposition for both partners. Advance planning and adaptation of the home can decrease these worries. Accessible peepholes in the front door, portable telephones with speed dial, automatic door openers, and "life-net" call systems that summon help in an emergency may provide security.

If there is no secure way to leave a person with a severe disability home alone, then don't do it! Find help or alternatives.

Part III: Hiring Help

People with disabilities often need significant help with daily care. Family and friends may not be able to do it alone and additional help may be needed. Unfortunately, this kind of help is not generally covered by insurance plans. Unless one of the carepartners has a long-term care

insurance policy with a home care provision, paid care will be dependent on what the family can afford.

Doctors often refer to specific professional nurses and therapist agencies. However, it is often less expensive to hire home care aides and domestic assistants independently. Hiring capable, reliable and trustworthy help will be easier if the needs and concerns of the person receiving care are discussed in advance. The person with MS should always be part of the interview process.

Other caregivers, the healthcare team and the National MS Society can be of help in locating reliable agencies that screen and refer potential candidates. They can also provide you with tips on how to find, interview and train home care workers on your own.

Neighborhood teenagers are an underused source of low-cost help. Some schools require community service, and many teenagers would like part-time work. Ask the honors program advisor at the local public high school for names of interested students. Be willing to write recommendation letters for students who work for you and be ready to teach them something about MS and disability. Be prepared to pay at least the minimum wage.

What level of care is needed?

It's important to be realistic about what the person with MS needs, and what the caregiver can provide in terms of time, kinds of care and financial responsibility. This is more easily said than done. Making changes — whether small

or large — can be enormously difficult. Coming to terms with chronic illness and disability takes time and strength. Rational decision making can be sidetracked by anger, guilt, grief, confusion or shame. Carepartners can benefit from speaking with a therapist, counselor, or other person outside the situation to get a clearer perspective.

Don't be afraid to ask for help. The cost of not asking for help may be very high for everyone involved.

Even people with a significant level of disability can live at home successfully. There are usually a number of solutions to practical problems. For example, someone who cannot transfer from wheelchair to bed or bath can be moved using the proper kind of lift. People with disabilities can be more independent when a home has wide doorways and grab bars. When the caregiver works full-time and the person with MS needs some aid and companionship during the day, adult day programs may be an option. Caregiver burnout can be avoided when the carepartners make use of respite care, friends and support groups.

Part IV: Other Care Options

Evaluating care needs is a joint effort and must be an ongoing process. Ask your medical team to assess what treatments, adaptations and other changes are necessary. For some, training in self-administering medical treatments, advice on coping with fatigue and occasional relapses, and some long-range financial planning will suffice. For others,

more at-home support will be needed. And for some, assisted living or a nursing home will be the better choice for all concerned.

Due to the complex clinical needs of MS, and the years of caregiving that might be required, providing care at home can become impossible for some families. If that time comes, it is important to explore all the options available. There are different kinds of live-in facilities, including assisted living, supportive housing, continuing care communities and nursing homes. Deciding what kind of facility is best will depend on individual needs and financial resources available.

The cost of care

All care options cost money — a situation that often coincides with a drop in the income earned by the person with MS. Researching possible resources begins with asking questions. Start with the National MS Society or with a social worker at your hospital, social agency or MS clinic.

Resources include local public agencies for people with disabilities such as independent living centers and agencies for senior citizens. (They often serve younger people with disabilities.) Some states have respite care and/or personal-care assistant programs for people who are not otherwise eligible for Medicaid and might allow a loved one to remain at home longer. Research the national organizations listed in the Resources section beginning on page 22 as well.

Part V: Practical Decisions

Most people with MS do not develop such severe disability that they require full-time, long-term care. But since there is no way to predict who will develop severe disability, it is wise to make contingency plans. This means investigating the kinds and costs of local long-term care options before a crisis occurs.

Financial and life planning

Financial and life planning for continued financial stability are essential and should be undertaken early. The process of long-term planning will help the carepartners feel more secure about their well-being, regardless of what the future brings. A book titled *Adapting: Financial Planning for a Life with Multiple Sclerosis* is available on the Society's Web site at [nationalMSSociety.org/financialplanning](https://www.nationalMSSociety.org/financialplanning).

Life planning includes an investigation of income tax issues, protecting existing assets, saving for future financial needs and end-of-life planning. People should seek advice about insurance, employment rights and state assistance, and discuss all options.

