MSAA National Health Fairs • Treating MS Fatigue

MSAA Spring 2004

Caring for a Loved One

If so, you can help to raise funds for MSAA – at no additional cost – by shopping through www.GreaterGood.com.

MSAA has selected the best on-line stores accessible through **www.GreaterGood.com**. When you shop online at GreaterGood.com, a portion of the profit from your purchases is donated to MSAA. Simply go to **www.GreaterGood.com**, select Multiple Sclerosis Association of America as your chosen charity, and link to your favorite on-line stores.

The following stores are showcased in our MSAA Shopping Village:

- A&E/The History Channel
- AVON
- Barnes and Noble
- Brookstone
- Chadwick's of Boston
- Coldwater Creek
- Dell
- Elisabeth by Liz Claiborne
- Gap
- Gateway
- Hallmark
- JC Penney
- J Crew
- Kenneth Cole
- L.L. Bean
- Lands End
- Linens and Things
- Old Navy
- Priceline
- Sharper Image
- Teva Sports Sandal
- Tupperware
- Vermont Teddy Bear
- Walmart
- *...and many more!*

Through **www.GreaterGood.com**, you can order the merchandise you want, AND benefit MSAA — and the purchases won't cost you a penny more.

Please use www.GreaterGood.com every time you shop on-line, and ask your family and friends to shop there too!

Published by the Multiple Sclerosis Association of America

MSAA National Headquarters

706 Haddonfield Road
Cherry Hill, NJ 08002
(800) 532-7667

www.msaa.com

The Motivator's purpose is to inform and educate those with MS and their families. MSAA does not endorse or recommend any products, services, or items mentioned in articles or advertisements that appear in *The Motivator.*

Cover Story

Caring for a Loved One 7
by Susan Wells Courtney
Being a care partner for a loved one can be both challenging and rewarding. Considerations for giving care in the home and the skills required are discussed. Issues that may arise, along with possible solutions, are included.

Caring for a Loved One, p. 7

Departments

Up Front 2
by Douglas G. Franklin
MSAA's Board of Directors Vice Chairperson Paul Favorite talks about his personal experience with being a care partner.

Ask the Doctor 20
MSAA's chief medical officer answers questions sent in by readers.

Research News 22
by Amanda Bednar
An overview of recent information on MS treatments is given, including news about Antegren®, oral cladribine, and MBP8298.

Program Notes 30
by Peter Damiri
Results of the first two of 10 scheduled MSAA National Health Fairs are reported, along with a schedule of upcoming MSAA Health Fairs.

Symptom Awareness .. 31
by Susan Wells Courtney
Fatigue with MS is discussed, including possible causes and various treatment strategies.

Regional News 44
A listing of events, programs, and newly-formed support groups are given from each MSAA regional office.

Spread the Word 48
Three informative books from MSAA's Lending Library are outlined for interested readers.

Breaking Down Barriers
Building Up Hope

Please Note: The Health & Wellness column will continue in the summer 2004 issue of *The Motivator*.

by Douglas G. Franklin

The cover story in our spring issue of *The Motivator* explains the challenging and rewarding role of the care partner. Whether caring for a parent, spouse, child, or another relative or friend in need of assistance, care partners must devote their time, energy, and emotions to helping a loved one.

With many of our cover stories, I am able to relate and reflect through my personal experiences. My role in a care partner relationship, however, has been limited. For this reason, I have asked MSAA's Board of Directors' Vice Chairperson Paul Favorite to provide some insight on this vital topic.

Paul's wife of 31 years was diagnosed with MS in the late 70s. Since that time, he has been dedicated to the happiness and well-being of his wife and their two grown children. While they have had many wonderful years together, Paul recently determined that his wife would be safer and more comfortable in a nearby home. (Please note that having one's MS advance to this degree is uncommon, and most individuals may continue to enjoy a full life in the comfort of their own home.) Difficult as this decision was, Paul explains how this has proven to be a positive move for both of them. Here's his story...

Paul and his wife, Anne Marie, realized something was wrong after the birth of their second child, and eventually came to find that Anne Marie was experiencing symptoms of MS. Anne Marie's father now believes that his daughter may have had her first MS event when she was just 15, but that was at a time when MS was even more difficult to diagnose, and the immunomodulating therapies had yet to be discovered. As with many people diagnosed with MS, Anne Marie began with the relapsing-remitting type of MS. Her illness, however, eventually became progressive.

Anne Marie was able to function well until the early 90s. Fortunately, by that time, the children were old enough that they did not need a sitter, and Paul took on the role of care partner. Wanting the children to still experience a normal childhood, he made every effort to keep the children from having to take on the extra burden of caring for their mother – aside from bringing her meals and doing other helpful tasks.

In addition to working full-time, Paul assisted his wife with daily care, including dressing, bathing, meals, and medications. He also handled the errands, routine chores, and housecleaning.

"The house would be messy sometimes," jokes Paul, referring to the fact that keeping up with housework was not always the top priority. Taking care of his wife always came first, and this sometimes meant extra time in the mornings and sometimes during the workday.

"Fortunately I have an understanding boss who was flexible with my hours." Paul continues. "That really helped. I was also able to have an aide come in twice each week to provide assistance, and eventually someone came in every day at lunchtime to visit and make lunch. This is a good thing to do if you can work it out financially."

Over the years Anne Marie's condition worsened, and she was affected both physically and cognitively. By this time, both of their children had finished college and moved out on their own. Friends, family, neighbors, and people from their church would come by regularly to visit and socialize. But despite everyone's efforts, Anne Marie would often be home alone.

"Having my wife home alone was a big worry to me. We had our dog to protect her, but there were other safety issues. We were especially concerned about fire, because she would have no way to get out of the house. Last year, Anne Marie and I made the difficult decision for her to move to a facility nearby."

While most people with MS are able to live a full and rewarding life in the comfort of their home, a few need the care and security that an assistive facility has to offer. Paul visited a few centers, talking to the administration and touring the facilities. He is very pleased with the one he found. Financial concerns were a big issue with getting care, but Paul was finally able to work out the details.

"Moving Anne Marie to a facility was actually a very positive thing. She receives excellent care and has constant socialization. This gives her the opportunity to interact with others throughout the day. The center also has daily programs, which include games, singing, and entertainment, plus an MS support group that meets regularly.

"While this is not what we had planned, it is a big relief for me. I can finally have the peace of mind to know that she is safe and happy. I love my wife very much and I visit her every day. This move has actually improved her quality of life greatly."

When asked about his role as care partner, Paul has kept a positive outlook. "Life is a process, and having a partner means being there through sickness and health. Everyone has problems, and I know there will always be others who are worse off than we are. Staying upbeat is very important; depression doesn't help anything. I do my best to change the things I can, always asking about my options, and I don't worry about the things I can't change. I'm very thankful for Anne Marie and our children. Being so close to my wife, I am fortunate that I could be the one to assist her throughout our years together." ◆

Douglas G. Franklin has been President and Chief Executive Officer of MSAA since April 1999. Mr. Franklin has 25 years experience in senior association management in the nonprofit sector and is an internationally published expert in the field of social marketing. A former national trainer for the Peter Drucker Foundation, Mr. Franklin has conducted workshops in strategic planning and marketing development in more than 15 countries worldwide. He is a firm believer in the benefits of social investment for both the private and public sector workplaces.

by Susan Wells Courtney

Introduction

Many people at one time or another enter into a care-partner relationship with a loved one. Whether caring for a parent, spouse, child, or friend, a care partner may be responsible for another's physical, emotional, and spiritual well-being.

