

Caring for Loved Ones with Advanced MS: A Guide for Families

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National
Multiple Sclerosis
Society

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Disclaimer

The content of this guide is based upon the clinical expertise of health care professionals and the life experience of caregivers who have cared for family members with advanced MS. It is intended to serve as a guide to family caregivers who are providing significant hands-on care, but is not meant to substitute for, or to supersede, individualized physician treatment and advice.

Caring for Loved Ones with Advanced MS: A Guide for Families

Introduction

This booklet is designed for families who are caring for a person with advanced multiple sclerosis (MS). By “advanced” we mean that the person with MS is entirely dependent on others for his/her personal care and daily activities, is rarely able to leave the home, cannot be left alone for any extended period of time, and has complex clinical issues. While this advanced condition in MS is not common, the level of care and attention required is complex and demanding.

The purpose of this booklet is to provide information, caregiving tips, and support to families providing significant daily care to a family member with MS. It is likely that your loved one is living with extremely limited mobility, on-going susceptibility to infections, and difficult-to-manage symptoms such as pain, impaired speech, cognitive deficits, eating and swallowing difficulties, and/or bladder and bowel incontinence. A central message of this guide is that family caregivers must attend to their own needs as well as those of their loved one. Too often the demands and needs of the individual with MS overshadow those of the caregiver. Many caregivers ignore their personal health and their need for emotional support, relaxation, and social activities outside the home. It is critical that caregivers pay attention to these needs. Doing so not only helps them to be better caregivers, it enables them to achieve better health and a better quality of life for all family members.

Emotional and Social Needs of the Caregiver

"If I could do it all over again, I would not have lost the 'me' in the responsibilities of caregiving. I would have worked in some time for me to get away on a regular basis."

In this section you will learn that taking care of yourself is critically important to your own health and the quality of your emotional and social life. Tips are provided for coping with the myriad of feelings that accompany life as a caregiver and for optimizing family communication. You will be encouraged to look for ways to share the responsibility of care and to be realistic about what you alone can do.

1. In light of the massive needs of a person with advanced MS, how can I maintain my own health?

- Realize that for you to take care of yourself is not an act of selfishness. You deserve to be healthy and feel well.
 - › Recognize the limits of your own endurance and strength.
 - › Understand your emotions and don't be afraid to acknowledge them. Learning to express feelings and to deal with tensions in constructive ways is vital to your emotional and physical health.
 - › Do not neglect your own medical exams, exercise, and nutrition.
 - › Be sure to plan for fun and supportive activities.

- Maintain facets of your life that do not include your loved one, just as you would if he or she were healthy.
 - › Listen to what your body is telling you. (rest? relax? exercise?).
 - › List ways you can nurture yourself. e.g., walking, reading, hobbies, faith-based activities.
 - › Maintain meaningful relationships. Family and friends can be a source of great comfort, help and pleasure.
 - › Consider getting breaks early in caregiving. If you wait until you are “burned out” these breaks will not be enough. It’s important to make a plan for regular breaks, decide on the time, date, and activity—then follow through!

At the end of the day, focus on one thing that went well.

2. How can I avoid feeling guilty about taking a break?

- Let go of hyper vigilance.
 - › Resistance to accepting help is a common cause of stress and depression among caregivers. Knowing your limits, and reaching out for assistance before you are beyond your limits, is important.
 - › Know that when you are doing everything that you reasonably can for your loved one, you have the right to do some things for yourself.
 - › Freely grant yourself a day or evening out; don’t feel you have to be a martyr.

- Reject any attempts to manipulate you through guilt.
 - › Take pride in what you are accomplishing and applaud the courage it takes.
 - › Set limits. You are not expected to just “take it” if your loved one is demanding, unreasonable or abusive.
 - › Talk with your loved one. Let him/her know that you expect to be treated respectfully, in the same way that you will treat him/her with respect.
 - › Think about seeing a counselor together if this is becoming a significant problem.

3. How can I share the responsibility of caring for my loved one?

People can best help if you tell them exactly what your needs are and how they can help. You can't expect others to “know” when help is needed.

- Be sure that everyone in your immediate and extended family is given the opportunity to help. Be prepared that some will be eager to help and some will not for various reasons. But don't be afraid to ask.
- Be specific with your request and be appreciative. When a friend or relative asks, “Is there anything I can do?”, be prepared with specific tasks, such as picking up some items at the market, stopping by the pharmacy to pick up a prescription, staying at home with your loved one for an hour while you take a walk, etc.
- Don't feel you must always fix, protect, rescue and direct.
- Keep expectations realistic.

- If you cannot get enough help from family and friends, seek out respite care services in your community so that you can have some time for yourself.

4. What is respite care?

The term 'respite' means a break from something trying or distressing, an interval of relief. For those providing intense, daily care to a loved one, respite means being relieved of those daily caregiving responsibilities for a time to relax and re-energize. Some families use respite on a regular basis so that caregivers can go out and do something for themselves, e.g. take a walk, go out to lunch with friends, have a haircut or manicure, etc. Others use it periodically when family members must be away for several days. Respite services are provided both inside and outside the home.

In-home respite includes help from supportive family and friends, as well as the paid assistance of home care workers or companions who come into the home to help with your loved one. These professional services can be purchased privately or provided through community or state-financed programs. Home-based respite care has the advantage of keeping the person in familiar surroundings. *Out-of-home respite* involves intermittent, planned short stays of your loved one in adult foster care homes, nursing homes or hospitals. Out-of-home respite is often used when family members need to be away from home for several days, for example to attend a wedding, visit colleges with high school children, attend a graduation, take a vacation, or visit family.

5. How is respite care different from home care services?

The services actually being provided might be the same, but the focus of the service is different. Respite is focused on you, the **caregiver**. Its purpose is to provide a caregiver with a break or 'respite' from daily caregiving responsibilities. Home health care services and personal

care attendants, on the other hand, are focused on the needs of the **person receiving care**, regardless of whether there is a caregiver involved. It is important to remember this distinction, as funding streams for community services are often targeted to either caregivers or care recipients. You want to make sure you are reaching out to both. A list of respite resources can be found at the end of this chapter. We will discuss home health care, nursing home care and hospice in more depth beginning on page 99.

6. If someone comes into my home to provide me with respite, how can I be sure they will understand the needs of my loved one and how to address a crisis that might arise?

There is so much that you personally know about the care of your loved one, but sometimes it's hard to remember it all, and it's tiresome repeating it all the time. So it is important that you have information pertinent to your loved one's care in writing and readily available for anyone who is providing care in your absence. Pulling together such information can be time-consuming, but it is well worth it when the process is completed. Consider developing a notebook for this purpose. Writing the information in pencil or on the computer makes it easier to change when needed.

You first want to make sure your notes include the following up-to-date information:

- *Doctors' names and phone numbers*
- *Insurance information*
- *Preferred hospital or ambulance*
- *Phone numbers of close family and friends/ who might stop by to visit*
- *Information re: medications and other aspects of care*
- *Medical alert equipment*

However, don't forget to include information on the following things as well:

- *Where to find personal supplies such as eyeglasses, dentures, hearing aids, lift*
- *Daily and weekly routines*
- *Food preferences*
- *Personal interests*
- *Favorite activities*
- *Things that might agitate or could calm your loved one*
- *Location of household and emergency supplies*
- *Pet information*

Organize this information in a way that is most useful to you. The above listing comes from *The Care Book*, a notebook created by two caregivers as a way to think about and organize important information. A few sample pages follow. If you would like to order the book in its entirety, there is contact information at the end of this chapter.

Daily Routine

Monday	Morning _____
	Afternoon _____
	Evening _____
Tuesday	Morning _____
	Afternoon _____
	Evening _____
Wednesday	Morning _____
	Afternoon _____
	Evening _____

Thursday Morning _____

Afternoon _____

Evening _____

Friday Morning _____

Afternoon _____

Evening _____

Personal Supplies

Item	Yes	No	Where to find
Glasses	<input type="checkbox"/>	<input type="checkbox"/>	_____
Hearing Aid	<input type="checkbox"/>	<input type="checkbox"/>	_____
Dentures	<input type="checkbox"/>	<input type="checkbox"/>	_____
Walker	<input type="checkbox"/>	<input type="checkbox"/>	_____
Wheelchair	<input type="checkbox"/>	<input type="checkbox"/>	_____
Cane	<input type="checkbox"/>	<input type="checkbox"/>	_____
Lift	<input type="checkbox"/>	<input type="checkbox"/>	_____

Other supplies used for care:

Item	Where to Find
_____	_____
_____	_____
_____	_____

Food Preferences

Breakfast

Food

Drink

Lunch

Food

Drink

Dinner

Food

Drink

Personal Interests

Favorite TV and Radio Programs	Time	Channel/Station
<hr/>	<hr/>	<hr/>

Favorite Activities

7. What are signs of caregiver stress?

There are many signs of stress that you must be able to recognize:

Emotional signs of stress include chronic irritability or resentment, feeling down in the dumps, continual boredom, excessive nervousness/ anxiety, feeling overwhelmed, and nightmares.

Thought-related signs of stress include worrying every day, distractibility, expecting the worst to happen much of the time, and difficulty making everyday decisions.

Physical signs of stress include clammy hands or sweating, constipation/diarrhea, dry mouth, headache, heart palpitations, stomachaches, nausea, muscle spasms or tightness, a lump in the throat, faintness, fatigue/weariness, sleeping too much/too little, and short and shallow breathing.

When you feel overwhelmed with stress, sharing problems with others not only helps to relieve stress but can give you a new perspective on problems. All National MS Society chapters have affiliated self-help groups and many chapters have groups and programs specifically developed for caregivers. Religious and spiritual communities can provide support and guidance. There are also several national caregiver organizations that provide materials specifically addressing caregiver stress. Tap into these sources of support.

(See page 22 for some practical tips for addressing stress).

8. Is it common to have feelings of hopelessness and despair watching a family member deteriorate?

It is not at all unusual for family caregivers to experience feelings of grief in the midst of their everyday duties. Depressed mood—with feelings of hopelessness and despair—can be part of this experience.

Fear, sadness, anger, guilt and frustration may also be felt. Living with the losses of MS can bring up spiritual questions of meaning and value. Speaking with a pastoral counselor or a mental health therapist about these issues will help relieve their intensity. Reaching out to a support group for caregivers could also be helpful.

9. What are signs of depression?

“Depression” is a term commonly applied to a wide variety of emotional states. It may range from feeling down for a few hours on a given day to severe clinical depression that may last for several months. It is important to distinguish between mild, everyday “blues” that we all experience from time to time, and clinical depression.

Clinical depression is more persistent and unremitting, with symptoms lasting at least two weeks and sometimes up to several months. Clinical depression, which must be diagnosed by a mental health professional, is a serious condition that produces flare-ups known as major depressive episodes.

Symptoms of a Major Depressive Episode are:

- Sadness and or irritability
- Loss of interest or pleasure in everyday activities
- Loss of appetite-or increase in appetite
- Sleep disturbances—either insomnia or excessive sleeping
- Agitation or slowing in behavior
- Fatigue
- Feelings of worthlessness or guilt
- Problems with thinking or concentration
- Persistent thoughts of death or suicide

If you are experiencing significant depression, counseling and medications can help you feel better, so don't try to get through it alone. Talk with your physician or other health care professional.

10. How do I handle the fear of hurting or neglecting my loved one?

Acknowledging the fear of hurting or neglecting your loved one is a start. Very often this fear arises from the anger and frustration that caregivers experience from their duties. Turning to other family members, friends, religious advisors, or counselors for needed support is an essential first step in preventing an occurrence.

Anger is a common caregiver emotion. The situation feels—and is—unfair. Hurtful words might be spoken during a difficult task, doors might be slammed during a disagreement, and shouting in frustration sometimes replaces conversation. Anger and frustration needs to be addressed and healthy outlets need to be developed before angry encounters become physically or emotionally abusive.

Abusive behavior is *never* acceptable. But tensions can mount in the most loving of families. While circumstances that produce frustration and anger are often unavoidable, an emotionally damaging or physically aggressive response is not okay. 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 caregiver during a transfer. Once anger and frustration reach this level, abuse by either partner can become more 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 both caregivers and care receivers. Therapists and marriage counselors can help families when tensions get to this level.

11. I often feel so anxious and overwhelmed when talking with doctors. How can I feel more confident and knowledgeable?

Be honest with your medical professionals about the limits of your understanding of a difficult diagnosis or treatment option.

- Take the time to do your homework (i.e. reflect on what you have been told).
- Summarize your concerns in a few phrases so your provider can focus discussion on those concerns.
- Be clear about what you do and don't understand.
- Be clear about what you can and cannot do.
- If your provider does not have the time or skill to communicate in detail with you, ask if support staff (i.e. a nurse or medical social worker) is available to you.
- Reach out to family and friends who have a medical background, discuss your knowledge gaps, and enlist their support for office visits when necessary.

Expect to do some research at your local library or on the Internet.

- Request the support of library staff to find the most reputable journals and resource materials.
- The American Medical Association (AMA) recently published guidelines for health information found on the Internet due to their concern for the quality of content and privacy on the web. AMA

associated sites are expected to post and review reliable, objective current material easily distinguished from advertising.

- The National Library of Medicine supports distribution of medical information in lay terms and provides many useful links (www.nih.gov and www.nlm.gov).
- Search engines (i.e. Google) provide links to disease related national associations whose sole purpose is to provide information and support to consumers.
- The website of the National Multiple Sclerosis Society provides extensive materials on MS and related topics (www.nationalMSSociety.org) for people with MS, family members, and health care professionals.

Twelve Steps for Caregivers

1. *Although I cannot control the disease process, I need to remember I can control many aspects of how it affects me and my loved one.*
2. *I need to take care of myself so that I can continue doing the things that are most important.*
3. *I need to simplify my life-style so that my time and energy are available for things that are really important at this time.*
4. *I need to cultivate the gift of allowing others to help me, because caring for my loved one is too big a job to be done by one person.*
5. *I need to take one day at a time rather than worry about what may or may not happen in the future.*
6. *I need to structure my day because a consistent schedule makes life easier.*
7. *I need to have a sense of humor because laughter helps to put things in a more positive perspective.*
8. *I need to remember that my loved one is not being difficult on purpose; rather the behavior and emotions are being distorted by the illness.*
9. *I need to focus on and enjoy what my loved one can still do rather than constantly lament over what is gone.*
10. *I need to increasingly depend upon other relationships for love and support.*
11. *I need to frequently remind myself that I am doing the best that I can at this very moment.*
12. *I need to seek out spiritual support and nourish my spiritual life.*

(Permission to reprint this list was granted by Carol j. Farran. DNSc, RN and Eleanora Keene-Haggerty, MA. They developed this list, based on the Alcoholics Anonymous Twelve Step Program, for caregivers of people with dementia. The authors believe it also has validity for caregivers coping with other chronic illnesses.)