Carepartners need to understand the coverage provided by their medical insurance, including Medicare, Social Security benefits and available private disability insurance. Some people may qualify for state programs such as public assistance, food stamps or Medicaid. Hospital or clinic social workers are good resources for information regarding these programs.

Caregivers also need a clear understanding of the ADA and other legislation that provide protections concerning housing, transportation, recreation, and employment. A booklet outlining the basics of the ADA is available from the National MS Society. Sometimes there needs to be planning around a move to more accessible housing. Moving to a place that is near public transportation, stores, and other public facilities can give a person with disabilities more choices. It might also make it easier to hire necessary help.

Since each person's situation is unique and the laws pertaining to legal and financial issues vary from state to state, it is wise to seek the advice of professional financial planners and "elder law" attorneys who specialize in disability-related law. Professionals can help sort through available options and explain the possible legal and tax consequences of various choices.

Advance medical directives preserve a person's right to accept or reject medical treatment. They are essential tools for maintaining personal control in the event of incapacitating illness or disability. Medical directives come in two forms. Both are needed for complete protection: (1) a living will, in which the person outlines specific treatment guidelines to be followed by healthcare providers; (2) a healthcare proxy in which the person designates a trusted individual to make medical decisions if the person is unable to do so. Advance directive requirements, like other legal and financial issues, vary from state to state. They should be written with the help of an attorney who is familiar with the relevant state laws. An attorney is not needed for advance directives naming a healthcare proxy.

Part VI: Resources

Books

These titles may be available from the National MS Society, the publisher or online booksellers.

- ***Caring for Loved Ones with Advanced MS: A Guide for Families***, Dorothy E. Northrop, MSW, ACSW, and Debra Frankel, MS, OTR, ed. 2010. 112 pp. Available in print or online from the National MS Society.

This publication provides caregiving tips and support to families providing significant daily care to a family member with MS.

- ***Multiple Sclerosis: A Guide for Families***, Rosalind C. Kalb, PhD, ed. Demos Health, (3rd Ed.), 2006. 256 pp.
- ***Multiple Sclerosis: The Questions You Have, the Answers You Need***, Rosalind C. Kalb, PhD, ed. Demos Health, (5th Ed.), 2012. 448 pp.

Contains chapters on topics ranging from emotional and cognitive issues, to sexuality and intimacy, to life planning.

Focuses on medical issues and treatment, with chapters on financial planning, insurance, and occupational therapy.

- ***Adapting: Financial Planning for a Life with Multiple Sclerosis***, National Endowment for Financial Education, 2003. 72 pp. Available in print or online from the National MS Society.

A guide addressing financial organization, planning, insurance options, employment concerns, and benefit issues with strategies to help families plan wisely for the future and meet financial challenges that often accompany life with MS.

- ***The Comfort of Home: An Illustrated Step-by-Step Guide for Caregivers***, by Maria M. Meyer with Paula Derr, RN. CareTrust Publications, (3rd Ed.), 2006. 326 pp.
www.comfortofhome.com

A practical guide to caregiving, from activities of daily living to emergency situations. Includes many illustrations.
- ***Helping Yourself Help Others: A Book for Caregivers***, by Rosalynn Carter, with Susan Golant. Random House/Time Books, 1995. 288 pp.

Lots of basic information for caregivers.
- ***Multiple Sclerosis: Your Legal Rights***, by Lanny Perkins, Esq. and Sara Perkins., Esq. Demos Health, 3rd edition, 2008. 153 pp.

A comprehensive guide to working with doctors and lawyers, making choices about employment and income, MS and your job, disability and other federal benefits, insurance issues, dealing with taxes, family law, handling debts, and getting around with MS.
- ***Primary Progressive Multiple Sclerosis: What You Need to Know***, by Nancy J. Holland, EdD, Jack S. Burks, MD, and Diana M. Schneider, PhD. DiaMedica Publishing, 2010. 166 pp. Available from the National MS Society.
- ***Dressing Tips and Clothing Resources for Making Life Easier***, by Shelley P. Schwarz, updated for 2001. 140 pp.
www.makinglifeeasier.com.

A guide to dressing for people with disabilities plus over 100 resources for custom clothing.