This article is a reference that may be used if someone is caring for a loved one with MS, but also for anyone, including an individual with MS, who is or will be caring for an ill or aging parent, other family member, or friend. Knowing the many responsibilities and dynamics involved can help someone to plan ahead and be prepared for common issues that may arise.

Receiving care at one's own home rather than residing at an assistive-care or nursing facility is becoming increasingly more common. For the person receiving care, the environment is comfortable, familiar, and promotes a feeling of security. Family and friends are often nearby. For the care partner, having the opportunity to provide assistance to a loved one at home can be a very rewarding experience. When both individuals are informed about care partnering, and are devoted to one another, the relationship may grow closer.

Compared to a sudden injury or acute illness, multiple sclerosis is unique in that it often enters the household gradually. For the majority of individuals with MS, family and friends have had several years to become familiar with the disease and its symptoms. This allows time for everyone

to slowly accept the changes MS brings and make whatever modifications are necessary to the home and schedule as the needs arise.

Over time, family members and friends will often act as care partners by helping with errands, chores, and meal preparation. They may also assist with childcare, housecleaning, and transportation to and from appointments. While these individuals are assisting with the workload, they are also interacting with the care recipient, providing vital emotional and social support as well.

As needs increase, so do the responsibilities of the primary care partner. This person may eventually take over several aspects of a loved one's daily activities, including such things as assisting with meals and personal care; performing medical care and administering medications; ensuring that the environment is both safe and comfortable; handling any business or legal matters; and seeing that the social and emotional needs of the care recipient are met.

Those who play the role of care partner must devote a large portion of time, energy, and emotion to their loved one. The care-partner relationship, however, may not always go as smoothly as one may hope. The relationship may go through several changes as responsibilities shift and various decisions are made.

Individuals involved in a care-partner relationship should understand the importance of care beyond one's physical needs. These include socialization, exercise, stimulating activities, and spiritual outlets. This type of care is not only important to the individual receiving care, but also to the care partners, who often find themselves ignoring their own physical as well as emotional needs.

Care Partner Responsibilities

Part I: Safety

First and foremost, individuals caring for someone who is disabled or ill have a responsibility to ensure the care recipient's safety. Care partners need to assess the home environment and take any necessary precautions against fires, accidents, or other specific dangers.

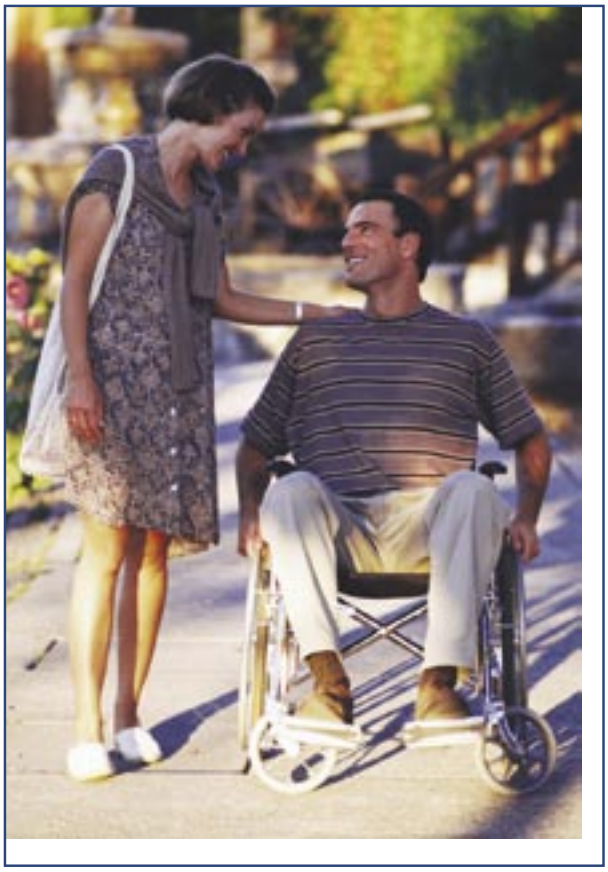
Regarding fire safety, a home must have strategically placed smoke detectors and fire extinguishers, and these should be checked regularly. Electrical cords should be in good condition and never overloaded. An emergency escape route should be planned and practiced.

For safety around the home, pathways need to be cleared of extra furniture, clutter, and throw rugs. Floors need to be kept dry and well maintained. Grab bars may be installed wherever needed, including the bathroom and along hallways. Nightlights in each room and in the hallways are also very helpful.

Non-skid rugs and bathmats are recommended for the bathroom. Lowering the water temperature to 120 degrees Fahrenheit will avoid serious burns if someone with mobility problems is unable to move quickly enough from hot water. Even little things – such as using paper or plastic cups in the bathroom versus glass, and making sure that footwear fits tightly and will not cause the wearer to slip – can increase safety.

If the individual receiving care is experiencing cognitive problems, many items around the home, such as medications, cleaning products, and other dangerous materials, will need to be kept in locked cabinets. Even food that has spoiled carries the risk of food poisoning and should be disposed of right away. Removing knobs from kitchen appliances, as well as making sure any firearms, dangerous tools, or even kitchen knives are put in a safe and secure place, will help to ensure a loved one's safety.

Other safety measures include enrolling in a CPR class and learning basic first aid. Keeping a well-stocked first-aid kit nearby is also recommended. Care partners need to take the time to write down emergency numbers (police, fire, doctor, etc.) and keep this information by the phone. Writing down one's own address and phone number can be helpful if an emergency occurs and one's mind is racing. The names and numbers of family and friends should also be kept by the phone, to call in case of an emergency.



Part II: Independence and Dignity

The physical care provided by a care partner can vary from simple assistance with errands, housework, and childcare, to taking care of many of the care recipient's activities of daily living. Sometimes in the care-partnering process, however, care partners may loose sight of certain fundamental principles that should be followed whenever possible. Perhaps they get too busy or maybe they become too earnest, but for whatever reason, care partners may do too much for the individual being cared for, putting his or her independence and dignity at risk.

Providing options throughout the care process allows an individual to have some control over his or her life, especially in situations where one's physical limitations prevent that individual from having the freedom to perform everyday activities. Choices regarding meal selections and times, scheduled activities, and which clothes are to be worn, are examples of options that care recipients should be given throughout the day whenever possible, allowing them the opportunity to express themselves.

Any activities that the care recipient is capable of handling, or may assist with, are important for the individual to perform. This promotes feelings of accomplishment, self-worth, and independence. For example, a loved one being cared for may

be able to write letters and pay bills, even though he or she may require some assistance and/or extra time to complete these tasks. Preparing an entire meal may be too demanding for someone with a specific disability, but he or she may have the ability to assist with various tasks involved, such as cutting vegetables, making a salad, or reading recipe instructions to the cook.