Resources

Organizations for Caregivers

Well Spouse Association

63 West Main Street, Suite H

Freehold, NJ 07728

800-838-0879

www.wellspouse.org

Well Spouse is a national membership organization that gives support to husbands, wives and partners of the chronically ill and/or disabled. Well Spouse has a network of support groups and also a newsletter for spouses.

National Family Caregivers Association (NFCA)

www.nfcacares.org

The NFCA site provides caregivers with tips, newsletters, advocacy updates, as well as information on communicating effectively with healthcare professionals. The site also offers a section on sharing your caregiving story.

Caregiving.com

www.caregiving.com

This site offers a monthly newsletter, "Spotlight on Caregiving", that is full of information about how to handle lifestyle changes brought on by caregiving. The website runs a program called "The School of You" that offers six different classes focusing on the emotional stress on caregivers. This site also offers a weekly tips segment and a support center full of stories written and sent in by caregivers.

ARCH National Respite Network

1-800-773-5433

www.archrespite.org

www.respitemlocator.org

This organization provides referral and information, and is also focused

on advocating in the public policy arena for legislation to support family caregivers.

Faith in Action

1-877-324-8411

www.fiavolunteers.org

Provides connection to volunteers offering non-medical assistance.

National Easter Seals Society

1-800-221-6827

www.easter-seals.org

Serves adults with disabilities with home services, camps, and adult day programs.

Strength for Caring

www.strengthforcaring.com

A caregiver initiative of Johnson & Johnson that includes many practical tips for providing daily care.

Resources for Documenting Care Needs

- **www.healthhistory.com**
- **www.cc-info.net** (Personal Health Notebook)
- The Care Book email: **thecarebook@comcast.net**

Respite Care Resources

- Contact your county and/or state Department of Human Services, or your local Office on Aging, to find out what kinds of programs are available for family caregivers. Some states are finding that offering family caregivers funding toward respite care helps to avoid more expensive nursing home stays. Although historically many of these programs have focused on elderly caregivers, an increasing number are now providing services to non-elderly caregivers as well. These programs might also be a way to access

homemaker services, personal attendant services, meal delivery, and case management services.

- Explore non-profit organizations and faith based groups who offer respite services. Faith-in Action, for example, is an interfaith network of volunteers nationwide who provide non-medical help and respite for people with long-term care needs.
- Check with your local National MS Society chapter to learn about services available in your community.
- Visit the website www.lotsahelpinghands.com, a national caregiver coordination service that allows family, friends, neighbors, and colleagues to more easily assist with daily meals, rides, shopping, babysitting, errands, etc.
- Check the website of the Family Caregiver Alliance (www.caregiver.org) for a state-by-state listing of respite and other services for family caregivers.
- Explore adult day programs in your community that provide respite to caregivers during the day.
- Learn about nursing homes that set aside beds for respite.
- Identify VA hospitals that offer respite.
- Finally, if you have no alternative and can manage it, hire and pay someone personally to provide in-home respite care. Remember, sometimes family members who cannot provide hands-on assistance are willing to assist with the expenses of paid services.

Regardless of the respite care or services you select, you will want to prepare for the service by answering these important questions:

- Do I need regular or occasional help?
- What times would be best for me?
- How much advance notice do I need to give the substitute care provider?

Reducing Stress

"We are all so tense all the time. It's a combination of worry, sadness and exhaustion."

Living with a chronic disease is stressful for everyone in the family. Finding ways to fit in relaxation, laughter and time away from MS are important for everyone. In this section we offer suggestions for reducing stress, and for nurturing that part of yourself that can give you the strength and resiliency that you need.

1. What are my options for dealing with caregiver stress and depression?

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 they have available to pursue their own interests and activities.

- Successful caregivers don't give 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 is critical that you have some time for yourself.
- Learning good stress management techniques to use everyday is also a sensible response. These may include meditation, visualization, progressive muscle relaxation, yoga, tai chi, and traditional exercise programs.

- Many emotional stresses are the result of poor communication. The caregiver needs to be able to discuss concerns and fears openly; the person receiving care isn't the only one who needs emotional support. Although collaboration isn't always easy or possible, working out long-term plans and goals together will help both the care receiver and care giver feel more secure.
- 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 is disrupting daily activities in the household, don't hesitate to consult a health-care professional. Ignoring a problem will not make it disappear. Anger, grief, and fear soon become guilt, numbness, and resentment. Some people find that talking about their concerns happens more easily when they schedule a regular time for conversation.

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.

- When making plans for outings, always include extra time for travel.
- Call ahead to check out bathroom facilities and entranceways. Buildings are not always accessible, even when they say they are.
- Don't make plans too complicated. When plans fall through, have an alternative ready. If the night out seems impossible, order pizza!
- A list of backup people who can be contacted for help at short notice is useful.
- Realize that you can't fix everything. Consider when your loved one is depressed, for example. People who are depressed often want to withdraw from activities, and the resulting lack of stimulation further reduces their quality of life, creating a downward spiral. While supportive family and friends may be able to help shake off

mild depression, psychotherapy and/or antidepressant medication are needed to treat clinical or severe depression.

2. What are some ways to manage stress?

Making time for relaxing activities can improve mental and physical well-being for both the person with MS and his/her caregiver.

Relaxation can reduce the physical and chemical changes that result from anxious or worried feelings. Some effects are decreased tension, anxiety, pain and fatigue as well as increased comfort and a sense of well being.

Try to set aside 15 to 45 minutes each day for a relaxing activity. It can be listening to music, reading, knitting—whatever is relaxing to you. If you find you are trying to deal with your stress in ways that can be harmful to you—overeating, increased alcohol consumption, addictive drugs—seek help right away.

3. Is there a particular daily relaxation exercise I can do?

Many people find engaging in an exercise like the one described here beneficial.

Find a time when you are not likely to be interrupted and make sure you are comfortable.

During the exercise:

- > Close your eyes
- > Pay attention to your breathing
- > Observe sensations
- > If your mind wanders, merely note the thought and bring it back to sensations of breathing or muscle tension

Options:

- > Basic Breathing: Focus on your breath moving in and out.

› Guided Imagery: Imagine a peaceful scene in your mind's eye while you practice basic breathing.

4. What are some other stress reducers for people with MS and their caregivers?

Although there is limited scientific research on the effectiveness of various stress-reducing strategies, many people report that the following strategies help to promote relaxation and reduce stress and tension.

- 1) **Aromatherapy** is the use of liquid plant materials known as essential oils and other aromatic compounds for the purpose of affecting a person's mood or health. The oils at the scent level activate an area of the brain called the limbic system as well as the emotional centers of the brain. Oils can be placed in a tea light diffuser to release their scents. A commonly used oil for relaxation and stress relief is lavender oil.
- 2) **Comfort foods** refer to any food or drink to which one habitually turns for temporary respite, to decrease stress, to find security, or for a special reward. There are no universal comfort foods since most are regional in nature and ultimately the eater defines what is comfort for them.
- 3) **Guided Imagery** is using the imagination to create mental pictures or situations using all the senses—sight, touch, hearing, smell and taste. Imagery can aid in relaxation, relieve boredom, decrease anxiety and stress, and facilitate sleep. There are audio tapes available that can guide people through the imagery practice.
- 4) **Massage** is a method of skin stimulation which relaxes muscles, increases relaxation and may relieve pain. Massage can be done by oneself or by another. Using slow, steady, circular motions, either with a bare hand or with warm oil or lotion, can help to relax the body and relieve pain. A back rub, foot rub, hand rub or head rub may be very comforting and relaxing.

- 5) **Meditation** describes a state of concentrated attention on some object of thought or awareness. It usually involves turning attention inward to the mind itself. Meditation has traditionally been recognized as a component of Eastern religions but it is becoming increasingly mainstream in Western culture as well. Meditation can be used for personal development or to focus the mind on religious ideals. Many practice meditation in order to achieve peace and serenity and a natural state of relaxation.
- 6) **Music therapy** uses music to address the physical, emotional, cognitive and social needs of individuals of all ages. The intervention can be designed to manage stress, alleviate pain, and express feelings.
- 7) **Pet therapy** is the therapeutic use of pets aimed at providing an ongoing source of comfort and focus for attention. Animals can bring out an individual's nurturing instinct, and help one to feel safe and unconditionally loved. Pets can help to reduce blood pressure, decrease muscle tension and reduce stress.
- 8) **Prayer** is used by many people as an active effort to communicate with a deity or spirit in order to offer praise, make a request, seek guidance, confess sins or express one's emotions or thoughts. It can be done privately or in groups with other believers. Those who practice prayer say that it decreases stress and anxiety, promotes a positive outlook, and strengthens their will to live.
- 9) **Reiki** is a Japanese technique for stress reduction and relaxation. It is done by a Reiki "master" and involves the "laying on of hands" and is based on the idea that an unseen "life force energy" flows through each person and is what keeps us alive. When this life force is low, one is more likely to get sick or feel stress. Benefits of Reiki are reported as relaxation and feelings of peace, security and well being.
- 10) **Relaxation Response** is a physical state of deep rest that changes one's physical and emotional response to stress. It can be learned quickly and takes 10-20 minutes when practiced.

- 11) **Yoga** is a practice which combines breathing, physical postures and meditation. It involves the practice of concentration and meditation to increase feelings of peace, joy and oneness and to increase spiritual awareness and the cultivation of compassion and insight.
- 12) **The Pleasure-A-Day Plan** involves indulging in some “decadent” pleasure every day—something you can really look forward to (i.e. a bubble bath, slowly sipping a rich chocolate latte, a walk in the woods, buying yourself a rose or a new bar of scented soap, curling up in your favorite chair with a fun read, watching a favorite TV show, going out for a beer or tea with a friend, etc.). Plan it, mix it up and do it everyday!

5. Is there any way to evaluate complementary therapies?

Many people explore alternative and complementary therapies to minimize the effects of living with chronic disease. Before considering any such therapy it is important to consult with a health care professional. It is also important to find out:

- What are the goals of the therapy—cure, palliation, reduction of side effects?
- Is there any scientific evidence to support achieving the goals?
- What are the expected benefits?
- What are the risks, if any?
- Does the therapy interfere with the effects of other therapies?
- Does the therapy enhance the effects of other therapies?
- What are the financial costs?
- What are the qualifications of the practitioner?

Resources

National MS Society Publications

800-344-4867

www.nationalMSSociety.org/brochures

- *Taming Stress in Multiple Sclerosis*
- *Clear Thinking About Alternative Therapies*

Complementary and Alternative Medicine and Multiple Sclerosis. 2nd edition, Bowling, A. (2006) Demos Medical Publishing, New York

Management of Severe Physical Symptoms

In this section the focus is on specific symptoms of advanced MS that pose particular challenges to family caregivers. Every clinical feature of MS is not addressed, nor is time spent focusing on basic caregiver knowledge and skills that have undoubtedly been mastered at this point in your journey with the disease. Basic and more general information on symptom management and assistance with daily living activities can be found in *The Comfort of Home, Multiple Sclerosis Edition*, Meyer, M. and Derr, P., 2006, CareTrust Publications, LLC., as well as other booklets and publications of the National Multiple Sclerosis Society.

As you review these symptoms remember that infections can be extremely serious, even life-threatening, in advanced MS. Fever and/or a significant increase in symptoms like spasticity, pain, swallowing problems or vision changes are frequently signs of infection. It is critical that, whenever you suspect an infection, you reach out for immediate medical attention and prompt treatment.

Bladder Care

“We resisted getting a suprapubic catheter but once we did, it was much better than anything we were doing before. For us, it was the right thing.”

Bladder problems are common among people with MS and especially those with advanced disease. For families, bladder problems can seem overwhelming. In this section information and tips are provided to help you better manage bladder issues, and medications and other procedures are discussed.

1. What is a neurogenic bladder?

Elimination of urine is dependent on intact pathways between the brain, spinal cord and bladder. Nerves and muscles of the urinary system work together to hold urine in the bladder and to release it when it needs to be emptied. In MS, these nerves may not work properly. A neurogenic bladder is a loss of normal control of bladder function caused by damaged nerves. There are two kinds of neurogenic bladder: overactive (spastic) and underactive (flaccid). The most common is a failure with storage; the less common, a failure with emptying. The location of lesions within the central nervous system primarily determines the kind of symptoms that are experienced.

Physicians and nurses can check how much urine is left in a bladder after a person urinates (post void residual) by doing a catheterization or using a bladder scanner. People with advanced MS who have underactive or overactive bladders should periodically be evaluated by a urologist because of the risk of urinary tract infection and other urinary complications. Urologists can do a thorough bladder evaluation called a urodynamic study.

2. What are symptoms of a neurogenic bladder?

- Frequency and urgency
- Leaking or dribbling urine or loss of control (incontinence)
- Change in the amount of urine
- Urinary hesitancy (difficulty initiating urination)
- Not being able to empty the bladder
- Continued pressure on the bladder
- Discomfort in the lower abdominal area
- Nocturia (waking up frequently during the night to urinate)

3. How Are Bladder Problems Treated?

- **Medications**

- › There are medications that can control urinary urgency (for example: Ditropan[®], Detrol[®] and Tofranil[®]) and other medications to relieve retention (for example, Levsinex[®], Levbid[®] and Urispas[®]). When someone does not respond to this “routine” type of bladder management, an evaluation by a urologist is needed.
- › Medications to control spasticity (baclofen, Botox[®] injections) can also be helpful.

* It is important to remember that Cipro[®], a medication that can be used to treat urinary tract infections, can be contraindicated in patients receiving tizanidine (Zanaflex[®]) for spasticity because of increasing sedation. Be sure the doctor is informed if tizanidine is being taken.

- **Mechanical aids and products** that help control the flow of urine and maintain hygiene include:
 - › **Absorbent products** that soak up urine, such as mini disposable pads that attach to underwear or disposable protective garments such as Depends. Some people prefer absorbent cloths that can be washed and reused.
 - › **Catheters**, thin, flexible, hollow tubes that can be inserted through the urethra (the tube through which urine leaves the body) into the bladder to drain urine. Several different types of catheters are available. Catheterization can be done intermittently, or a permanent catheter can be inserted and changed monthly by a nurse or trained family member. Indwelling catheters require monitoring and care so that complications such as infection or bladder stones are minimized.
 - › **A suprapubic catheter, which requires minor surgery**, involves a tube system placed directly into the bladder through the abdomen just above the pubic bone. The insertion site must be cleansed one or more times daily, as advised by a health care professional. This kind of catheter may be more appropriate for long-term management of urinary problems as it is associated with fewer complications than a urethral catheter.
- **Surgical Procedures:**
 - › A diverted urinary system.
 - › A sphincterotomy that relaxes “exit” muscles of the bladder so that the person voids continuously into an external collection device. This procedure is done only in males because an external device such as a condom catheter can be used.

4. How does a urinary tract infection (UTI) occur?

Urine that is held too long before being eliminated often leads to infections of the bladder or kidneys. Although many people can have a UTI without any symptoms, there is usually at least one sign or symptom listed on page 33.