Caregiver support

- **Caregiver.com**
www.caregiver.com

 - Maintains one of the most visited caregiver sites on the internet.
 - Publishes *Today's Caregiver* magazine.
 - Provides links to many resources such as government and nonprofit agencies.
- **Today's Caregiver Magazine**
www.caregiver.com/magazine
 800-829-2734

 - A bi-monthly caregiver magazine.
- **Caregiver Action Network (CAN)**
www.thefamilycaregiver.org
 202-454-3970, info@caregiveraction.org

 - The nation's leading family caregiver organization working to educate, support, empower and improve the quality of life people who care for loved ones with a chronic illness or disability.
- **The Well Spouse Association**
www.wellspouse.org
 800-838-0879, info@wellspouse.org

 - Advocates for and addresses the needs of individuals caring for a chronically ill and/or disabled spouse/partner.
 - Publishes *Mainstay*, a quarterly newsletter.
 - Provides networking/local support groups.

- **AbleData**
www.abledata.com
 800-227-0216 (Voice), 703-992-8313 (TTY),
abledata@neweditions.net

 - A premier source for impartial, comprehensive information on products, solutions and resources to improve productivity and ease with life's tasks with a database of over 29,000 products that can be searched by type or topic.
- **Making Life Easier**
www.makinglifeeasier.com

 - Web site offers practical lifestyle information and helpful strategies for people whose lives have been affected by chronic illness and disability.
- **National Council on Independent Living**
www.ncil.org
 Toll Free: 877-525-3400, 202-207-0334 (Voice),
 202-207-0340 (TTY), ncil@ncil.org

 - Refers callers to local independent living centers.
 - Offers publications and advice related to disability issues.
 - Advocates for policy changes.
- **National Rehabilitation Information Center for Independence**
www.naric.com
 800-346-2742 (Voice), 301-459-5984 (TTY)
naricinfo@heitechservices.com

 - A database of research information about assistive technology and rehabilitation.
- **TenTen Sinclair Housing Inc.**
www.tenten.mb.ca

 - Promotes, develops and administers affordable, accessible housing and support services in keeping with the independent living philosophy.

Home care agencies/hiring help

- **National Association for Home Care and Hospice**
www.nahc.org
 202-547-7424

 - Represents the nation's 33,000 home care and hospice providers as well as the interests of the chronically ill and disabled and the caregivers who provide them with in-home health and hospice services.
 - Provides referrals to state associations, which can refer callers to local agencies.
- **Hiring Help at Home**

 - A fact sheet from the National MS Society. To order, call 800-344-4867.
- **Paralyzed Veterans of America**
www.pva.org
 800-424-8200, info@pva.org

 - Working to provide veterans and people with disabilities, and their families, with everything they need to live full and productive lives.
 - Publishes *Managing Personal Assistants: A Consumer Guide*, with information on recruitment, interviewing, reference checking, training, being a good manager, maintaining a good working and personal relationship, problems that might arise and how best to solve them, service dogs, assistive technology, and tax responsibilities. Contains sample forms and letters.

Assisted living facilities and nursing homes

- **American Health Care Association**
www.ahcancal.org
202-842-4444
 - Provides consumer information on services, financing, public policy, nursing facilities, assisted living and subacute care.
- **Leading Age**
www.leadingage.org
202-783-2242
 - Provides information on not-for-profit nursing homes, senior housing facilities, assisted living and community services.
- **Assisted Living Federation of America**
www.alfa.org
703-894-1805
 - Offers referrals to local facilities listed by state.

Respite services

- **ARCH National Respite Network and Resource Center**
www.respitelocator.org
 - Provides caregivers with contact information on respite services in their area.
- **CJE SeniorLife**
www.cje.net
773-508-1000, info@cje.net
 - Provides support, education and respite for caregivers.
- **Eldercare Locator**
www.n4a.org
202-872-0888
 - National Association of Area Agencies on Aging.
 - Supplies information about many eldercare issues, including respite care.
 - Provides referrals to local respite programs and area agencies on aging.
- **United Way**
www.unitedway.org
703-836-7112
 - Supplies referrals to local United Way offices.
 - The United Way focuses on strengthening and supporting families, improving access to healthcare, promoting financial stability and community service projects.

The National MS Society is a collective of passionate individuals who want to do something about MS now — to move together toward a world free of multiple sclerosis.

We help each person address the challenges of living with MS through our 50-state network of chapters. The Society helps people affected by MS by funding cutting-edge research, driving change through advocacy, facilitating professional education, and providing programs and services that help people with MS and their families move their lives forward.



**National
Multiple Sclerosis
Society**

nationalMSsociety.org

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