Dignity is another vital right that must be considered throughout the care-partner relationship. Enabling your loved one to make his or her own decisions helps the individual to feel in control. Listening to one's thoughts and concerns, understanding his or her feelings of frustration or loneliness (for example), and respecting the person's viewpoints and wishes, are key to preserving one's dignity.

Initially, personal care can be particularly uncomfortable for both the care partner and the care recipient. Both may feel embarrassed, which is normal. Telling an amusing story, turning on the TV or radio, or even singing a song, can help to ease the situation.

The care partner may minimize any discomfort and embarrassment by keeping activities such as bathing and dressing as private as possible. Choosing a time when no one else is at home or when outside activity is quiet may be a good plan. Keeping the person covered-up with a robe or towel while giving a bed bath, massage, or performing personal care, all help to allow an individual to feel more comfortable and less self-conscious. Care partners and others need to show respect of their loved one's privacy by taking the time to knock on the door before entering, and closing the door when performing personal care.

Part III: Medical Skills and Duties

Being a care partner entails learning certain medical skills. These may include:

Basic healthcare:

- Monitoring vital signs (respiration, temperature, pulse, blood pressure)
- Giving medications
- General first aid (learning CPR and emergency care)
- Recording medical information (doctor's names and numbers, health problems, allergies, medications and doses) and keeping list near phone in case of emergency

Controlling infection by:

- Using gloves
- Washing hands often
- Disinfecting around the home
- Providing good nutrition
- Ensuring proper personal hygiene
- Promoting good general health

Providing assistance with walking (as instructed by a medical professional or physical therapist):

- Having a clear, safe, and planned pathway
- Using safe, well-fitting shoes (non-skid)
- Proper selection and use of assistive equipment
- Assisting with instruction on pace, posture, lifting foot, turning, and climbing stairs
- Guiding and/or supporting individual

Providing assistance with a wheelchair (as instructed by a medical professional or physical therapist):

- Learning correct procedure for transfer
- Planning and explaining transfer in advance; clearing space
- Learning and using proper equipment and padding
- Taking recommended safety precautions by locking brakes, moving footrests, and placing feet

Physical Care Tips and Benefits

Part I: Bathing

One of the jobs of a care partner may be to bathe their loved one. In addition to getting washed, a bath can provide other benefits. For instance, a bath is relaxing. Positioning oneself in and out of the tub or shower, or lying in bed while having one's arms, legs, and body moved and stretched, provides a certain amount of exercise. The heat of the water and movement of a washcloth on the skin also improve circulation.

The care recipient should be encouraged to participate as much as physically possible – whether able to wash oneself completely or if only able to wash a few areas. This promotes feelings of accomplishment and independence. Good personal hygiene also builds self-pride and confidence.

Despite the many benefits, time in the tub or shower should be limited, because it can also cause someone to tire from the heat of the water, especially with MS. Prolonged exposure to water can also cause dry skin. Provided one's doctor approves, following

the bath with a brief massage using skin lotion will moisturize the skin, help with circulation, and relax the muscles. While bathing, brushing teeth, or giving a massage, care partners should check the individual's skin, nails, and teeth for any changes, such as swelling, redness, or pain.

Part II: Diet and Digestion

A care partner may be the one in charge of their loved one's meals and dietary plan. The importance of a healthy diet cannot be understated; good nutrition is essential for everyone and provides the following benefits, enabling the person to:

- feel well
- maintain proper weight
- have energy
- improve strength and endurance
- help fight infection or illness
- heal wounds

Some individuals may require special diets to treat various health conditions, such as high blood pressure, high cholesterol, or diabetes. Care partners should check with the care recipient's physician to be sure they are providing the correct diet and supplements to meet all of the care recipient's needs. Generally speaking, healthy foods such as fruits, vegetables, grains, and proteins should be selected from the different food groups, but any diet should be confirmed with a medical professional to be sure the patient's condition is not being aggravated by a certain food or additive.

A good appetite is equally important and many factors can affect one's desire to eat. These include emotional problems (such as depression or anxiety) and physical discomfort (such as nausea, pain, illness, difficulty swallowing, mouth sores, dental problems, and side effects from medications).

The first step in treating loss of appetite is to look for and treat whatever is affecting one's desire to eat, which may require seeing his or her physician. Care partners should make an effort to keep their loved one interested in eating, and feeding small meals and making the food look attractive are a few suggestions that may help.

Watching fluids is important to avoid dehydration, which may be caused by illness, fever, or a hot environment. The amount of fluids taken in should be equal to the amount that leaves the body, via sweating, breathing, and waste elimination. Eight ounces of fluid eight times daily is the general recommendation, but this should be checked with one's physician. Foods that melt into a liquid, such as creamed cereal, gelatin, and pudding, count toward one's fluid intake. Dehydration can quickly become serious, so a care partner needs to watch for symptoms which include a decrease in body fluids (tears, urine, and saliva) and possibly confusion.

Digestive problems will often indicate when a diet needs to be adjusted. A care partner should watch for nausea, vomiting, diarrhea, or constipation, and consult a physician to resolve these problems. To assist with waste elimination, an individual should be given plenty of time and privacy.

Having to look to another for assistance with waste elimination is often embarrass-

Teva Neuroscience presents:

Staying Well Connected.

YOU'RE INVITED **to attend a FREE seminar specifically designed for people living with multiple sclerosis (MS) and their CarePartners.**

Learn about the latest developments in research and treatment options. Arm yourself with the latest information about the advancements in the fight against MS and hear from multiplatinum-selling **RCA recording artist Clay Walker** about his personal battle with MS and how he is managing the disease with his busy singing career.

Each patient seminar features local and national MS experts who will answer your questions about managing MS, followed by a live Q&A session with Clay Walker.

Refreshments will be provided.

City:	*Date:*
Cleveland	April 20
Chicago	April 21
Minneapolis	April 22
New York City	May 5
Boston	May 6
Nashville	May 11
Philadelphia	May 12
Pittsburgh	May 13
Jacksonville	June 23
Charlotte	June 24

SPACE IS SURE TO GO FAST, SO RESERVE YOUR SPOT TODAY BY CALLING TOLL FREE, 1-866-244-8079 OR VISIT *WWW.MSDIALOGUE.COM*

Dates and locations may be subject to change.

04260004/0331C4

ing for the care recipient, and incontinence can be devastating. When a care recipient loses control over his or her urine or bowel movements, he or she tends to feel very alone and self-esteem is greatly affected. Treating incontinence can be difficult for the care partners as well, but those providing care need to imagine how their loved one must be feeling and provide them with support and understanding.

Part III: Sleep and Exercise

Adequate rest is vital to one's ability to function and feel refreshed. When well rested, an individual's ability to cope with daily challenges is improved. He or she may be able to focus better on the various activities of daily living, and rest also helps to relieve stress and anxiety.

When not getting enough sleep, individuals will often be irritable and restless. They may look tired, have less mobility, and yawn frequently. Individuals not getting enough sleep may have trouble cognitively (with memory and concentration). Similar to a good diet, adequate rest is necessary for energy and to fight illness.