Urinary Signs & Symptoms of Infection

- A burning sensation when urinating
- Feeling the need to urinate more often than usual
- Feeling the urge to urinate but not being able to
- Leaking a little urine
- Foul smelling urine
- Cloudy, dark or bloody urine
- Chills & fever
- Pain

5. Is there any way to avoid urinary tract infections?

There are certain strategies in the areas of diet, increased fluids, hygiene, and catheter care that can help to limit urinary tract infections. Monitoring fluid intake is important. Some people with MS have reported that using cranberry juice or cranberry extract in gel cap or tablet form, or avoiding caffeine, can decrease infections. Wiping the urethral area several times a day and frequently changing incontinence pads as they become wet can minimize the amount of bacteria. Keeping pubic hair clipped is helpful. Wearing gloves is advised when caring for any area that may be open or exposed to bodily fluids. Of course catheters must be properly cleaned or they can become a vehicle of infection.

6. How are urinary tract infections diagnosed and treated?

Symptoms of a UTI can be very similar to bladder problems caused directly by MS (for example, urinating frequently), so a physician or nurse will need to test for infection. Some people seem to get more infections than others, even with exemplary hygiene. People doing

intermittent self-catheterization are likely to have bacteria in their urine that can be seen in the laboratory, but this is different from having a real infection.

The diagnosis of a urinary tract infection is made by a urinalysis and a urine culture in which urine is collected in a sterile manner and tested for the presence of bacteria. An antibiotic will be prescribed, and symptoms will usually go away 1 to 2 days after starting the medication. It is essential that the medication be taken as directed for the complete time period indicated. If someone routinely takes medications to control urgency or urinary incontinence, these medications might be stopped while there is an infection.

7. What should I do if there is leakage around the Foley or suprapubic catheter?

Strategies to control leakage will depend on the cause of the problem.

<i>Blockage</i>	Check to see if the catheter is draining properly. If there is no urine in the drainage bag, the catheter may be obstructed, so check for kinking of the catheter or drainage tubing.
<i>Bladder spasms</i>	Increase fluids to dilute urine Ask about medications to reduce spasms, such as Detrol® or Ditropan®
<i>UTI</i>	If you suspect an infection, advise your health care professional
<i>Constipation</i>	A Fleet® or mini-enema may be necessary. Talk with your health care provider

Note: Increasing the size of the catheter will probably not stop leakage and may cause serious injury to the urethra.

Resources

National Association for Continence

Consumer advocacy organization dedicated to public education regarding causes, prevention, and management of incontinence.

www.nafc.org

Continence for People Living with Multiple Sclerosis

(2004) National Association for Continence

1-800-BLADDER

www.nafc.org

National MS Society Publications

800-344-4867

www.nationalMSSociety.org/brochures

- *Controlling Bladder Problems in Multiple Sclerosis*
- *Urinary Dysfunction and MS*

Bowel Care

“Once we got the bowel problems under control, life was much easier for everyone. It was humiliating for my husband to have accidents and it wasn’t fun doing the clean-up.”

People with MS, especially those with advanced disease, often experience a change in their bowel patterns. Some individuals have problems moving their bowels, while others have accidental bowel movements. These are difficult issues to manage, and very upsetting to people with MS and their caregivers. Some people must deal with both issues. This section focuses on helping you better understand the bowel problems associated with MS and provides some tips and suggestions for managing these problems more effectively.

1. What are the bowel issues people with MS face?

Bowel movements are dependent on nerve pathways between the brain, spinal cord and intestines. Nerves and the muscles of the bowel system are meant to work together to hold stool in the intestine and to release it when the time is appropriate. In MS, the nerves that carry these messages may not work properly. Constipation, bowel incontinence (loss of bowel control), and sometimes diarrhea, are problems that affect people with MS. Disease-related factors such as muscle weakness and paralysis, decreased activity, fatigue, and acute or chronic pain can all impact the bowel.

Constipation

Constipation is characterized by infrequent bowel movements (usually fewer than two bowel movements per week), or by frequent straining to pass fecal matter. Inadequate fiber, lack of physical activity,

and depression all affect the digestive system. Medications and supplements may also contribute to constipation.

Signs of Constipation

- Infrequent bowel movements (BM)
- Hard stool
- Straining during BM
- Bloating sensation
- Abdominal pain & discomfort
- Sense of incomplete emptying
- Excessive gas/flatulence

Bowel Incontinence

Bowel incontinence is the loss of voluntary bowel control or involuntary leakage from the bowel. It can often lead to irritation of the skin, skin breakdown, and discomfort. Bowel incontinence often comes as a result of constipation. Other causes include lack of contraction of the rectal muscles, muscle weakness in the colon, a history of rectal surgery or a tear after childbirth, diet, medications (antibiotics or laxatives) or gastrointestinal infection.

2. How can bowel problems be diagnosed and/or evaluated?

Having a person with MS and /or family members provide a history of bowel habits, diet, and activity level is critical to diagnosing and evaluating bowel problems. Sometimes an abdominal X-Ray or abdominal CT scan (CAT scan) is necessary. An evaluation by a gastroenterologist might also be indicated. Gastroenterologists can use x-rays to help analyze the way the rectum and anus are working, make

measurements of squeezing pressures of sphincter muscles, or use a very small telescope to inspect the lining of the bowel (endoscopy and colonoscopy).

3. What measures can I take to prevent bowel problems as much as possible?

- **Monitor bowel habits**—Keep a diary of bowel movements (time, consistency, shape, number of movements, presence of blood, etc.), but remember that not all bowel problems are related to MS.
- **Maintain a regular bowel program if possible**—Establish a regular time for emptying the bowels. Unfortunately the disease might block the natural increase in activity of the colon following meals, but 20-30 minutes after breakfast is a good time to try to benefit from the gastro-colic reflex (a reflex that stimulates a wave of contractions in the bowel). Try to wait no more than 2-3 days between bowel movements.
- **Provide privacy when possible**—Having to rely on others to be ‘toileted’ at a specific time is a huge barrier to people being able to perform. It can be difficult to have a family member stay around during that time. Provide privacy when you can.
- **Access the right equipment**—If your loved one is able, consider using a commode chair or elevated toilet for comfort during the bowel routine. Elevating the knees by placing the feet on a small stool may be helpful. If getting out of bed is not possible, positioning on the left side might help. An occupational therapist or physical therapist can prescribe the right equipment to help the process.
- **Maintain fluid intake**—Try to have your loved one drink several glasses of water daily. Cutting back on fluid intake makes constipation worse. Lack of water may harden the stool, making it

more difficult to pass. In addition, increased pressure from the stool on the urinary system may increase bladder problems.

- **Encourage drinking something hot as the first beverage in the morning**, such as tea or prune juice, to help stimulate a bowel movement. People with MS with swallowing problems should use thickeners as needed. Those with gastric or j-tube should receive water via the tube as recommended by their clinicians.
- **Maintain fiber intake**—Eating plenty of fresh fruits and vegetables and whole grain breads and cereals is the best way to maintain the amount of fiber in the diet. Your health care provider may recommend a fiber supplement such as Metamucil®. People with MS with swallowing problems and a feeding tube might need to consult with a nutritionist.
- **Encourage Exercise**—If physical activity is not possible, active or passive range of motion may increase bowel motility. Any activity level can promote bowel motion.
- **Be sure your loved one receives a routine colonoscopy** (earlier than age 50 if there is a family history of colon cancer).
- **Discuss issues such as persistent rectal bleeding, unexplained severe pain or discomfort, a lump or mass in the abdomen, or extreme fatigue with your primary physician or gastroenterologist.**
- **Perform a medication review**—Review medications with the nurse or doctor. Some types of drugs commonly taken in MS are known to cause constipation, and it may be possible to switch to a similar drug that won't affect the bowels, or perhaps just a change to a different dose of the medication.

Medications that can cause constipation

- Over-active or spastic bladder medications such as oxybutynin (Ditropan®), tolterodine (Detrol®) or others
- Anti-depressants (Selective Serotonin Reuptake Inhibitors such as Prozac®)
- Anti-hypertensive (Medications to lower blood pressure)
- Medications to treat heart problems
- Medicines to treat heartburn or reflux disease
- Painkillers (pain relief medications) containing codeine or morphine
- Medications containing iron (like a multivitamin tablet, iron supplements)

4. What can help if constipation becomes a problem?

- **Bulking agents** (natural bran, Metamucil® and others)—These agents increase the mass of the stools and stretch the bowel wall to help emptying by stimulating waves of contraction in the colon
- **Stool softeners** (sodium docusate-colace)—These help the stools become moist and soft as they pass through the colon. The stool softeners can be used once or more daily based on individual needs.
- **Laxatives**
 - › *Osmotic laxatives* (lactulose)
These agents allow the stool to have some water in it so that not all the water is absorbed. The aim is for stools to stay soft and bulky. Too much lactulose or other osmotic laxatives and the stool becomes liquid.
 - › *Stimulant laxatives* (senna/senekot, and bisacodyl (Dulcolax®))

These contain medications to stimulate the pressure waves in the colon. They may cause cramping.

- **Suppositories and enemas**—These agents stimulate the wall of the rectum to push stool out. The bowel movement occurs immediately after enemas, 5-10 minutes after mini-enemas (e.g. Therevac[®] and Enemeez[®]), and 10-30 minutes after using a suppository. The glycerine suppositories are medication free, and they have a mildly irritating action that promotes emptying of the bowels. It is best to begin with a glycerine suppository and progress to suppositories containing a stimulant such as bisacodyl suppository or enemas if needed. The glycerine suppositories can be used on a regular basis for the long term.
- **Digital stimulation**—Some people with MS or family members are taught a method of using their finger (protected with a latex finger cover and lubricated with petroleum jelly) to help the stool out. Digital stimulation massages the anal sphincter muscles to get the rectum and anus to respond and expel stool.
- **Abdominal massage**—Applying firm massage to the abdomen in the direction of the flow of the colon for several minutes may be helpful.
- **Biofeedback**—This is a way of trying to retrain the bowel. A course of biofeedback sessions may help people become more aware when their rectum is full, or strengthen and retrain the anal sphincter muscles.
- **Surgery**—Surgery is a rare last resort for constipation, only performed after a thorough evaluation by the doctor. Surgeries that can be considered include a colostomy (diversion of the large bowel-colon to an artificial opening in the abdominal wall), or ileostomy (diversion of the small bowel to an artificial opening in the abdominal wall). These surgeries, although not first-line interventions, can often result in improving the quality of life for people living with advanced disease and severe disability.

5. How is incontinence evaluated?

Just as with constipation, the first step to managing bowel incontinence is through a thorough assessment of the problem. It is important to determine whether the problem is related to MS or to other factors, and to assess the extent of nerve or muscle damage, in order to recommend the best treatment. Any assessment will include an extensive list of questions for the person with MS and/or family members to identify when and under what circumstances the incontinence developed, how it is impacting daily activities, current medications and diet, relevant medical history, and current bowel routine. Ultrasound or x-rays can be used to determine if there are structural problems, such as tears or polyps.

6. What can I do if incontinence is a problem?

- **Check & change diet as recommended:** Your loved one should have an individualized diet plan. High-fiber foods, caffeine, milk products, chocolate, alcohol, spicy food and artificial sweeteners can have the effect of producing loose stool in some people. It is worth experimenting to see if anything upsets bowel control or makes stools firmer.
- **Schedule a bowel routine:** Try to establish a regular routine for bowel movements. A set routine can help encourage the bowel to develop a regular pattern.
- **Give bowel medications as needed:** Use suppositories and laxatives to regulate a timed bowel movement every day or every other day. Some individuals with MS can schedule a routine every third day and be comfortable.
- **Check medications:** Many medications can cause loose stool.
- **Take steps to control leakage and diarrhea:** When symptoms are mild, an anti-diarrhea drug like loperamide (Imodium®) may be effective in treating loose stool. Bowel leakage may stop if the

bowel is cleared with a suppository, enema, or digital stimulation. Remember that diarrhea may occur because of other reasons, i.e. viral or bacterial infection or food poisoning.

- ***Utilize exercises for strength and control:*** Squeezing the muscles that control voluntary exit of stool may help strengthen them and thereby improve control. It takes time for exercise to make muscles stronger.
- ***Consider a rehabilitation program:*** A physical therapy or occupational therapy program is sometimes recommended for strengthening exercises and to assist with the bowel routine and the use of proper equipment.

Resources

National MS Society Publication

800-344-4867

www.nationalMSsociety.org/brochures

- ***Bowel Problems: The Basic Facts***

Pain

"I didn't realize pain was a problem in MS. When we really sat down with our doctor and discussed how to aggressively treat the pain, it made a world of difference in my wife's mood and general outlook."

Pain is experienced by as many as two thirds of people with MS. People in the advanced stages of MS can have pain related to spasticity, infection, pressure sores, headache, muscle contractures, as well as muscle and bone pain that can come from their limited ability to move. Survey studies of MS pain tell us that people with greater disability scores or advanced MS, and those with greater time from diagnosis, are more likely to experience pain.

In this section we discuss the possible sources of pain in advanced MS and ways to treat it and cope with it. Pain is usually all-consuming and miserable for the person experiencing it and very distressing for family members to observe. Pain deserves serious attention from both caregivers and health care providers, particularly physicians and nurses.

1. What are the types of pain in MS?

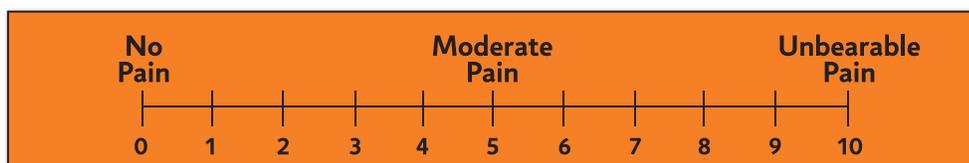
- *Excruciating, sharp, shock-like pain* in cheek and forehead, lasting seconds to minutes (trigeminal neuralgia)
- *Brief muscle twitching* or sudden, sharp muscle spasm; may also burn or tingle (tonic spasms)
- *Painful burning, aching, or itching* of any part of the body, more common in the legs
- *Migraine, tension, or cluster headaches*
- *Ice-pick like eye pain* (optic or retrobulbar neuritis)

- *Chronic burning, tingling, tightness, a pins-and-needles feeling, or a dull warm aching.*
- *Muscle cramping, pulling and pain (spasms)*
- *Pain caused by the physical stress of immobility (musculo-skeletal pain).*
- *Pain caused by MS treatment, such as steroid-induced osteoporosis, interferon side-effects, injection site reactions.*
- *Pain associated with pressure sores, stiff joints, muscle contractures, urinary retention, urinary tract infection, and other infections.*

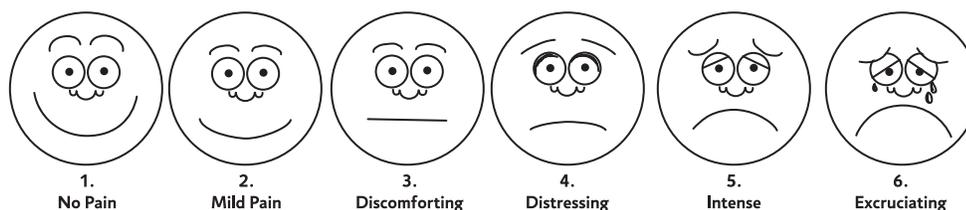
2. How do I know if my loved one is experiencing pain, particularly if he/she can't communicate very clearly?