Difficulty sleeping may be attributed to pain, inactivity, daytime napping, various stimulants (such as caffeine, alcohol, or nicotine), emotional problems, side effects from medications, and other factors. Care partners may need to look at the possible causes and try alleviating the problem. Strategies may include avoiding caffeine, reducing the time spent napping, and adding activities or exercise (as recommended by one's physician).

Care partners should also make the environment as conducive for sleeping as possible, by keeping the lights low, adjusting the temperature, and eliminating outside noise. A physician should be consulted if the problem continues. For information on sleep problems and tips, please refer to the fall 2003 issue of *The Motivator*, or call MSAA's Helpline at (800) 532-7667.

Exercise is vital to one's health, but should only be done under the guidance of a medical professional. If approved by one's physician, moderate exercise two to three times weekly can be helpful in terms of feeling better, getting more restful sleep, improving mobility, and possibly increasing strength and energy.

Care partners and recipients should both be instructed by a physical therapist or other health professional on specific exercises and how to perform them safely. In addition to the physical benefits, exercise can help reduce depression, and if done with others, offers social benefits as well.

Care Partner Stress and Emotional Issues

Given the many duties that a care partner may be responsible for, related stress and emotional issues can arise. This section features Lara Krawchuk, MSW, LSW, MPH. She is a therapist who specializes in chronic and life-threatening illnesses, seeing both care recipients and their care partners. Ms. Krawchuk is an instructor at the University of Pennsylvania School of Social Work and is Director of Clinical Services with the Conill Institute for Chronic Illness.

Ms. Krawchuk explains, "Illness impacts the entire family and those around them. Everyone who cares about the person – family and friends, professionals, and colleagues, are all affected. While the primary care partner typically provides physical care, a care partner is also anyone who cares, and his or her role may be for emotional support rather than physical care. People may be care partners regardless of whether they live a short distance or a long distance from the care recipient. Care partners may be spouses caring for their partner, adult children caring for a parent, and/or parents caring for their child.

"Care partners will often experience negative feelings, such as sorrow, grief, anger, guilt, or resentment, and at the same time, may experience positive emotions as well, feeling close, competent in their role, and happy to help their loved one. A care partner may be riding the same 'roller coaster' of emotions as the care recipient, although the two are riding in different cars… so the one is not always in sync with the other. One may be up while the other is down; one may be feeling fear and doubt, while the other is feeling hopeful; these emotional differences can cause problems.

"The differing emotional experiences of the care partner and the care recipient sometimes require outside help to fully understand and get both persons' emotional needs met. Both individuals may need to look beyond their close circle of family and friends to be heard and have their pain understood. Speaking with a professional, friends, support groups, or calling a hotline for support are some excellent ways to get help."

"Speaking with a professional and/or support group should not be looked upon as a sign of weakness," Ms. Krawchuk points out. "Instead, seeking outside help exhibits strength, and illustrates that you recognize a need for assistance and know how to go about getting help.

"While many care partners adjust quite well to their new role, approximately 25 percent or more are at risk of suffering from different emotional problems as a result of handling day-to-day needs. They may suffer from significant depression, anxiety, panic, physical exhaustion, and sleeplessness. Care partners tend to minimize their own needs, missing out on proper exercise, nutrition,

New Booklet Available!

MSAA is pleased to announce the arrival of our new booklet on the benefits of cooling technology for individuals with MS. For a free copy, please call MSAA's Helpline at (800) 532-7667.

and social interaction, while devoting their best care to a loved one who is sick."

"I see two types of care-giving disturbances. The first is care-partner fatigue, which is very normal and expected, due to the intensity of providing care and its emotional and physical demands. When care-partner fatigue occurs, the individual experiences increased stress and decreased energy, and this has a cumulative effect. The more care-partner fatigue is ignored, the more it builds up, and the more difficult it becomes to feel normal again. The best way to handle care-partner fatigue is to be proactive and get help immediately, to avoid progressing into care-partner burnout.

"The second type of care-partner disturbance is burnout, and this is a much more severe condition. Burnout takes quite a while to reach, but once there, the care partner is in trouble. When this occurs, the care partner experiences significant emotional and physical problems, affecting his or her ability to provide care for oneself or others. If ignored, the individual will eventually become completely unable to give care."

According to Ms. Krawchuk, every effort must be made to treat care-partner fatigue before it reaches care-partner burnout. To follow is a list of strategies to fight care-partner fatigue, and she suggests that people be creative in finding time to help themselves.

Strategies for overcoming care-partner fatigue

- Use resources; by connecting with an advocacy organization, individuals may explore additional resources within the community
- Consult family and friends; ask for their help to reduce the care burden
- Consult a medical professional or therapist to treat any serious emotional problems, such as depression and anxiety
- Talk openly with the care recipient; discuss any possible changes in roles and work breakdown; re-negotiate how tasks are handled
- Use journaling; research shows that writing in a journal on a regular basis will improve one's emotional and physical well-being; journaling provides an outlet for whatever emotions a care partner is experiencing
- Practice relaxation techniques; learn and practice guided imagery (with a tape or support group), meditation, deep breathing, or yoga; one may also go outside, take a

long walk, and enjoy nature
- Exercise; this may be done alone to get a break, or with the care recipient to share as an enjoyable experience together
- Get emotional support; talking to a therapist, family and friends, and/or support group, will allow the care partner to process the emotions he or she is feeling
- Spend time away from one another; this may be difficult or even scary initially, but being together all of the time is not good for either the care partner or the care recipient… and the same is true for any relationship
- Take time for oneself; ideas include going for a massage, having lunch with a friend, or doing something special outside of the home

Ms. Krawchuk continues, "People can feel as though they have burnout, but if they can take a break and come back, it is most likely just care-partner fatigue. They shouldn't get overly alarmed about it, but it is something to pay attention to and address.

"Families need to remember that children may be care partners too, and they may express their pain, fears, and worries differently than adults. Children may act out their feelings versus expressing them verbally. They need an outlet for these emotions. While children should be allowed to be a part of the care-giving relationship – and even little children will want to help – they also need to be kids, to play and go out with friends. This can be a very challenging boundary to define, and one needs to know where to draw the line to find the right bal-

ance.

"Little children may be sad for just a few minutes and then play. This is age-appropriate behavior. But they could be showing their emotions through how they play. Having open communication with the child's teachers is a good idea and may give parents insight into how their child is feeling. Parents should look to other resources, such as books, websites, and professionals, to learn about age-appropriate behavior and emotional stress in children.

Ms. Krawchuk notes that certain issues commonly arise in the care-giving relationship that can be particularly difficult for the care partner. These are:

- Emotional stress and distress
- Role changes; coping with shifts in one's responsibilities and abilities
- Financial disruption resulting from reduced income
- Sexual changes; intimacy may become complicated for both physical and emotional reasons
- Communication; being open with one's feelings and concerns is critical
- Time management; having no time for oneself to enjoy outside activities or even to run errands
- Disruption in social life
- Relationship issues
- Isolation; feeling very alone, as if no one understands and no one wants to help

"To deal with the emotional stress from these issues, and to get some relief from giving care around the clock, a care partner needs to look to others for help with the physical care," Ms. Krawchuk advises. "This may include seeking out advocacy groups, churches, synagogues, neighborhood organizations, or groups of friends for possible assistance.