You can ask if pain exists and how severe it is on a scale from 0 (no pain) to 10 (worst pain of my life). Facial expressions, such as grimacing, frowning, looking sad, or wrinkling the brow can be an indication of pain. Note if there is clenching fists or pulling at or touching a body part or area. Pain can also be assessed by observing usual activities. Look at the ability to rest and sleep, and the ability to enjoy family, friends, and recreational activities, such as watching television and reading.

Numeric Rating Scale (NRS)



Faces Pain Rating Scale



3. How can MS pain be treated?

Pain in MS presents a challenge as it is often unresponsive to standard therapies. Management of the root cause is essential to control the resulting pain.

Below are some medications used to treat MS-related pain.

Medications Used to Treat MS-related Pain	
Brand Name (Generic)	Type of Pain
Cymbalta® (duloxetine hydrochloride) Neurontin® (gabapentin) Lyrica® (pregabalin)	Pain directly caused by damage to the central nervous system
Dilantin® (phenytoin) Elavil® (amitriptyline) Pamelor®; Aventyl® (nortriptyline) Tofrani®I (imipramine)	Burning sensations, pins & needles, stabbing pains in the arms and legs
Klonopin®; Rivotril (clonazepam)	Tremor, pain, and spasticity
Tegretol® (carbamazepine)	Shock-like pain, such as trigeminal neuralgia (facial pain)

Over-the-counter medications and narcotics are generally not effective in relieving MS-related pain. However, there are many people with advanced MS who are prescribed opioids. If someone is taking opioids, constipation can be a difficult side effect to manage, so stool softeners/stimulants must be prescribed. It is also important to know that, in advanced MS, opioids can further complicate respiration and swallowing, as well as cause sedation. The fentanyl patch might be the preferred choice of opioid due to fewer side effects and more sustained effect.

4. Besides medications, what other strategies can treat pain?

Massage and exercise have been used to address pain, as has acupuncture, a technique where special needles are inserted into the body at certain points and at various depths and angles. Acupuncture is based on the theory that particular groups of acupuncture points control specific areas of pain sensation. Acupuncture should always be done by a practitioner with specialized education and training in the technique.

Passive range of motion can be given, as well as stretching to ease pain associated with spasticity. Transcutaneous Nerve Stimulators (TENS) is a small machine that delivers a high, medium or low buzzing or vibration to a painful area. The theory is that the buzzing sensation minimizes the sharper pain sensation. Application of heat or cold, pressure stockings and isotonic gloves can minimize neuropathic pain, especially at night. Change of position and positioning support can prevent and minimize pain.

Distractions can also be helpful. Arrange for visitors. Consider laughing-out-loud videos and cartoons (a whole movie may require too much concentration). Explore relaxation and meditation (audio tapes are available to assist with this practice). If your loved one is able, hypnosis and biofeedback might also be potential strategies.

5. What options are available if nothing we are doing is managing the pain?

Trigeminal neuralgia pain is excruciating and nearly unbearable. Various injections into the trigeminal nerve and other nerves involved in the pain may be considered, and are often helpful. Drugs injected into the spinal cord are also relatively safe.

Neurosurgical procedures that deaden or cut nerves that carry pain signals to the brain are known to offer relief but may not be permanent relief, and may (in a small number of cases) increase the original pain. A risk of surgical procedures is residual numbness or tingling. When weighing risk benefit, however, freedom from excruciating pain such as trigeminal neuralgia may be worth experiencing facial numbness. Several studies have indicated both the safety and efficacy of injections of glycerol to block the facial nerves that cause the intense and often intractable pain of trigeminal neuralgia.

Resources

Trigeminal Neuralgia Association (TNA)

Gainesville , FL 32608

www.tna-support.org

American Chronic Pain Association

Rocklin , CA 95677

www.theacpa.org

National Chronic Pain Outreach Association (NCPOA)

Millboro, VA 24460

www.chronicpain.org

Mayday Fund (for pain research)

New York , NY 10011

www.painandhealth.org

American Pain Foundation

Baltimore , MD 21201

www.painfoundation.org

National Foundation for the Treatment of Pain

Houston , TX 77270

www.paincare.org

National MS Society Publication

800-344-4867

www.nationalMSsociety.org/brochures

- *Pain: The Basic Facts*

Respiratory Care

“The thought of her having difficulty breathing really scared us. Getting help with this early on, knowing what to look for and trying to prevent problems helped us all.”

In this section you will find information and ideas for preventing and managing respiratory problems. Not all persons with advanced MS will develop respiratory problems; however, if they do, these problems can be serious and even life threatening unless caregivers are educated and prepared. Being aware of what to look for, and knowledgeable of how to treat these problems, will give you greater confidence in preventing crises associated with the respiratory tract.

1. What are respiratory problems that are common in advanced MS?

MS can cause weakness of muscles used for breathing. When muscles are weakened, respiration can become labored. Decreased mobility can contribute to pneumonia. People with MS can have difficulty fighting bacteria and viruses.

Aspiration pneumonia is a serious complication which results from problems with swallowing and is common in advanced MS. Problems can begin very subtly or happen “out of the blue.” You might notice a gradual increase in coughing when feeding fluids or solid foods. Total obstruction of the airway may suddenly occur when feeding solids. Certain medications that cause drowsiness such as Valium® can affect the ability to manage anything taken by mouth.

2. How can I prepare for possible respiratory problems?

Caregivers are often focused on the more common problems of MS such as spasticity, pain, mobility, and bladder and bowel impairment. It might only be when a person experiences a bout with pneumonia or has a choking episode that any attention is given to this area. Knowing the signs and symptoms of respiratory involvement is important in avoiding crises, and dealing with difficult situations when they arise.

3. What specific things can I do to prevent respiratory problems?

- Pay attention to respirations. Are they quiet, clear, and unlabored?
- How many breaths per minute does he/she take? The normal breaths per minute are usually in a range of 16 to 20.
- Pay attention to how all medications affect breathing (do certain medications make the person sleepy or lessen the number/depth of respirations?). If so, do not give anything to eat or drink until he/she is more alert.
- Encourage taking 10 deep breaths every hour to keep lungs clear.
- Buy an inexpensive stethoscope and just listen to the lung sounds. They should be clear all throughout the chest.
- If confined to bed, make sure the person is turned every 2 hours to improve oxygen flow.
- Watch for difficulty chewing and/or swallowing food.
- Keep sick individuals away (especially those with respiratory infections). If a caregiver or family member has a cold and must be in the same room, wear a mask.
- Annual flu and pneumonia vaccines are important.

- Have all family members who provide hands-on care take a course in CPR and learn the Heimlich Maneuver.

4. What are signs and symptoms that respiratory problems are developing?

Once any of these are noted, your loved one's physician should be notified immediately.

- Increasing frequency or difficulty swallowing foods and fluids.
- Food not being chewed well.
- Coughing becoming more frequent.
- Mucous from the mouth or nose no longer clear.
- Respirations becoming quicker and labored.
- Increased fluid build-up.
- Fever develops (you should already know at what temperature your doctor wants to be notified).
- Complete obstruction of the airway, even if only one time, necessitating use of the Heimlich Maneuver.

5. Once respiratory problems have developed, what can I do?

- Continue frequent deep breathing and coughing exercises.
- Continue to turn every two hours.
- Eliminate any foods that appear to cause chewing, swallowing, or choking problems.
- Change the diet to include either soft or blended foods. Do not include anything that requires much chewing.

- Utilize a thickener such as Thick-It® to improve the ability to handle fluids such as soups and blended foods.
- Have the person sitting so that he/she swallows with less difficulty.
- If you feel uncomfortable with continuing food and fluids by mouth, tube feeding can be initiated in a hospital setting. (See Swallowing and Nutrition on page 68.)
- If diagnosed with pneumonia, make sure all of the antibiotic is given. Do not stop, even if temperature returns to normal and no more abnormally colored secretions are present.
- For very serious situations, obtain a bedside suction machine.

Skin Care

“Skin care is all about prevention. Once you’ve got pressure sores, it takes a lot of care to make sure they heal well and stay healed. Do everything you can to prevent them in the first place!”

In advanced stages of MS, a person’s skin is more likely to break down. Even when receiving very good skin care, research has shown that the number of skin wounds rises due to risk factors such as lack of movement and muscle spasms, taking in less food and fluid, a weak immune system, loss of the ability to feel pain, and loss of bowel and bladder control. This section provides tips and advice on caring for skin. Your role may be ‘hands-on’, i.e., checking the skin for signs of redness or irritation, applying moisturizing creams, changing dressings, turning and positioning, or applying booties, lambskin or other pressure-reducing surfaces in order to prevent or treat pressure sores. Or your role could be one of “manager”, i.e., supervising home health staff, or calling nurses or other clinicians regarding skin status in order to ensure that appropriate care is being provided.

1. What are pressure sores and why do they develop?

A pressure sore is an injury that damages the skin and underlying tissue. These sores are also referred to as pressure ulcers or bedsores and they range in severity from mild (minor skin reddening) to severe (deep craters down to muscle and bone).

Unrelieved pressure on the skin squeezes tiny blood vessels that supply the skin with nutrients and oxygen. When skin is starved of nutrients and oxygen for too long, the tissue dies and a pressure sore forms. Skin

reddening that disappears after pressure is removed is normal and not a pressure sore.

Dehydrated or damaged tissue is less tolerant of pressure, friction and shearing, especially over bony areas. Damage occurs with high pressure over a short period of time or with less pressure over a long period of time. Current research indicates that damage begins inward and is unseen until it moves outward with surface skin destruction.

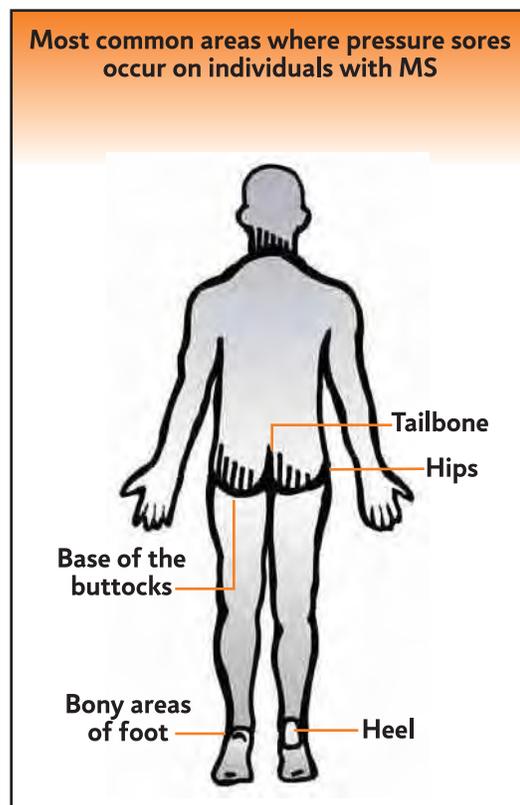
Other factors cause pressure sores too. If a person slides down in the bed or chair, blood vessels can stretch or tear and cause pressure sores. Even slight rubbing or friction on the skin may cause minor pressure sores. Medical conditions, such as diabetes (which leads to decreased circulation), severe weight loss, and cancer (which causes tissue wasting) may further increase risk.

2. What can be done to prevent pressure sores from developing?

Keep in mind that recent research indicates that even with the best care, some bed sores are unavoidable. Sometimes they are just an indicator that the person is very sick. Nonetheless, the following measures may help to prevent pressure sores.

- Inspect skin at least once a day.
- Bathe when needed for comfort or cleanliness.
- Prevent dry skin—use moisturizers.
- Clean skin as soon as soiled or wet from urine and pat dry.
- If moisture cannot be controlled, use absorbent pads and/or briefs with a quick drying surface. Cleanse skin as soon as possible with no-rinse cleanser and a durable barrier product. These products are readily available in your local drugstore.

- Don't massage bony prominences (areas where the bones protrude slightly below the skin).
- When repositioning, reduce friction by lifting rather than dragging.
- Use cornstarch on the skin to reduce friction.
- Encourage a balanced high-protein diet or explore nutritional supplements.
- Consult a dietician about protein and calorie intake.



3. Are there specific things I should do if my loved one is confined to a wheelchair?

Persons confined to chairs should be repositioned every hour if they are unable to do so themselves. If they can shift their own weight, changing position every 15 minutes is recommended. Use foam, gel, or an air cushion to relieve pressure. You can consult a physical therapist to learn more about the best cushion, but it is strongly suggested you avoid donut-shaped cushions. Pillows or wedges can be used to keep knees or ankles from touching each other.

4. What if my loved one is confined to bed?

Changing position at least every two hours is very important. Keep bed linens clean, dry, and without wrinkles. Special mattresses that contain foam, air, gel, or water are recommended. It is advisable to raise the head of the bed as little as possible and for as short a time as possible

(No more than 30 degrees or it can increase the chance of bedsores). Placing a pillow under the legs from mid-calf to ankle helps to keep heels off the bed.

5. What should I do if a wound develops?

Remember, as was pointed out previously, wounds can develop, even if someone has received the best of care. The important thing is to consult with a physician or nurse as soon as you see a wound beginning to develop.

For a superficial wound, treatment consists of alleviating pressure to avoid more exposure to the cause of the injury. Soft protective pads and cushions are often used for this purpose. Increased hydration and nutrition is important.

If the wound is more developed (a blister either broken or unbroken), the goal of care is to cover, protect, and clean the area. There are a wide variety of products for this purpose. Skin lotions and barrier creams are used to hydrate surrounding tissue and prevent the wound from worsening. Padding and protective items are used to absorb and decrease pressure on the area. Close attention to protection, nutrition, and hydration is important.

At the next stage, the wound extends through all the layers of skin. It is a site for infection. The goals of alleviating pressure and covering and protecting the wound still apply but with an increased emphasis on nutrition and hydration. Medical intervention is critical. This type of wound will progress to the next stage very rapidly. Infection is a real concern. Pain, particularly as dressings are changed, is a significant issue.

A more severe wound, where the wound extends through the skin and involves underlying muscle, tendons and bone, is very serious and

can produce a life threatening infection, especially if not aggressively treated. All of the goals of protecting, cleaning and alleviation of pressure on the area still apply, and nutrition and hydration are critical. Medical intervention is absolutely essential.

6. Would getting a special mattress help?

Positioning and the selection and use of appropriate support surfaces can be complicated for caregivers. To be effective, support surfaces must distribute body weight evenly over the entire body. The degree of head elevation shifts pressure to the lower back and hips. The surface must be able to permit prominent areas of the body to sink into the support.

For the person confined to bed, mattress overlays and mattress replacements can provide pressure relief. For pressure ulcer prevention, foam, gel and water mattress overlays that do not require electricity may be adequate. For a person with multiple pressure ulcers on the trunk or pelvis, a powered surface may be needed. Alternating air overlays with mechanical pumps are available as mattress overlays and whole bed systems. For the person with ulcers that have not improved with comprehensive care, sophisticated air-fluidized beds may be necessary. A wound specialist should be consulted. Your insurance carrier may cover the cost of such equipment, but this needs to be determined.

When considering a support surface, look for moisture control and skin temperature (the surface should not make the person sweat). The surface should not promote bacterial growth or be flammable. The owner's manual should describe how to clean and maintain the surface.

7. When changing the dressing I have noticed an odor in the wound. Is this significant?

Wound odor and drainage can occur and can have a negative psychological effect on the person with MS and the caregiver. The problem can be addressed by using an antimicrobial wound cleanser, removing non-living tissue from the wound, and changing the dressing more frequently. Because excessive drainage can contribute to further deterioration of the wound, consultation with a wound specialist is advised.

8. What do I need to know about managing pain that's caused by pressure sores?

The pain associated with pressure ulcers is a source of anxiety and distress and can be difficult to relieve. Pain can make it difficult to sleep or eat and can deepen depression. Aggressive interventions with a combination of pharmacologic and non-pharmacologic measures to prevent and relieve pain are encouraged. An effective pain management strategy takes into consideration side effects (constipation, sedation, etc.) of the measures used.

Pre-medication at least twenty to thirty minutes before dressing changes, plus scheduled analgesics, can make a significant difference in comfort. Mild to moderate pain can often be managed with non-steroidal anti-inflammatory medication (NSAID's such as Aleve®). Moderate to severe pain may require opioids which will require a prescription. At times, combinations of antidepressants and anticonvulsants can help reduce pain. Topical applications are often effective in the management of nerve pain. Consulting with a pain clinician to assess and manage wound pain can help establish and maintain optimum levels of comfort for your loved one.

Resources

National Pressure Ulcer Advisory Panel

(Offers information for caregivers, families providing care at home, and others)

SUNY at Buffalo

Beck Hall

3435 Main Street

Buffalo, NY 14214

716-831-2143

Spasticity

"I found that spasticity in his legs made it almost impossible to bathe him properly."

Spasticity is characterized by an increase in tone in a muscle group so that there is stiffness and resistance as the muscle is moved. In MS it can impair mobility, produce pain, and significantly impact daily living. Spasticity can increase intermittently (cramping) or increase chronically. Complications from spasticity include pain, joint contractures, frozen joints, impaired bladder or bowel function, skin ulceration, and abnormal postures and falls.

In this section we talk about how to best deal with spasticity, a painful symptom that can impact almost every activity of daily living.

1. What can I do to manage spasticity and limit its impact?

Factors that can precipitate spasticity include changes in position, elevated body temperature, painful stimuli, bladder or bowel distension, and infections. Spasticity can either be localized to the muscles of one extremity, or be more generalized in nature.

Maintenance of range of motion is the key to preserving functional ability and should be initiated as early as possible for those joints at risk for restriction from full movement. Daily stretching can be very helpful. Each joint should be slowly moved to its full range of motion. Proper positioning techniques in the bed and chair are also important. If a person is able to walk or stand, this is helpful. Any home exercise program that focuses on the muscle groups of the hip, knee, and foot can be beneficial.

Cooling therapies can be helpful in warmer climates, including cooling garments and locally applied cool packs/towels. Orthotics such as splints and braces can help by maintaining good positioning. Monitor things like in-grown toenails, tight-fitting orthotics, and bladder/bowel functioning. Consult with a physical or occupational therapist to determine what regimen would work best in your situation. If a muscle spasm does occur, the activity should be stopped until the spasm passes before proceeding. Encourage your loved one to move slowly and smoothly. Quick jerking and sudden moving can often set off a spasm.

2. How is spasticity assessed and treated?

Spasticity is measured by the degree of passive resistance to the stretch of muscles around joints, using the Ashworth or modified Ashworth scales. Treatment of spasticity involves both medications and physical approaches. Over-treatment of spasticity can impede mobility.

Medications

Two mainstays of treatment are **baclofen (Lioresal®)** and **tizanidine (Zanaflex®)**. The major side effect of both drugs is sedation, which can be partially ameliorated by starting with a small dose and increasing slowly over time.

Second line therapeutic choices include **benzodiazepines (such as Valium®)**, **gabapentin (Neurontin®)**, and **dantrolene (Dantrium®)**. Drowsiness is seen as a limiting factor for this group. Dantrolene has a more extensive side effect profile, including nausea, diarrhea, incoordination, and possible liver toxicity.

For people with severe spasticity resistant to oral medications, a few more aggressive approaches can be considered.

- For focal spasticity, Botox® can be effective but must be targeted to specific muscle groups and repeat injections are required every

3-4 months. It can take 10-14 days to take full effect and needs to be combined with a stretching program and physical therapy to be optimally effective.

- Intrathecal Baclofen, administered through a baclofen pump, can produce dramatic improvement for more generalized spasticity in lower or upper limbs. The programmable pump is implanted in the abdomen and delivers a liquid form of baclofen directly to where it is needed—in the spinal canal. This route of delivery avoids the sedative effects of oral baclofen and allows small doses to be used. These pumps can be adjusted to deliver the appropriate amount of medication at the optimal time of day. Regular refilling of the pump, usually by a nurse, is needed.

Candidates for the pump are initially assessed prior to implantation with a small test dose of baclofen. A positive response to the test dose gives confirmation that the implanted pump and catheter will be effective. The dose of baclofen is titrated up over the months after implantation to achieve an optimal effect. Potential complications may include catheter or pump failure that can lead to baclofen withdrawal syndrome due to the sudden decrease of the medication, and infection.

A table of common antispasticity agents is summarized below.

Table. Common Antispasticity Agents			
Agent Generic (Trade)	Route	Potential Adverse Effects	Typical dose
baclofen (Lioresal®)	oral	sedation, weakness, confusion, withdrawal symptoms	20mg-80mg/ day divided 3x/ day or 4x/day

Agent Generic (Trade)	Route	Potential Adverse Effects	Typical dose
tizanidine (Zanaflex®)	oral	sedation, high blood pressure, abnormally slow heart rate, dry mouth	8 mg every 6-8 hrs
diazepam (Valium®)	oral	sedation, fatigue, incoordination	2-10mg every 8-12 hrs
gabapentin (Neurontin®)	oral	sedation, dizziness	300-600mg every 8 hrs
dantrolene (Dantrium®)	oral	sedation, dizziness, nausea, diarrhea, liver toxicity	100mg every 8-12 hrs
botulinum toxin type A (Botox®)	intramuscular injection	pain, tenderness & bruising at injections site, weakness of non-target muscles	dependent on muscle injected, generally 10U-200U per muscle injection (Botox A)
Intrathecal Baclofen	intrathecal catheter (directly into the spinal fluid through an implanted pump)	pump and catheter failure, baclofen withdrawal symptoms	100-800 micrograms/day

3. What can be done if neither Botox® nor the baclofen pump work?

When spasticity is unresponsive to medications or physical therapies, phenol nerve blocks are a possibility where phenol is injected into a nerve in large muscle groups, mainly in the thighs. There are also palliative surgical techniques that may offer improvement in symptoms and prevent contractures. These include tendon releases, dissection or cutting of peripheral nerves, and surgical severance of spinal cord roots.

4. Are there complementary or alternative medicines that can help spasticity?

There have been few studies examining the effects of complementary and alternative medicine on spasticity in people with MS. Therapies that have been identified as promising and low risk from a few small studies include biofeedback, cooling, hippotherapy, massage, tai chi and yoga. There is also some limited evidence to suggest that oral cannabinoids may be effective in relieving spasticity in people with MS.

Resources

National MS Society Publications

800-344-4867

www.nationalMSSociety.org/brochures

- *Controlling Spasticity in MS*
- *Stretching for People with MS*
- *Stretching with a Helper for People with MS*

Speech and Communication

“Not being able to talk the way we used to is a terrible loss.”

Speech difficulties are common in MS and especially in people with advanced disease. Speech difficulties result from damage to areas of the brain that control language, speech production, swallowing, breathing, and cognition, and range from mild difficulties to severe problems that make it difficult to speak and be understood. Speech problems can be very isolating and extremely frustrating for caregivers. This section offers guidance on maximizing the ways you and your loved one can continue to communicate.

1. What types of speech problems do people with MS experience?

One pattern of speech dysfunction commonly associated with MS is scanning speech, in which there are long pauses between words or syllables of words. People with MS may also slur words intermittently as the result of weak tongue, lip, and mouth muscles. Dysarthria is the term that describes a disorder characterized by slurred speech, abnormal rate of speech, and low voice. The cause of dysarthria is weakness, incoordination of the speech muscles, and incoordination of breathing and sound production.

2. What are the most common manifestations of speech problems?

- Slurred speech
- Slowed speech
- Monotonous (dull) voice
- Mispronunciation of words
- Low voice
- Inability to complete words

3. How are speech problems diagnosed and treated?

The first step is a thorough assessment of the problem and its cause. A speech/language pathologist can conduct a thorough assessment and may be able to help people with MS improve their speech patterns, pronunciation of words, and oral communication. If your loved one is able, oral exercises can enhance speech. Exercises focusing on the lips, tongue movement, and strength can make the speech clearer. In addition, decreasing the rate of speech and increasing breath support can make the speech better.

4. Is there anything we can do so that I can understand difficult speech better?

If volume is a problem in understanding speech, voice amplifiers may be helpful. They are usually small and battery operated, and totally portable. Positioning of the device is important, and avoiding competing background noise is critical. Also consider 'speech conservation', making the most important points first when energy levels are highest.

5. What can be done if speech ability is totally lost?

The inability to speak is devastating and its loss is felt deeply by both the person with MS and family members. However, there are many assistive devices available that may help with communication. These range from alphabet cards to computers. People with disabilities can control computers using adaptive keyboards, sticks held in the mouth, or wireless devices worn on the head or eyeglasses. There are even computers that can be controlled by blinking the eyes.

The goal for people with MS and their caregivers is to learn to use compensatory mechanisms or aids to improve communication and better understand each other's needs (A speech therapist can help). As

the disease progresses, an augmentative communication system might be considered. See Assistive Technology on page 80 for ideas about augmentative communication device.

Resources

National MS Society Publication

800-344-4867

www.nationalMSSociety.org/brochures

- *Speech and Swallowing: The Basic Facts*

Swallowing and Nutrition

“Food used to be such a source of pleasure for us—cooking, eating with friends, finding new and interesting tastes and textures. If you can retain any of that, it really helps.”

In advanced MS, there is often weight loss or very poor dietary intake. These problems can be attributed to swallowing problems, depression, fatigue, side effects of medications, shaking/tremors, and/or cognitive changes. It is not uncommon for individuals to become dehydrated along with consuming too few calories. People with MS can become dehydrated very quickly. This section addresses nutrition and eating. Even when MS causes swallowing problems, there may be ways to derive pleasure from eating.

1. What are problems related to appetite and nutrition in MS?

- Appetite decline:*** Appetite decline is a common symptom in people with advanced MS and can lead to depleted protein stores that impact skin health and overall well-being.
- Poor fluid intake:*** Water is a major component of blood and dehydration reduces the body’s blood volume. This reduces oxygen and nutrient delivery to the skin. Baseline fluid requirements for an adult are a minimum of 1.5 liters (quarts) per day. With swallowing problems, and sometimes concerns about incontinence, many people with MS do not take adequate fluids.

Swallowing problems: Coughing after drinking liquids, or choking while eating certain foods, particularly those with crumbly textures, are signs of swallowing difficulties, or dysphagia.

When this kind of coughing or choking occurs, the food or liquids are inhaled into the trachea (windpipe) instead of going down the esophagus (gullet) and into the stomach. Once in the lungs, the inhaled food or liquids can cause pneumonia or abscesses.

2. How can I help to prevent problems of dehydration, choking, and malnutrition?

The following are food safety tips that might be helpful to address swallowing problems and avoid dehydration, poor nutrition, or the risk of aspiration pneumonia. The goal is to help your loved one get the most nutrition and pleasure from food and drink while keeping discomfort to a minimum.

- The best position for eating is sitting.
- Avoid having the head tilted backwards.
- For those using wheeled mobility, consider a water bottle called a drink-aide that allows wheelchair users to drink independently, even if they have limited or no upper body movement. (www.drink-aide.com)
- Consider beginning a meal with something icy and thick—a sherbet shake, or a fruit or vegetable smoothie. The cool temperature will improve crucial nerve conduction.
- Take one small bite or sip at a time. Never try consecutive swallowing.

- Never wash food down with a liquid. Instead, add moisture to the solid food. Use sauces, broth, soup, water, or milk.
- Think about spoon size and what works best.
- Choose soft, moist foods first, as they are easier to swallow. Dry solids and thin liquids are more difficult, and require closer attention for safe swallowing.
- Avoid thin liquids altogether when fatigued. Consider consuming thin liquids in the morning and thicker liquids in the late afternoon or evening.
- Identify and then avoid foods that cause choking or coughing, such as potato chips.
- Experiment with a kitchen blender. Some favorite dishes can be pureed without losing their familiar flavor.
- Check with a speech therapist if your loved one starts to slow down during a meal, pause and switch to something icy.
- Make mealtimes a calm and social part of the day and save discussion of “hot” topics for times when no one is trying to eat.
- Offer mouth care frequently.

3. How can nutritional and swallowing problems be evaluated?

Swallowing problems are initially diagnosed by a careful history and neurologic examination of the tongue and swallowing muscles. A special imaging procedure called a modified barium swallow (videofluoroscopy) is used to evaluate a person’s ability to chew and swallow solids and liquids. In this test, the person drinks a small quantity of barium, which makes the structures of the mouth, throat, and esophagus visible on x-ray. The movement of these structures is recorded on videotape by a videofluoroscope as the person eats or

drinks foods of varying consistencies—thin liquid, thick liquid, and solid. The precise location and manner of a swallowing defect can then be identified, and treatment prescribed.

It is important to remember that the testing might not replicate your experience at home. Swallowing, like many other MS symptoms, can change from day to day and hour to hour. Therefore, the timing of the test, whether it is in the morning or afternoon for example, could make a difference in the results.

A speech/language pathologist is the professional who diagnoses and treats swallowing difficulties. Many people who have difficulty swallowing also have speech disorders. Speech/language pathologists also evaluate, diagnose, and treat these problems. The National Multiple Sclerosis Society can provide referrals to qualified speech/language pathologists.