"Care partners need to directly ask family and friends if they want to listen and if they want to provide physical and/or emotional help. One cannot just assume that others will offer; family and friends may want to help but don't know how to ask, and they may feel uncomfortable bringing up the idea."

Lara Krawchuk notes that several books, websites, and organizations may be contacted for additional information on care giving. Two books in particular that she recommends are:

- *The Complete Bedside Companion* by Rodger McFarlane and Philip Bashe
- *In Sickness and in Health: Sex, Love, and Chronic Illness* by Lucille Carlton

Anyone wishing to get more information on the topic of care partners and care-partner stress may log onto Conill Institute for Chronic Illness website at www.conillinst.org. For those without internet access, they may contact the institute at (215) 746-7267 to leave a message and a staff member will return the call as soon as possible.

Changes, Issues, and Emotions in the Relationship

Relationships naturally go through changes as those involved adjust to new situations. In the care-partner relationship,

certain issues commonly arise, sometimes causing anger, frustration, and resentment. Such emotions need to be openly discussed and resolved before the problems escalate to a point where the relationship, and possibly the individuals involved, are harmed.

In the typical care-partner relationship that involves illness or aging, the care partner will need to take on increasingly greater responsibilities, as the care recipient becomes unable to accomplish various duties and activities. This is not a fair situation for either person, and this begins a cycle of mixed emotions.

For instance, spouses who serve as care partners often have a full-time job, and when not at work, they will need to care for their loved one. From there, they may have the additional responsibilities of caring for the children, preparing meals, cleaning house, running errands, handling finances, and arranging appointments.

As a result, care partners frequently experience exhaustion, while feeling sad over their loved one's illness or disability. They will feel happy that they can help, and angry over the unfairness of the situation. They may feel trapped and unable to find time for themselves.

Conversely, care recipients have been forced to give up some of their independence, activities, and social life, often spending much of the day at home alone, waiting for their care partner to return. They may have things for the care partner to do – from housework to personal care. They often look forward to their care partner's company and become disappointed when the care partner cannot spend quality time with them.

Care recipients commonly feel frustrated over their own disability, which may prevent them from cleaning, physically caring for the children, or going to work. They may be angry at their misfortune, and feel guilty that their care partner must do their work for them.

Frustration and conflict may also increase over other issues. With little available time or energy, the care partner may not be able to take care of the cleaning or shopping as well as before, and this can cause frustration for both individuals. They may disagree over modifications to the home; one may want more things set up and more changes made

to the living areas, while the other may want to keep things as "normal" as possible. As a result, the care recipient may feel that the care partner is either going overboard, or not caring enough.

Money is often another area of conflict,

Continued on page 39

Dr. Jack Burks
Chief Medical Officer for MSAA

Q: I am receiving physical and occupational therapy for a broken hip, but the nurses do not understand the variable nature of MS, and are pushing me beyond my capability. How can I get the hospital or nursing home staff to understand MS?

A: Rehabilitation for hip fractures can be more difficult for individuals with MS for many reasons. MS-related fatigue, spasticity (stiff muscles around the hip and thigh), muscle weakness, movement-triggered spasms or sudden jerking, pain, bladder and bowel problems, and lack of coordination, can all complicate the hip fracture rehabilitation process.

In spite of all of these added issues, dynamic rehabilitation therapy is important to get the hip working to its maximal capacity. Inadequate rehab will likely lead to even more problems in the long-run. The key to successful rehabilitation is a balancing act to provide adequate therapy while dealing with the challenges of MS outlined above.

Insurance coverage dictates that a certain number of hours each day must be devoted to rehabilitation in an effort to minimize one's hospital stay. You may try requesting that you be allowed to rest between each half-hour session to better cope with fatigue and other MS symptoms.

This answer may help you and the hospital rehab team to work together within your limits. A consultation with the rehab team and an MS expert in neurology or rehab may also be helpful. A list of comprehensive MS centers is available through the Consortium of Multiple Sclerosis Centers' (CMSC) website (at www.mscare.org) or by calling MSAA's Helpline at (800) 532-7667.

Q: What is the status of research and trials with stem cells?

A: I believe stem cell research has exciting potential for individuals with MS. Two types of stem cell research are usually associated with MS – the first is a stem cell transplant, also known as a bone marrow transplant (BMT). The second uses embryonic stem cells which may come from the blood in the umbilical cord.

Bone marrow transplants are only used for those who are severely affected by MS and who are not responding to the ABCR drugs (Avonex®, Betaseron®, Copaxone®, Rebif®). This process knocks out the immune system and puts back cells that are not activated to attack myelin. Bone marrow transplants carry a high risk and are still experimental, so they are only recommended in extreme cases.

Embryonic stem cells may be able to make new brain cells, with the potential to help individuals with MS as well as other neurological conditions, such as Parkinson's

and Alzheimer's disease. While these stem cells appear to mature into brain cells, the challenge involves getting these cells into the right location of the brain and functioning in place of damaged or destroyed cells in patients. This research is still in its infancy, but as I stated earlier, its potential is exciting.

Q: What are the best treatments for individuals experiencing cognitive problems with MS? Should they be referred to a neuropsychologist for evaluation? How often should they be tested, and what cognitive symptoms should be of greatest concern to family members?

A: My approach to people with MS experiencing cognitive problems is to:

1) Evaluate their medications to see if they may play a role; many medications contribute to cognitive problems
2) Evaluate for depression, anxiety, or other emotional problems that contribute to cognitive dysfunction
3) Evaluate for infection, such as thyroid problems, urinary tract infection, anemia, blood chemistry, cell abnormalities, and other medical conditions that might contribute to cognitive changes
4) Arrange for a neuropsychology evaluation, including testing combined with a plan for dealing with both cognitive and emotional issues

Some MS cognitive symptoms are not obvious. In addition to "forgetfulness," some individuals with MS have more trouble with organization, judgment, focusing, and other "executive functions" which are not easily recognized. Some people have trouble restarting a project that has been interrupted. Family members may misinterpret these subtle changes as "stubbornness, belligerence, or laziness." Many of these symptoms can be managed with the help of a therapist.

After the evaluation, the focus turns to treatment. Strategies to help stay organized, such as keeping lists, are a first step. Staying with each task until completion (avoiding interruptions) often improves work performance dramatically. A cognition retraining expert can make even more specific suggestions.

Medication is another option. Drugs for Alzheimer's disease have been tried to help people with MS. The results have not been dramatic, but some neurologists use these medications and believe they may be helpful for some. The interferons have also been shown to assist with cognitive functioning.

In summary, identifying and treating cognitive problems is very complicated. Most individuals with MS, however, may be helped by conducting a careful evaluation and developing a thoughtful treatment plan. ◆

Jack Burks, MD, is a neurologist who specializes in MS. He is the chief medical officer for MSAA and president of the Multiple Sclerosis Alliance. Additionally, Dr. Burks is a clinical professor of medicine in neurology at the University of Nevada School of Medicine in Reno, Nevada, and a member of the Medical Advisory Board of the National MS Society. He has edited two textbooks on MS, and in the 1970s, Dr. Burks established the Rocky Mountain MS Center in Colorado, one of the nation's first comprehensive MS centers.