4. What happens if things get worse?

Treatment of swallowing problems typically consists of dietary changes, exercises, or stimulation designed to improve swallowing. In very severe cases that do not respond to these measures, feeding tubes may need to be inserted to provide the necessary fluids and nutrition. It is important to remember that using a feeding tube does not necessarily mean that a person cannot continue to eat by mouth as well. It does not have to be an “either-or” situation.

Feeding tubes are placed directly into the stomach or small intestine under local anesthesia. Called a PEG—percutaneous endoscopic gastrostomy—this can help maintain nutrition and hydration. Once the tube is in place, food products made for tube feeding are inserted. The food resembles a milkshake and contains lots of vitamins, minerals, and other nutrients. Food can either be administered as a continuous drip, or given more like a meal 4-6 times a day. Of course it is important to

keep the tube stable so that it is not moved by accident. The tube also needs to be flushed out with a little water after each use. A feeding tube inserted through the nose, although not requiring surgery, is uncomfortable and may lead to complications.

As people with feeding tubes become better nourished and hydrated, they may have a better ability to take some food by mouth. This should be determined by a speech therapist or other professional who can assess swallowing.

There is no question that the move to using a feeding tube is a major transition. Not only is new learning required of family members but there are also implications with regard to professional caregivers who are providing care. In many states certified nursing assistants cannot help with tube feeding and a higher level of provider needs to be involved, such as a licensed practical nurse (LPN) or registered nurse (RN). Be sure to ask questions of your physician, the speech pathologist, and any home care agency providing you services so that you understand what to anticipate if possible insertion of a feeding tube is part of the plan.

Resources

National MS Society Publication

800-344-4867

www.nationalMSsociety.org/brochures

- *Speech and Swallowing: The Basic Facts*

Cognitive and Mood Changes

"I found her memory problems to be terribly frustrating and her thinking just seemed so slow. I suppose these problems were frustrating for her, too. But I had to keep reminding myself that these were symptoms of MS and not something she could really control."

Cognitive problems occur in more than half of people with MS. Like other MS symptoms, it is highly likely that, over time and with duration of disease, cognition will be affected. Cognitive changes vary greatly from person to person, and advanced physical disease does not necessarily mean advanced cognitive decline.

This section will help you recognize cognitive dysfunction, understand the impact of cognitive dysfunction on your loved one and the family, and provide you with some practical suggestions to manage cognitive challenges. It will also briefly discuss altered mood states, euphoria, and altered levels of consciousness as sometimes seen in advanced multiple sclerosis.

1. What is meant by cognitive dysfunction?

Cognition involves knowing, thinking, remembering and reasoning abilities. The five senses are used to gather information, organize and store that information, and give it back in the form of expressive ability. Cognitive changes in MS range from mild short-term memory problems and easy distractibility, to difficulties with planning and problem solving. Quickness, cleverness, being "on the ball", sharp... these are attributes of the mind that can be sacrificed to MS cognitive dysfunction and can often be seen in advanced MS.

2. What are some clues to cognitive dysfunction?

Memory problems top the list. Forgetting names, appointments, phone numbers, movie plots, what to do next, or what goes into the favorite family recipe, are examples of memory deficits. There can also be difficulty learning new information and concentrating on a task or conversational topic.

Slowed information processing is also a frequent problem. Everything takes longer. It may be impossible to play games that are time sensitive. Response time is slowed. It may take longer to shave, bathe and dress.

Attention and concentration suffer. Inability to focus, difficulty following a conversation or remembering details from a conversation, problems relating a story, difficulty reading, concentrating, or following a movie plot are examples of attention deficits. Being easily distracted and flitting from task to task or idea to idea are examples of difficulties with concentration.

The ability to **multitask** or shift between tasks becomes difficult or impossible.

Reasoning and problem solving difficulties, making poor decisions, and having poor judgment can be difficult to recognize and more difficult to deal with for caregivers. Slowness to understand analogies or parables, difficulty “getting” jokes, taking things at face value, being literal or concrete, and finding it difficult to analyze complex situations, are all evidence of cognitive decline.

Executive functions such as the ability to plan and carry out a task like planning a daughter’s wedding or a holiday trip are affected in advanced MS. Becoming overwhelmed by a pending task can result in confusion over where to begin, and may be associated with compensatory anger and withdrawal.

Visual perceptual function and spatial orientation problems can include difficulty following directions or programming a VCR, confusion over right and left, and difficulty visualizing how a certain piece of adaptive equipment could be useful.

3. Why can cognition sometimes be hard to identify?

In advanced MS, when physical disability limits activity and confines an individual to wheelchair or bed, deficits in cognitive function can be more difficult to discern. Increased sleepiness, physical inability to hold a book to read, or not participating in family life fully make it difficult to assess attention and concentration, memory, reasoning, executive function, multitasking, or visual and spatial orientation. The only obvious clue might be the effect of cognitive dysfunction on mood, where frustrated thinking or poor decision-making results in anger and withdrawal.

Decisions must be analyzed for logic, realism, and feasibility of implementation. It is not uncommon for those with advanced MS to make unhealthy and illogical decisions regarding their own care—firing a home health aide abruptly or stopping a medication against doctor’s orders. Refusing care, or imagining care needs inappropriate to the situation, can occur.

4. How can cognitive changes be managed in advanced MS? Are there medications that can help with cognitive decline?

In advanced MS, cognitive decline, like physical decline, cannot be reversed. However, cognitive disorders can be treated with medication and behavioral methods. Donepezil (Aricept®), commonly used in Alzheimer’s disease, has shown a modest effect in several small trials of memory in people with MS. The use of ginkgo biloba in a small randomized controlled trial reported positive effects on attention

and memory for people with MS. Symptom management of fatigue, depression, stress and pain can also have a positive impact on cognition.

5. How can I help my loved one to compensate for cognitive losses?

Studies show us that routine, ritual, symbols and simple patterns offer support and well-being. In dealing with advancing physical and cognitive decline, developing and sticking to simple routines performed consistently day after day, will offer comfort, structure, and safety, and will ease the cognitive burden for both you and your loved one.

- Use a large calendar to write routines and appointments.
- Bring to the living space family photos, a clock, a calendar and seasonal or significant visual displays.
- Limit sensory stimuli. Have a one-at-a-time rule. Limit to one, the sound of TV or radio or conversation.
- Use music or smells to trigger happy memories, such as playing a favorite radio station or baking chocolate chip cookies.
- Maintain a simple, clutter-free environment. Find a place outside your loved one's room to store containers of diapers, catheters, and bed pads. Do not allow stuff to clutter the room.
- Explore voice activated computers to maintain calendars and lists, such as lists of topics to go over when visiting the neurologist.
- Don't forget the usefulness of tape recorders for recording important conversations, creating verbal reminders, etc.
- If your loved one is able, initiate conversations about political and social events. Allow sufficient time for thoughts to process.

- Encourage expression of opinions and thoughts by discussing a news or current event story. Read a book or newspaper aloud. Listen to books on tape.
- Change the environment. Get outside in the sunshine whenever possible.
- Help your loved one write a daily “to-do” list and prioritize the items. However, certain activities of daily living should not be negotiable, such as getting out of bed (if possible) every morning, washing, eating, toileting, range of motion exercises, drinking several glasses of fluid, taking medications, and getting outside.

6. How can I help with decision making?

Decision-making is a challenge for the cognitively impaired. Decisions can be made that are illogical, unrealistic and harmful. To assist your loved one in the process, write out the pros and cons to make the situation more visual. Confer with a knowledgeable source such as a lawyer, doctor, pastor, neutral observer, or relative if you need to.

If there are important decisions to be made, such as life planning or financial decisions, try to address these issues when cognitive decline is first noticed and before decision-making is significantly impaired.

7. What is meant by altered mood states?

Altered mood states are considered neuropsychiatric rather than cognitive deficits. Neuropsychiatric changes can include mood swings, depression, irritability, anxiety, inappropriate and excessive cheerfulness (euphoria) agitation, apathy, and disinhibition.

Mood swings can fluctuate quickly between anger or rage and normal behavior. A separate mood disorder termed pseudo-bulbar

affect, also known as Involuntary Emotional Expressive Disorder (IEED), is characterized by uncontrollable episodes of laughing and/or crying, and affects 1 in 10 people with MS. These episodes are not necessarily associated with the person's underlying emotion, and can be inappropriate to the external circumstance. A minor stimulus, such as watching a television commercial or receiving a gift, can cause uncontrolled tears for example, while learning of a death can bring on uncontrolled laughter.

Euphoria and disinhibition (inappropriate sexual talk or behavior, loss of "social graces") can occur in people with advanced MS.

Treatment for altered mood states may involve medications, and successful management is possible. Ask a neurologist, mental health professional, or nurse about current treatments.

8. What is meant by altered levels of consciousness?

Consciousness level refers to how awake and alert a person is. Levels of consciousness include: alert, confused, drowsy, and unresponsive. Situations that might alter consciousness are medications (for example pain medications), infection, fluid and nutrition intake, or the underlying disease process. Infection, such as aspiration pneumonia, can worsen respiratory effort and affect level of consciousness. Poor nutrition and hydration can also lead to states of altered consciousness.

Persistent vegetative state (unresponsiveness with no brain function beyond bodily activities such as heartbeat) can occur in multiple sclerosis. Care of these individuals is focused on maintaining dignity and hygiene. Life expectancy is 2 to 5 years.

Resources

National MS Society Publications

800-344-4867

www.nationalMSSociety.org/brochures

- *Solving Cognitive Problems*
- *MS and the Mind*—Reprint from *InsideMS*

Assistive Technology/Adaptive Equipment/Home Modifications

“My advice is to anticipate that the disability will be long, and will likely get worse. Buy a house and equipment that are readily adaptable to increasing disability.”

Assistive technology (AT) is any item, piece of equipment, or product system that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities. These items can be acquired commercially off the shelf, modified, or customized. They include wheelchairs, lifts, bathroom equipment, communication aids and more.

In this section we provide ideas for how assistive technology and adaptive equipment can make life easier.

1. I know that there’s equipment that might help me but I want my house to continue to be a warm and comfortable place. How can I make sure my loved one’s room doesn’t feel like a hospital room?

There are many devices available that are useful and yet are increasingly being made with an eye toward aesthetics as well as function. Hospital beds, at one time always looking like medical equipment, are now being made to look more like bedroom furniture. Lifts and power chairs are becoming more compact and less bulky. Many items once found only under “disability” are now being sold to wider audiences and are therefore more sensitive to aesthetic sensibilities. For example, voice activated computers that were once targeted primarily to people with disabilities are now being marketed

to people who don't like to type! A physical therapist, occupational therapist, or speech therapist can familiarize you with the kind of equipment that is available.

2. Showering and bathing has become nearly impossible. What can we do to make this easier and safer?

There are many types of devices and equipment that can improve ease and safety in the bathroom. Bath seats/benches, transfer seats, hand-held showers, wheel-in showers, and shower chairs are all options that may be useful, depending on the physical environment of the bathroom and the person's abilities. 'Low tech' items that can make bathing easier include soap-on-a-rope, a washcloth mitt, and different colored sponges that can be used for different parts of the body.

If bathing must take place in bed, a 'bath-in-bed' unit might be a possibility. Such a unit requires no plumbing connection and can be used with standard or electric beds. It includes a soft, flexible underliner surrounded by a collapsible aluminum frame that supports the liner to create a 'bathtub'. There is also a 'shower anywhere' portable shower that can be used with it if the head of an adjustable bed can be raised.

3. Are there any low-tech (that is, inexpensive) devices that can help with every day tasks like dressing and eating?

There are many inexpensive, low-tech items that can be extremely useful. For example, reachers, weighted utensils, Velcro® closures on clothing, special drinking straws, non-skid bowls, and built up handles may support independence.

4. Any ideas to help with toileting? I can sometimes get my husband into the bathroom on the toilet, but other times he is too tired.

There are a variety of commodes and bedpans that can be used. Commode features such as adjustable height, removable arms, seat lifts and those that double as a shower chair are available. There are urinals for men and women and a variety of bedpans that can be used for toileting in bed, many coming with lids to avoid spills.

5. My husband used to be able to drive his power wheelchair with a joystick control, but now he doesn't have the movement in his arm or hand. Is there any way he can still drive it?

Many wheelchairs can be adapted for driving with options other than a joystick. Driving mechanisms for power wheelchairs include headrests with driving controls, a breathing type control system called 'sip and puff', tongue and cheek switches, a specialized touch pad, and more. A creative and experienced vendor and an occupational or physical therapist who understands MS can take advantage of any remaining active motion to control a wheelchair. For more information about local vendors, contact the National MS Society.

6. My home is on two levels and I can't keep going up and down the stairs every time my wife needs something.

There are both high and low tech options available. If possible, you may want to consider moving the bedroom to the main floor.

Residential elevators and stairlifts are very helpful for moving a person with limited mobility up and down stairs, although they can be expensive. There are elevators specifically designed for home use, such as the "Minivator", an elevator that rides on two steel rails and is designed for situations where space is limited. Remember, when it

comes to a stairlift, a person must be able to transfer and have good sitting balance. Be careful if it seems less expensive to rent a device than buy it. Be sure to ask if the rental price can be put towards the purchase price.

Some towns and states have funding available for home modifications. Contact your state department of social services, your independent living center, and the National MS Society for ideas about funding home modifications. It may be possible to buy some of this equipment second-hand. Be sure you are getting the equipment from a reliable source, however, and that it is appropriate to your loved one's needs and the layout of your home.

Another option to save time going up and down the stairs is an "electronic aide for daily living unit", formerly called an environmental control unit, that can be located by the bedside and can operate the TV, telephone, lights, call system, and other devices through the use of one or more switches. The control system can be adapted with a variety of switches—head switch, bite switch, finger switch, etc. Using such a device promotes independence and means family caregivers may need to be called upon less often.

There are a number of devices that can help you hear your wife when you are needed. These range from a bell or buzzer system to baby monitor-type devices to personal amplifiers.

7. What can I do to help my Dad, who can't transfer in and out of a wheelchair, get in and out of our minivan more easily?

There are many devices that can help keep your Dad mobile. Options range from lowered floor minivans to special seats and wheelchair lifts that can lift him into the van. Some power wheelchairs have elevation and rotation features to facilitate such transfers.

Other options include rear entry kneel vans, and vans equipped with a powered lift system capable of lifting up to 600 pounds. The National Mobility Equipment Dealers Association (NMEDA) can help connect you with companies in your area that specialize in working with people with disabilities to help meet their transportation needs.

www.nmeda.org

If you are buying a new vehicle and need it to be adapted, most carmakers offer rebates. Talk with your dealership or the National MS Society for a list of rebate programs. Another option is to purchase a used vehicle. The cost is significantly less and they often come with substantial warranties. Search via the internet. Companies that rent wheelchair accessible vans often sell them to their customers at a reduced price.

8. Is there funding available to help with the purchase of a lift system for the bedroom and bathroom?

Funding can be hard to obtain, but groups such as the National MS Society, Centers for Independent Living, Veterans organizations, faith-based organizations, and fraternal groups may be helpful in obtaining funds.

Medicaid, in some states, covers lift systems. It's important to know that every state has an assistive technology financial loan program (<http://www.resna.org/AFTAP/index.html>). These programs provide low cost loans to enable people with disabilities to obtain equipment and make home modifications.

9. Since I am having an increasingly hard time transferring my husband in and out of the bed and chair, what kinds of lifts are available that could fit into the limited space of our home?

There are many different types of devices that can be helpful for getting your husband in and out of a bed or chair. There are lifts that

attach to the ceiling or wall and take up minimal space, as well as lifts that roll on the floor. If the person has some mobility and can sit up, there are also transfer type lifts.

Typically the ceiling, wall, and floor lifts use either a hydraulic system or a motor to lift the individual. The sling or harness goes around the person and then attaches to the lift. The lift is then raised either with a pump, crank or button depending on the type of lift (manual or electric/battery).

There are many styles of slings and harnesses. It's a good idea to investigate all options before making a purchase. The slings and harnesses are made with many different fabrics and materials. They are an essential part of these devices. Modern type slings can easily slide behind and around the person so that the individual does not need to sit or lay on the sling all day (which may cause pressure on the skin).

Medicare will often pay for renting a manual type lift. In some states, Medicaid may pay for the lift, either a battery or electric type. Other resources for information and funding are the Assistive Technology Program in your state and the National MS Society.

If possible, try the lift out in your home. Many of the vendors will bring samples to your home. They may send a video or DVD to aid in making decisions. The advantage of electric lifts is that they are easy to operate. Depending on the lift and the individual with MS, however, some lifts may require two caregivers to operate the unit, which might not always be practical. Don't hesitate to ask questions.

10. Since my wife can't transfer out of bed anymore, we're having trouble keeping her skin in good shape. What can we do?

See page 53 for tips on good skin care. One resource for an evaluation is to have a home care nurse or a physical or occupational therapist familiar with wound care do an evaluation. There are many different

types of support surfaces that are available for use on a bed. Home medical companies that specialize in support surfaces for beds can help you select from the various types and models. Some of the options include alternating pressure pads, gel pads, and fluidized beds.

11. Are there any assistive devices available to help with communication?

Augmentative communication devices help people with serious speech problems communicate more easily and effectively. These devices range from a board with pictures representing a person's daily needs, to electronic speech synthesizers.

Manual communication boards are an inexpensive and practical mode by which an individual can communicate. The term "manual" refers to the fact that the system does not involve any mechanical or electronic parts. An object i.e. toothbrush, a photograph, a symbol, and/or printed words can represent the user's message and the individual with MS points or gestures to the symbols. Word or letter boards can be created so that the person can point and spell out words or everyday phrases.

A higher technology approach includes augmentative speech devices, and amplification devices. Computer software is available that converts text to speech, and recognizes speech (even slurred speech), Modifications can be made to the keyboard and mouse, and head and eye control systems are available for inputting data and more.

12. Any ideas for ways to just enjoy ourselves and pass the time?

There are many products specifically designed for just having fun! A large screen TV can help someone with poor vision enjoy TV and movies. Low tech items such as playing card holders, or books on

tape may be useful. A camera mount is available to mount a camera to a wheelchair, opening up photography as a hobby for someone who might not be otherwise able to hold a camera. Wheelchairs with special tires can be mobilized over sand or rough terrain, opening up possibilities for outings to the beach or woods, and several gardening adaptations are available.

Many families continue to enjoy travel and sightseeing. There are many travel agencies, travel guides and other resources specifically oriented to people with disabilities. Many cruise lines and hotels provide wheelchair accessible space and other services. An occupational or physical therapist can help you brainstorm ideas to make a trip enjoyable for you, e.g. traveling with a portable bed rail to use in a hotel that will make bed mobility and transfers easier.

13. We have lots of equipment that we don't use anymore. I hate to see it go to waste.

There are more and more options for recycling medical or assistive technology. Check with your state's assistive technology program (state listing can be found within the RESNA website noted on page 88) or with your local chapter of the National MS Society.

Resources

ABLEDATA

www.abledata.com

Provides objective information on assistive technology and rehabilitation equipment available from domestic and international sources to consumers, organizations, professionals, and caregivers within the U.S.

National Assistive Technology Technical Assistance Partnership (NATTAP)

<http://www.resna.org/taproject/at/index.html>

A sponsored project of the Rehabilitation Engineering and Assistive Technology Society of North America, RESNA. This website has a section devoted to organizations and projects that deal with assistive technology.

The National Mobility Equipment Dealers Association (NMEDA)

www.nmeda.org

Connects people with disabilities to companies that can help meet their transportation needs.

Beyond Barriers

www.beyondbarriers.com

Catalogue of innovative accessibility products to enhance independence

National MS Society Publication

800-344-4867

www.nationalMSsociety.org/brochures

- *At Home with MS: Adapting Your Environment*

Life Planning and Advance Directives

“Looking back, I would have amassed more information, more quickly about both her condition and about our financial and legal situation.”

Many people living with MS and their families follow the oft-quoted phrase “plan for the worst and hope for the best”. This philosophy helps us to be prepared for difficulties before they happen, if they happen. In this section we discuss anticipating needs that might arise in the future, identifying legal documents that need to be in place, and taking steps to assure that your loved one’s wishes and values are reflected in future medical and end-of-life decisions.

1. What do we mean by life planning?

Life planning is a way to anticipate what the future may hold and prepare, in advance, for those possibilities. It involves anticipating changes that may be in store. Planning in advance includes thinking about and communicating wishes and preferences about health care, end-of-life and daily care. It also includes making financial and legal arrangements in advance of need so that families are not caught off-guard when these events come to pass.

Planning ahead requires clear communication among all family members and clarity regarding the values and wishes of all family members. We all know from the Terry Schiavo case in 2005 what can happen when families do not have a clear understanding of their loved one’s wishes. Planning ahead means taking ownership of the future, reducing medical and financial risk, and doing all one can to assure security and the best possible quality of life.

2. What are future losses that I might encounter?

People with MS and their families can be robbed of many things as they live with MS, including physical abilities, independence, financial earning power, emotional ties, and options for the future. It can be frightening to consider all the changes that can happen over time. Losses that may need to be anticipated include:

- ***Loss of income because of caregiving duties and changes in family roles.*** In addition to probable loss of income by the person with MS, caregiving can also result in lost income as more and more time is required at home. This can cause a significant financial burden on families.
- ***Loss of time to care for one's own needs.*** Family caregivers providing 24-hour care often cut back on making time to take care of themselves.
- ***Reduction in friends and family being involved in you and your loved one's life.*** There are often two types of people in our life... individuals who are very important to us, and those who are more acquaintances. The acquaintances may drop out of your life. But if you can focus on the people most important to you, they are likely to stay around and be supportive.
- ***Changes in your partnership with your loved one.*** It may be that he or she finds it more and more difficult to communicate. Ability to speak and cognition may become impaired. Intimacy may fade in many ways, from companionship and conversation to the loss of sexual intimacy. Finding joy in the small things of life, and spending time to nourish things that both of you care about, will become increasingly important.
- ***Physical mobility often becomes impaired to the point that moving on one's own becomes impossible.*** When this happens, total care and assistance is needed. Total dependence impacts caregiver

independence significantly and requires planning to be prepared, should this occur.

Because of all of the challenges and changes that can come with MS, anticipating ahead and being prepared for challenges that might come in the future are extremely important. It can enable your family to make decisions in a much more deliberate and thoughtful fashion, rather than being caught off-guard and having to make decisions in the midst of crisis.

3. MS is such an expensive disease. Are there things I can explore right now that could help our family financially?

Maximize your income tax deductions. You probably already know that you can deduct out-of-pocket medical expenses for doctors, hospitals, ER, therapies, etc. if these expenses exceed a certain percentage of your income. However, you may not realize that other costs related to living with a chronic medical condition, such as room and board for a personal care assistant, wheelchair repairs, modifications to your home for medical reasons, wages for personal care services, etc. might also qualify as medical deductions. It is important that you consult with a qualified tax professional to be sure you are holding on to as much income as you can.

Maximize your health insurance benefits. Know what your health plan covers, whether it be an individual policy, employee policy, Medicaid, Medicare, or TRICARE, in terms of at-home nursing care, rehabilitation, durable medical equipment, mental health benefits, etc. If your plan offers a disease management or care management program, this could provide additional coordination of care.

Explore all resources regarding disability income—private long-term disability insurance, social security disability income (SSDI),

supplemental security income(SSI) if you have very minimal income and resources. Also remember that programs such as Social Security and the Veterans Administration provide benefits to family members as well. Be sure to explore all options.

Investigate Medicaid waiver programs in your state. Many states are focused on keeping people with long-term care needs out of the nursing home and in the community as long as possible. Although you might not have a low enough income to qualify for Medicaid, there are Medicaid waiver programs that provide services to families who have more financial resources than the traditional Medicaid recipient but require long-term care services. It's definitely worth a call to your Medicaid office. Also remember that any income you are spending to meet the medical needs of a person with MS can be deducted when Medicaid eligibility is being considered.

Consult with a certified financial planner or an elder law attorney to be sure you are optimally managing your finances and protecting your assets.

4. Why is it important to have legal documents regarding future health care decisions for my wife?

It is important that someone is authorized to make health care decisions on behalf of your wife, should the time come when she is unable to make these decisions. Since some of these decisions are apt to be life-or-death decisions, you want to make sure that enough information has been shared so that decisions reflect your wife's wishes.

5. What are the different types of advance directives?

Advance directives help people achieve a sense of control over their health care in the event they become unable to make a decision for themselves. The most common directives are:

- **Living will.** A living will spells out a person's wishes about medical care in case he or she is physically unable to state those wishes. It addresses specific medical situations such as the placement of a feeding tube or the use of mechanical ventilation if respiration fails. The living will spells out what the person wants to have happen in those situations. Many states only allow a living will to be utilized when a person is terminally ill, in a coma, or in a persistent vegetative state. Sometimes this document is referred to as an advance medical directive.
- **Health care proxy.** This directive allows a person to name a personal representative or agent who will make medical decisions on his/her behalf, should personal decision making become impaired. It is critical that this representative understand the values, beliefs, and desires of the person being represented, and that any decision he/she makes reflects the person's wishes as outlined in their living will. Health care proxy is sometimes called a medical power of attorney.
- **Do Not Resuscitate Order.** This document instructs medical personnel not to use CPR (cardiopulmonary resuscitation) if the person's heart stops beating. Some states have a variation of this directive specifically for Emergency Medical Services personnel.

It is important to review these documents regularly, and execute new documents when wishes have changed. Also, as long as the person is mentally able, these directives can be revoked at any time.

6. Is it important for me to have these types of legal documents as well?

Everyone, even those in good health, should prepare these documents because we never know when we might become unable to express our wishes. It is also good to keep in mind that if one does not choose an agent to make medical decisions, then a court will do so.

7. Do we need wills?

Everyone should have a will. You and your loved one should have a current will drawn up by an attorney and be sure that you keep it up to date. If you do not, your state law will dictate where your property goes and who will administer the estate. A will allows you to make your own choices. It also provides an opportunity for wishes to be stated with regard to guardianship of minor children and management of their assets until they are old enough to assume control. If these plans are not made, most state court systems make this extremely expensive. You may also want to consider a living trust in place of a will—this allows your estate to escape probate.

8. If we sit down as a family to talk about possible care needs in the future, what should we discuss? What would our goal be for this conversation?

Practical considerations such as costs of care, transportation for treatment, necessary equipment and the need for outside help should be discussed. What is known about all of these issues? The emotional and social needs of each family member should be discussed, and it is important to speak honestly about personal limits and the burden of stress involved in caring for someone who is seriously and chronically ill.

You want to tap into the strengths and abilities of all your family members. What services do you need to know more about? Who can do some research on the internet? Who can explore financial eligibility for some community services? Who can find out more about equipment and assistive technology that might help make things easier? Who can review legal and financial documents? Discuss together what needs to be done and prioritize a “to-do” list. Sometimes this planning conversation takes place in one long meeting;

other times it involves several discussions. The important thing is to develop a plan for how to go forward, and see that the plan is written and distributed to all involved. Keep in touch with each other, so that the best possible care can be provided.

9. Are there ways that caregivers can set aside money for loved ones so that, if they must rely on Medicaid in the future, they can have access to additional funds without jeopardizing their Medicaid eligibility?

One resource to consider is a special needs trust, sometimes referred to as a supplemental needs trust. This is a legal document prepared by an attorney who specializes in planning for disability and special needs. An advantage of special needs trusts is that they can help to protect financial resources for a person with a disability who must at some point rely on Medicaid to pay for long-term care services. This option is particularly attractive to elderly parents who are looking for a way to leave an inheritance to their adult child but want to make sure it will not jeopardize government benefits.

People who are under 65 and disabled can also establish a special needs trust for their own benefit to shelter assets. This allows them to keep the assets and also be eligible for government benefits such as Supplemental Security Income (SSI), Medicaid, or housing vouchers. This can be particularly useful when there is an inheritance or personal injury settlement expected.

This kind of specialized financial planning is an extremely important matter to discuss with your family. It is also a complex area of the law and requires an attorney experienced in the field.

It is also important for you to know that there are options available if you as a caregiver are overwhelmed and cannot carry out the financial

planning role. Find out about conservators or guardians, professionals who can be given the authority to make financial decisions and handle financial affairs under court supervision.

10. Can a person with MS donate tissue or organs?

Anyone can donate organs and tissue. For people with MS, these donations will be used for research rather than for transplants. For those considering donating tissue, planning ahead is essential. Brain tissue must be prepared within hours after death to be of use in research. Resources for tissue donation are provided at the end of this section.

11. Is it recommended that funeral arrangements be discussed in advance?

The more details that can be discussed, the easier it will be to administer funeral arrangements according to stated wishes. This also helps to decrease family stress at the time of death. If the wish is to be cremated, most states require the consent of the next of kin. To avoid that delay, your state may allow preparing a statement of wishes, rather than relying on the consent of others. Some of the decisions that can be made in advance include:

- the type of service desired
- the type of casket or urn
- the type of disposition of the body that is preferred (burial, cremation, etc.)
- details related to the service (funeral service vs. memorial service, clothing for burial, make up, hair, viewing or not, open or closed casket)

Resources

The National Academy of Elderlaw Attorneys, www.naela.org, or the Special Needs Alliance, www.specialneedsalliance.com can provide caregivers with referrals to local resources for creating special needs trusts.

Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO). This is a national consumer initiative to improve care at the end of life, supported by a grant from The Robert Wood Johnson Foundation. Their website, www.caringinfo.org, includes sections on care giving, advanced care planning, financial planning, grief and hospice.