Antegren Submitted One Year Early for FDA Approval

The makers of Antegren® (Biogen Idec and Elan Corporation) announced they are going to be submitting an application for approval of Antegren (natalizumab) as a treatment for multiple sclerosis to the U.S. Food and Drug Administration (FDA) one year earlier than planned. They expect to submit the filing mid-year 2004. The decision came after reviewing the one-year data from the two ongoing two-year phase III trials. The companies did not disclose the one-year data to protect the integrity of the trial.

About the Trial

Approximately 900 patients are participating in the AFFIRM (natalizumab safety and efficacy in relapsing-remitting MS) trial, a two-year randomized multi-center, placebo-controlled, double-blinded study. The focus of this trial is to evaluate Antegren's ability to slow the progression of disability in MS and reduce the rate of clinical relapses.

The second trial, SENTINEL (safety and efficacy of natalizumab in combination with Avonex® [interferon beta-1a]), includes approximately 1200 patients with relapsing-remitting MS and is a two-year, randomized, multi-center, placebo-controlled, double-blinded study. The study is evaluating the effect of the combination of Antegren and Avonex compared to the treatment with Avonex alone in slowing the progression of disability and reducing the rate of clinical relapses.

The protocol of both studies includes a one-year analysis of the data. The primary endpoints for both phase III two-year trials in MS are based on the Expanded Disability Status Scale (EDSS) and relapse rates.

Background on Antegren Trials

The Motivator has chronicled the development of Antegren from its clinical phase. The 2002 winter issue of *The Motivator* article focused on the clinical trial and previewed both the AFFRIM and SENTINEL trials. The 2003 winter issue of *The Motivator* reported on the progress of the two trials and the important process of affirming the results in a "peer-reviewed" publication. The results of the study were published in the January 2, 2003 issue of the *New England Journal of Medicine* (David H. Miller, et al., A Controlled Trial of Natalizumab for Relapsing Multiple Sclerosis, vol.348: 15-23). Anyone wishing to see copies of these two MSAA articles may request them by calling MSAA's Helpline at (800) 532-7667.

More on Antegren

Antegren works by interfering with the movement of potentially dangerous immune system cells (activated lymphocytes and monocytes) from the bloodstream across the blood-brain barrier (BBB), into the brain and spinal cord. Passing through the BBB is the necessary step for the cells to attack the myelin and cause damage to the nerves of the central nervous system (CNS). To cross the BBB, immune system

cells must first adhere to the blood vessels. Glycoprotein alpha 4 integrin appears on the surface of these damaging cells, enabling them to adhere to the blood vessel walls and then migrate into the CNS. Antegren is an alpha 4 integrin antagonist, thus interfering with the alpha 4 integrins ability to move immune system cells into the CNS.

Antegren was originally developed by the Elan Corporation, and has since joined with Biogen Idec Incorporated (makers of Avonex) to test and ultimately seek approval for Antegren.

Oral Cladribine Efficacy Trials Slated to Begin This Year

Recently, Serono (makers of Rebif) and Ivax Corporation announced their test results from two clinical trials with a new oral formulation of cladribine. The study results showed that the formulation of oral cladribine has met the targets for an orally administered product, with blood levels of cladribine reaching the desired levels. Cladribine inhibits immune reactions by disrupting the production of certain white blood cells, particularly lymphocytes, which are involved in the disease process of multiple sclerosis. Investigators are planning further efficacy studies of oral cladribine in MS patients for late 2004.

Previous phase II and phase III clinical trials of injectable cladribine demonstrated some effects in people with MS. In these trials there was a reduction in new lesion development in the brain as seen on MRI scans, although total lesion volume did not appear to be affected. Individuals with relapsing-remitting MS also experienced clinical benefits (with an exacerbation rate approximately half of the rate experienced by individuals taking placebo). Disability in terms of EDSS was not affected. The results of these studies, however, were considered to be mixed and could not be replicated in a recent phase III study (which may be due to participants having more advanced MS than in previous studies).

Researchers determined that further studies were needed, employing participants who have MS in earlier stages. But in these upcoming trials, investigators will be able to use an oral formulation rather than giving the drug through injections. Medications in drug trials are frequently administered via injection, as this method can deliver higher amounts into the blood system as opposed to drugs taken orally. As mentioned earlier, however, the oral formulation of cladribine was able to reach the desired level in the blood. For this reason, investigators are now able to conduct trials with the oral version, which is both painless and more convenient for the participants.

More Patents and Trials Continue with MBP8298

BioMS Medical, based in Edmonton, Alberta, has recently received 17 additional patents for MBP8298 in conjunction with the University of Alberta. In total, 50 patents have been granted to the University of Alberta for MBP8298 in 29 countries worldwide, including three patents issued in the United States. MBP8298 stands for Myelin Basic Protein Peptide and is comprised of 17

amino acids. The drug, which has been in research for 26 years, is going to phase III of clinical trials, with successful results in the pre-clinical, phase I and phase II human clinical trials in Canada.

Background on MBP8298

MBP8298 works by reducing the disease-associated production of a group of anti-MBP antibodies that are reactive with the central nervous system. The four-year phase II trial enrolled 32 patients with either primary or secondary-progressive MS. The study had two phases, a two-year randomized double-blinded, placebo-controlled phase, followed by a two-year open label phase. During the double-blinded phase patients were given 500mg of the MBP8298 peptide intravenously every six months. Data from the trial was analyzed both in terms of overall results, and in terms of patients who carried either HLA-DR2 or HLA-DR4 immune response genes ("DR2/4"). These genes are associated with helper T-cells involved in the production of anti-MBP antibodies targeted by the MBP8298 peptide.

In the normal population, the DR2/4 gene is relatively low. In the MS population, however, individuals with either the DR2 or DR4 genes account for approximately 75 percent of the estimated two million MS patients worldwide. Of the 32 participants enrolled in the double-blinded phase of the trial, there was a representative sample of 20 patients that carried either the DR2 or DR4 genes, which were evenly divided between patients dosed with MBP8298 and placebo. ◆

— Amanda Bednar

Barrier-Free Housing Vacancy in North Carolina

MSAA owns and operates five barrier-free apartment complexes which provide accessible, affordable housing for physically disabled adults in an independent living environment. While interested people must go on a waiting list for occupancy in our four New Jersey locations, our North Carolina location presently has vacancies.

These one-bedroom and efficiency apartments are designed to meet the needs of people with MS or others with physical disabilities. Amenities include step-less entries, widened doorways for wheelchair passage, roll-under kitchen sinks and counters, lowered light switches, large roll-in showers with grab bars and a pull-down bench, air-conditioning, and other features to ensure a safe and comfortable living environment.

The apartments are also very affordable as rent is subsidized through the government. As a result, rental payments are a portion of the tenant's adjusted gross income. Candidates for residency must meet certain characteristic standards, which include having a disability by government standards and being age 18 years or older. Certain income limitations also apply.

Anyone interested in MSAA's Barrier-Free Housing Program in North Carolina needs to request an application for residency by contacting the complex directly at the address and phone number listed below.

MSAA Suites at Jacksonville
1711 Hargett Street
Jacksonville, NC 28540
910-938-3632
Offers 12 apts.

Successful Start for MSAA Health Fairs

"The small group format was the best conference I have ever attended. The patient individual focus was unique in my 15 years experience in MS workshops."

"This was also a great help to me in explaining things to my husband. I rarely speak of MS, not wanting to admit any thing is wrong, or that I can't do as much as I once could. It was very helpful for him to hear from other MS patients."

"Thank you so much for remembering small town America."

These are just some of the comments we have received following the first two of 10 scheduled MSAA National Health Fairs. Funded by an unrestricted educational grant from Serono, Inc./Pfizer, Inc., MSAA National Health Fairs are full-day seminars which join a small group of 20 to 25 clients and their care partners with nationally recognized healthcare professionals and resource specialists. The purpose of these seminars is to share information and develop individual strategies for the successful management of MS.

MSAA launched the first Health Fair on Saturday, March 6th in Fredericksburg, Virginia. The event featured MS experts Dr. James Simsarian and Carol Saunders, BSN, MSCN, both from the Neurology Center of Fairfax, Virginia; and physical therapist Valerie Gibson of Advanced Physical Therapy. MSAA President and CEO Doug Franklin was on hand to kick-off the program and to provide an overview of the organization's programs and services, as well as the goals of this new initiative.

The second Health Fair was held on Saturday, March 27th in Ocala, Florida. Presenters included Dr. Ben Thrower, medical director of the MS Center at Shepard in Atlanta, Georgia; Constance Easterling, RN, MSCN of the Multiple Sclerosis Comprehensive Care Center of Central Florida in Orlando, Florida; and physical therapist Patricia Ann Bobryk of Orlando Regional HealthCare, Sand Lake Hospital.

The goals of the Health Fairs are to educate and empower clients to overcome the ever-changing challenges of MS. The program uses an Action Plan as its tool for success. In the program packet, clients are given an Action Plan, which asks them to identify their main areas of concern regarding the successful management of MS. They are instructed to bring their Action Plan as they go through the day and meet with the panel of experts. Clients then develop strategies on how to solve their issues based on the information exchanged in the breakout sessions. MSAA copies each client's Action Plan and provides ongoing follow-up support to help ensure these goals are met.

Adding to the uniqueness of this program are the selected locations of the Fairs. Where possible, MSAA has selected smaller

Continued on page 46

Coping with Fatigue

Causes of Fatigue in MS

Fatigue can be one of the most challenging symptoms of MS. It is also one of the "invisible symptoms" and can easily be misunderstood by others who are unfamiliar with the effects of MS. Friends, family, and even coworkers may question how someone can appear perfectly normal while claiming to be overwhelmed with fatigue. Some may think that the person is simply being lazy or needs to be motivated to snap back to normal. But no degree of motivation will help most forms of fatigue found with MS.

Individuals with MS may experience fatigue as a result of a number of reasons. Common causes include:

- demyelination
- spasticity
- sleep deprivation
- overexertion
- becoming overheated
- side effects from medications
- stress
- depression
- poor nutrition
- infection (particularly urinary tract infection, for which fatigue may be the primary symptom)
- kidney disease
- anemia
- other medical conditions

Regarding demyelination, individuals with MS often experience fatigue as a result of damaged myelin (protective nerve covering) and axons (nerve fibers). As the body requires increased effort to send nerve impulses along a damaged nerve, valuable energy is used up and the person becomes fatigued. This type of fatigue is often evident when a person with MS exercises beyond his or her limitations, possibly with the added stress of using weights.

Spasticity is a symptom of MS that can greatly contribute to fatigue. Stiff muscles require more energy to move and to control. This is one reason why treating spasticity through stretching exercises, physical therapy, and/or medications, can help reduce the amount of fatigue someone experiences.

Sleep deprivation is another difficulty often associated with MS that can directly impact one's level of energy throughout the day. Sleep may be interrupted several times each night by such symptoms as spasticity or urinary frequency (having to visit the bathroom often). Treatments sometimes used to fight fatigue, particularly excessive daytime napping or caffeine late in the day, can also contribute to difficulty sleeping.

Strenuous exercise, including exercise that uses weights, can completely drain a person's energy. Excessive exercise, as well as a warm environment, can also increase temperature, which can slow down nerve impulses and lead to fatigue. Ironically, keeping muscles inactive will lead to de-conditioning, and this too can also cause fatigue.

Many people with MS experience a type

of fatigue known as "lassitude," which is extreme sleepiness during the day. This can come on suddenly and is thought to be a result of chemical changes in the brain.

Treatment for Fatigue in MS

When a physician treats an individual with MS who is suffering from fatigue, the doctor has many issues to consider. The physician must look at the person's lifestyle (for things such as overexertion and heat exposure), other symptoms (including spasticity, urinary frequency, and sleep problems), emotional state (to look for depression and stress), physical condition (including poor nutrition, possible infection, and other superimposed medical conditions), and medications that the individual is taking which could include fatigue as a side effect. These are all possible causes that the physician must consider before determining that demyelination or lassitude are the culprits. Chances are, a combination of factors is involved with each person's fatigue.

The first line of treatment is to address the issues that can directly cause fatigue. The physician will need to identify these causes and develop a plan for the patient to follow.

The physician may suggest changing medications if they are thought to contribute to fatigue. The physician may also treat the other MS symptoms (such as spasticity, urinary frequency, and sleep problems) as well as infection or any other conditions through health-maintenance strategies and/or medication. Good nutrition and a healthy lifestyle may be emphasized to be sure an individual is getting the food, vitamins, exercise, and rest that he or she needs. Treatment may also be recommended for emotional problems such as depression.

Energy conservation is an important part of the treatment plan to fight fatigue. Scheduling, planning ahead, using adaptive equipment, and learning tips to make household chores easier and cooking less complicated, can greatly impact the amount of energy used throughout the day. Taking breaks and spreading out activities will also have a positive effect on energy.

Carefully monitored aerobic exercise can build endurance, keep muscles moving, and actually increase energy in the long run. Individuals with MS should be careful not to overstress muscles when using weights in their workouts. Yoga has also been found to help individuals feel less fatigued.

In addition to the many types of strategies that may be used to fight fatigue, MSAA has been actively involved in the research and distribution of "cool suits" to provide temporary relief from fatigue for a portion of the MS population. Studies have shown that nerves with damaged myelin are sensitive to changes in temperatures, noting that a rise in temperature may cause a failure in the effective transmission of signals from the brain to the body (nerve conduction), and a reduction in temperature may allow more signals to be transmitted across the dam-

aged nerve.

Cooling therapy, when used correctly, may help reduce some symptoms of MS, including problems with fatigue (as well as vision, spasticity, motor function, and cognition). Cooling needs to be controlled and done slowly through special equipment; otherwise it will not relieve any MS symptoms, and will result in shivering and vasoconstriction. As with any therapy, not all people receive the same benefit or any benefit at all. Cooling therapy should be viewed as an adjunct to disease modifying drugs, not as an alternative, and should only be done with the approval of a medical professional.