Adapting: Financial Planning for a Life with Multiple Sclerosis

A 72-page publication addressing financial organization, planning, insurance options, employment concerns, and benefit issues important to people with MS and their families. This financial planning guide provides information and strategies to help families plan wisely for the future and meet financial challenges that often accompany life with MS.

Download/view in PDF format at www.nationalMSSociety.org or call your chapter to be mailed a free copy.

National MS Society Collaborative Program with Financial Education Partners

The Financial Education Partners (FEP) program has been established by the Foundation for Financial Service Professionals to provide pro bono financial counseling and education to individuals with special health or financial circumstances. The services can be accessed through a referral from any of the chapters of NMSS nationwide. The pro bono services are offered by members of the Society of Financial Service Professionals. Call the Society for more specific information.

Tissue Donation Resources

Rocky Mountain MS Center

Research Division

701 East Hampden Avenue , Suite 420

Englewood , CO 80110

303-788-4030

www.mscenter.org

MS Human Neurospecimen Bank

Veteran Affairs Medical Center

11301 Wilshire Boulevard

Los Angeles, CA 90073

310-268-3536

310-478-3711 after hours and weekends

www.loni.ucla.edu/uclabrainbank/

Home Care Services

“I want to keep my husband at home, but I know I will need help to do it.”

MS, even when progressive, can still be unpredictable. There can often come a time when it becomes extremely difficult for the family to carry all of the responsibility for providing necessary care. Planning ahead makes things easier. The best time to become an ‘educated consumer’ is not when you are in crisis, but when you can take your time learning about options and gathering information for future reference. In this section you will learn about various community home services that can provide clinical and emotional support to your family.

1. What does “home services” include?

There are a myriad of services in the community that are focused on serving individuals with chronic disease and disability in the home. They include the following:

- ***Certified Nursing Assistants (CNAs) or home health aides***—assist patients with daily living tasks under medical supervision, usually a visiting nurse.
- ***Personal care attendants or personal care assistants***—employed by individuals with disabilities to help with activities of daily living such as dressing, bathing, grooming, toileting, transferring, eating, etc.
- ***Nursing care***—assistance with medications, catheter-care, wound care, etc.
- ***Housekeeping***—basic homemaking tasks, light cleaning, errands, laundry, cooking.

- **Rehabilitation**—occupational therapy, physical therapy, speech therapy.
- **Companionship**—conversation, monitoring for safety, someone to talk to.
- **Care management**—health professionals who understand the health and social systems of the community and can help to link families to benefits and entitlements for which they might be eligible.

Check with the National MS Society, the Well Spouse Association, the National Family Caregivers Association, or your local Center for Independent Living to learn about what's available in your community.

2. If I am thinking about looking for some help at home, what would my first steps be?

The first thing you need to do is think about exactly what services you need. The level of skill for each service varies, as does the cost. A companion or homemaker is going to be less expensive than a home health aide providing hands-on care; a home health aide is going to be less expensive than a nurse. You need to think about exactly how much help you need and when you will need it...is it a couple of hours a day, morning and evening, or during overnight hours?

The second thing you need to do is decide whether you are going to hire privately, or if you are going to contract with a service agency in the community. Many times this decision is based on financial resources and/or a person's health insurance coverage. Government benefits such as Medicare and Medicaid can determine one's options. Medicare services are focused on skilled care needs and are usually provided intermittently, not long term; Medicaid, on the other hand, is more focused on chronic care needs and promoting independence, but the low income and asset eligibility may be hard to meet.

Therefore, what each program is willing to cover in terms of home services will be different. In Medicare, an assessment by a nurse or rehabilitation therapist will probably be required to determine the need for 'skilled care'. In Medicaid, a determination that the person receiving services needs a nursing home level of care may be required.

3. Is hiring privately complicated?

If you are hiring a personal care attendant you need to decide on the qualifications you will expect in an applicant. Colleges, hospitals, community centers, independent living centers, service organizations, clergy, and word-of-mouth are helpful resources for finding someone to hire. You will also have to think about who will interview the applicants, where they will be interviewed, and who will oversee paying them. You will probably need to have someone available to help with the financial responsibilities of being an employer in terms of taxes, insurance, etc. It is important that a background check be conducted, and that personal and professional references are checked. If you are hiring someone as a live-in, you will want to address privacy issues for both you and the employee.

4. Is there an advantage to using a home health agency rather than hiring privately?

When you use an agency, that agency does the hiring and training as well as the record keeping, scheduling, and billing, all of which can take a burden off an overwhelmed family. If you are receiving Medicare, private insurance coverage, or using long-term care insurance benefits to pay for home services, using an agency will probably be required. On the other hand, if you are paying out of pocket, hiring your own personal assistant will almost certainly be less expensive than going through an agency.

5. Is there a difference in what personal care attendants and home health agency aides can do?

Personal care attendants are consumer directed. Those who receive the care decide on the tasks they want done and when they want them done. There is a lot of flexibility in their role. Home health aides, on the other hand, are nurse directed and are prohibited from engaging in certain tasks that a personal care attendant might do, such as dispensing medications or performing suctioning, for example. If you contract with a home health care agency, a nurse will make a home visit and determine the plan of care. Responsibilities of the home health aide will be incorporated into that care plan.

6. Our local hospital provides a palliative medicine program. What does that mean?

Palliative programs focus on those in declining health who have long-term, often life-limiting, conditions, whose illnesses cannot be cured, and who often need additional help with symptoms such as pain, nutrition, and respiration. Palliative medicine expands beyond traditional disease-focused medical treatment to include a more holistic approach to care. It focuses on intensive symptom management in order to enhance quality of life and optimize functioning. It can also help families with decision making and looking to future care needs.

You might want to explore this program further if your loved one is facing increasingly complex clinical issues, is experiencing weight loss, or is having multiple hospitalizations. A palliative program can also help if there is uncertainty about goals of care or prognosis.

Resources

National MS Society Publication

800-344-4867

www.nationalMSSociety.org/brochures

- *Hiring Help at Home: The Basic Facts*

“Obtaining Personal Assistance”, Frankel, D, Cavallo, P, *Multiple Sclerosis: A Self-Care Guide to Wellness*, 2005, Paralyzed Veterans of America

The Personal Care Attendant Guide: The Art of Finding, Keeping, or Being One, Katie Rodriguez Banister (2007), Demos Medical Publishing, New York

Centers for Independent Living

A network of centers that offers technical advice, training, and advocacy to promote people with disabilities remaining in their own homes. To locate a nearby center, go to www.ncil.org.

Nursing Home Care

"I never thought I would have to consider nursing home care, but I just can't do it anymore."

MS is a disease that can progress to a point where, not only is 24 hour care necessary, but 24 hour skilled nursing care is essential. At this point the needs of the person with MS frequently exceed family resources. Significant cognitive loss, incontinence, nutritional compromise, and/or respiratory issues require complex clinical care. Caregivers may no longer be able to carry the burden for a variety of reasons, even with additional assistance at home. In this section we take a closer look at nursing home care and what to anticipate if that choice needs to be made.

1. I feel guilty even thinking about a nursing home for my loved one. How can I get to the point of even considering this as an option?

As someone has said, caring for a loved one with progressive disease is a marathon. It can take place over the course of many years, and often things come along that require a change to be made. This can be due to many reasons. These are just a few of them:

- Responsibility for other life roles such as parent, partner, employee, etc. may not be able to be balanced with the weight of care any more.
- The health of the caregiver may be deteriorating.
- A change in who is living in the family may impact the amount of family help available.

- Caregivers may be too young to take on additional responsibilities, or caregivers may be aging and no longer able to carry the burden.
- Safety and isolation of the person with MS at home may become an issue.
- The clinical care becomes more specialized and complex, beyond the capabilities of the family.
- There is a lack of support services from the community.

Even beyond these very specific situations, the many years of caring for a person with progressive MS can deplete a family's emotional and physical energy. It is at this point that exploring nursing home care can become a reasonable and viable course of action, both for the overwhelmed family and for the person with MS.

2. If a nursing home is necessary, how can I avoid feeling like I am abandoning my wife?

The fact that your wife is receiving care in a nursing home does not mean you are no longer involved in her life. In fact, many family members find that their relationship improves when all of their energy is not being spent meeting heavy daily care needs. Many family members visit the nursing home frequently, sometimes to help with tasks like feeding, but oftentimes just to visit and be together. You can stop thinking of yourself as a caregiver all the time, and go back to being a husband. If you are feeling less stress, your times together will probably be less stressful as well. Remember, also, that placing your wife in a nursing home does not necessarily mean she will never be home again. Many nursing home residents return home for holidays and special visits. There are indeed many ways you can continue to be involved.

3. How can I cope with the feeling that a nursing home will never take care of my loved one as well as I can?

It is true that a nursing home cannot provide the individualized, one-on-one care that you have undoubtedly provided over the years. No matter what the staffing of the nursing home facility, that level of care is not possible at all times. However, there are things that can be gained as well. Nurses are now available 24 hours a day, and other health care professionals can be involved more easily. It is a busier place, with more activity and opportunity for socialization. For someone who has been basically isolated at home, or perhaps even confined to bed, this environment can be more stimulating. You can play a pivotal role in helping the nursing home staff become educated about MS and sensitive to your loved one's needs.

4. What if I become concerned that the nursing home is not providing adequate care?

First of all, you are probably going to be at the facility regularly, and if you have concerns, you can always speak with administrative staff or ask for a family meeting. If you cannot get things resolved yourself, every state has an Ombudsman program to provide oversight and resolve concerns. Remember, you are a consumer. If the facility continues to be deficient, you can always seek a transfer to another facility.

It is also important to know that more is being required now of nursing homes in terms of providing quality, individualized care than ever before. They are moving as an industry to become more resident focused, less rigid, more home-like, more focused on quality of life. This is happening for several reasons. One is that regulators are becoming more demanding, and that the results of facility surveys are now being posted publicly. Another is that the consumer voice in long-term care is becoming louder and more effective. And there is no question that

the industry is under significant pressure due to the appeal of assisted living and expanded home and community based services. Nursing homes are facing competition, and competition is good. One result of this competition is that they are targeting certain populations to serve, and people with MS are definitely a potential market. Check with the National MS Society to see if there is a specialized nursing home program for people with MS in your community.

Resources

Center for Medicare & Medicaid Services (CMS)

www.cms.gov

“Nursing Home Compare” on their website evaluates nursing homes around the country in terms of several key indicators.

NCCNHR

www.nccnhr.org

A national consumer voice for quality long-term care. Website provides a connection to all of the ombudsman programs around the country.

End-of-Life and Hospice

1. How can we as a couple or family discuss difficult issues, such as end-of-life care, particularly when there are differences of opinion or conflict? Who is the ultimate decision maker?

As MS progresses, it can be frightening to see your loved one's abilities change. It is important to talk with your loved one about the kinds of medical care that he/she wants to receive, particularly if MS continues to progress. Talking about this is difficult, but it is crucial if you want to ensure that the wishes of the person with MS are followed in case he/she can't communicate those wishes in the future.

Choice belongs to the person who has the illness. Modern medical ethics supports the right of each individual to make his or her own medical decisions. Generally people with chronic illness do not feel unduly burdened in making these choices, but are relieved to be informed and to have an opportunity for meaningful conversation. However, they might also feel overwhelmed by the process and welcome the help of family and friends.

As to cause of death for people with MS, many do die of complications related to their disease. However, many also die from issues such as cardiac and vascular disease as well. As more patients with MS survive to older ages, a greater proportion can be expected to die of causes unrelated to MS.

It is not unusual for families to uncover conflicts during this process of decision making, as it can trigger strong emotions and unresolved issues. Remember, it is acceptable to agree to disagree. Often those who are more comfortable with mortality issues can be found on one side and family members who are hoping for a cure and don't want to talk about end-of-life are on the other. If you know of someone

who is skilled in facilitation, invite him or her to the table to help the conversation. Contact your local chapter of the National MS Society for a referral to a mental health clinician with expertise working with families involved in this process. If your loved one lacks decision-making capacity, most states have a legal mechanism for naming a surrogate in that event.

2. What kind of questions regarding end-of-life decisions need to be considered by our family?

There are many questions that can arise as the end of life approaches. It is important to think about choices that may need to be made. Family members need to be clear on all of these issues:

- Hospital or no hospital
- Intubation/ventilator or not (this is different from CPR)
- Antibiotics or not
- Continued nutrition or not (this can be complicated if a feeding tube is already in place)

Decisions revolve around how aggressive medical treatment and management should be. There is no right or wrong answer. It is a matter of personal preference, values, and quality of life. Opinions and thoughts of the same person might differ over time as well, particularly if a critical hospital emergency occurs, so it is important to revisit this discussion periodically.

3. What does hospice do?

Hospice refers to a philosophy of care designed to provide comfort as well as spiritual and emotional support for those who are approaching the end of life. In hospice the focus is no longer on curative care but on the relief of pain and control of symptoms for someone who is

expected to die within six months. Hospice care usually covers all the services, equipment, medications, respite care, and hospitalizations needed as they relate to a terminal illness including 24-hour access to a doctor or nurse and regular visits by a nurse. In this way family caregivers are often freed from most of the financial and management aspects of care. Medicaid, Medicare, and most private insurance plans cover hospice services. Hospice can be offered in the home, assisted living, or nursing home.

4. How would I know if it is time for hospice?

There is no question that it is not always easy to identify a terminal phase of MS, even if someone has been confined to bed with significant health issues for a long time. However, if your loved one is clinically compromised and coping with significant respiratory weakness, UTI infections leading to sepsis, critical nutritional impairment, or other life threatening complications, you might look into hospice as a potential support for you.

Although there is no definitive check-list that end of life is near, these might be triggers for seeking hospice support:

- Multiple ICU admissions with shorter periods of stability
- Hospitalizations that result in infections
- Significant changes in cognitive/functional status
- Respiratory insufficiency
- Critical nutritional impairment
- Stage 4 pressure sores

Of course it is understandable that turning to hospice is a difficult step to take. It requires coming to terms with the fact that end of life is probably going to happen soon.

5. Will any hospice program accept a person with MS?

Those with advanced, rapidly progressing MS often do not fit into the normal criteria that the insurance companies (including Medicare) use to qualify a person for hospice care. Death may not come within the expected 6 months. Therefore, a hospice may not consider it a terminal illness. There may be hospices out there that will not take a person with rapidly progressing MS, but just keep looking. There are many that will.

6. What happens if I elect hospice but am currently receiving home care services under Medicaid?

When electing hospice it is important to consider current home care services, particularly if they are being paid by Medicaid. The number of days and hours in place for a personal attendant will transfer with the individual, if hospice is selected. However, the specific home attendant may not necessarily transfer. This would be determined by the hospice.

Resources

Hospice Foundation of America

www.hospicefoundation.org

Not-for-profit organization that provides leadership in the development and application of hospice.

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**WE ARE PEOPLE WHO WANT TO
DO SOMETHING ABOUT MS NOW.**

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