MSAA has recently published a new edition of its booklet, Multiple Sclerosis and Cooling. To receive a free copy, please call MSAA's Helpline at (800) 532-7667.

Medications are sometimes prescribed to fight fatigue. Modafinil (Provigil®) is the newest and one of the most commonly prescribed drugs for MS fatigue and lassitude. Other drugs prescribed include: amantadine (Symmetrel®); antidepressants fluoxetine hydrochloride (Prozac®), paroxetine (Paxil®), and sertraline (Zoloft®); and tricyclic antidepressants protriptyline (Vivactil®, Triptil®) and nortriptyline (Pamelor®, Aventyl®). The effects of these drugs differ between individuals and can change over time for a person taking the drug(s). Physicians may need to try various medications and dosages, possibly using a combination of drugs, to see what works best for a patient. Stimulants such as pemoline (Cylert®) and methylphenidate (Ritalin®) are used infrequently because of potential liver toxicity and addiction, respectively.

In conclusion, the significant fatigue that is experienced by many individuals with MS can be caused by a variety of factors. Visiting one's physician, following his or her treatment plan, taking steps to conserve energy, and looking into additional strategies such as cooling, yoga, and moderate exercise (all under the guidance of a physician), are the best ways to approach this challenging symptom.◆

— *Susan Wells Courtney*

MSAA's articles are for informational purposes only, and should not be used to determine one's treatment plan. All changes to one's diet, exercise, medications, or lifestyle, should only be done under the guidance of a medical professional.

References for this article include MSAA's publication, *Multiple Sclerosis, Managing Symptoms*, and Demos Medical Publishing's *Managing the Symptoms of Multiple Sclerosis*, fourth edition, written by Randall T. Schapiro, MD.

Continued from page 19

with many households switching from two incomes to one. Finances are further depleted through the additional expense of medical costs, care-partner help, equipment, and child care. Disagreements may occur over how money is spent, and what is saved for things like retirement and the children's education.

The frustration, anger, and guilt that may accompany the care-partner relationship need to be resolved to keep the relationship positive and productive. Talking with family and friends may help, but they may not know what to do.

As emotions build, they may eventually lead to abuse, and this is not acceptable in any situation. Angry words may be exchanged, doors may be slammed, and the care partner and care recipient may begin to yell at one another. Sometimes control is lost and physical abuse may occur while care is given. For example, the care partner may start handling their loved one roughly, brushing hair or washing the body harshly. The care recipient may scratch or hurt the care partner while being transferred. All efforts must be made to avoid reaching such a point, and professional help must be sought to return to caring behavior.

Open communication and professional help are recommended to keep a relationship healthy and productive. Communicating openly and effectively is important to all relationships. Couples need to take the time to discuss their concerns and feelings, to listen to one another, and to work together to develop solutions.

When MS is involved, symptoms such as fatigue and cognitive issues may prevent lengthy discussions. For this reason, couples facing such challenges need to find the time to talk, especially at an hour of the day when the individual with MS is feeling his or her best. When problems are discussed, the ideal approach is to handle one disagreement at a time and work out a solution.

Sometimes disagreements are too difficult to resolve and the emotions are running high. When this happens, couples or other people involved in the care-giving relationship should seek professional help through a marriage counselor or therapist who has experience working with long-term illness. This type of professional is trained to help couples resolve issues and manage various problems in the future. This will ultimately lead to more positive feelings and less frustration and anger. A qualified therapist is a vital member of one's healthcare team.

The relationship with one's children may change too, as teens, adolescents, and grown

children may not want to bother a parent already burdened by illness or disability. They may hold back their feelings and concerns about problems in their own life. A disability or illness, however, does not prevent a parent from wanting to hear about a child's life; and provided cognition is not severely affected, it does not prevent a parent from providing valuable support and advice. Most parents enjoy close talks with their children, and children should be encouraged to speak with their parent as they have always done in the past. Consulting a family counselor can be instrumental in helping children and parents adjust to the changes that may occur when someone becomes ill or disabled.

The Emotional and Spiritual Health of the Care Recipient

Care recipients often have less independence and may no longer have the ability to participate in outside activities as freely as they had done before. For example, their ability to attend classes, go to church, exercise, run errands, go to their children's activities, or work outside the home, may have become limited. Their social circle of family and friends may be reduced as well, as care recipients spend more time at home.

Individuals experiencing such losses will often feel a number of emotions, such as grief, guilt, depression, loneliness, and anxiety. Their self-esteem is commonly affected as well. These types of emotions can have serious effects on the individual, and care partners need to recognize when their loved one is suffering from such emotions. Warning signs can include crying, angry outbursts, sleep problems, sweating, trembling, nausea, feelings of hopelessness, and even thoughts of suicide.

Seeking professional help is the first line of action to be sure nothing medically is causing these symptoms, and to ensure a loved one's safety. The care recipient may be given a new medication and/or have other medications adjusted. After the individual has been examined and treated medically, seeing a therapist to help work through these emotions is another important step.

Care partners may do many things to help their loved one feel better emotionally. They need to listen, show genuine concern, and make efforts to help fill the void left by an illness or disability. Spending social time with the loved one without providing care is helpful, along with arranging time for him or her to socialize with others. The care recipient should always be given choices whenever possible, continually promoting a sense of independence.

People receiving care must have their spiritual needs met as well. If unable to attend an outside service, this may be accomplished through visits by someone from the clergy, or by bringing in books and recordings of religious services, hymns, and sermons. Meaningful materials (such as a bible, rosary beads, or religious picture) may be kept near the bed for inspiration.

Activities are vital to raising one's spirits. By joining a loved one in an enjoyable activity, both the care partner and the care recipient may experience greater happiness and decrease the symptoms of depression. Ideas

for activities include:

- Doing artwork or a craft
- Calling friends or family members to talk on the phone; inviting them over for lunch; or writing a letter together
- Taking a trip outside, visiting a park, or going for a ride
- Cooking or baking together
- Playing games or doing a puzzle
- Doing yard work, planting a garden, and/or arranging freshly cut flowers

- Visiting with pets or going to the zoo
- Reminiscing about family, friends, and old times; sharing stories
- Making a scrapbook
- Working together on the internet
- Making popcorn and watching a rented movie or special show together
- Listening to music or singing
- Practicing yoga or exercising together.

Providing support, reassurance, and interesting activities are all part of the care partner's job, and help to overcome many negative feelings. Encouraging proper rest and diet can also help someone to feel better. Individuals who have become dependent upon another still need to have goals and interests, and care partners need to promote specific goals and create new ways for their loved one to participate in activities that he or she enjoys.

For More Information

A great deal of information is available on the topic of care partnering. Many books have been written on the subject, some of which are available through MSAA's Lending Library. Please see p. 48 for highlighted books and instructions on how to request a full listing of publications. Borrowed books are delivered to a client's home and returned to MSAA at no charge.

Several agencies offer extensive instruction, advice, and advocacy through phone contacts, publications, and websites. Below is a listing of resources for care partners and their loved ones. Taking advantages of these resources can assist with the care-partner relationship while providing useful tips on safety, personal care, and emotional health. ◆

Resources for More Information

MSAA's Helpline
(800) 532-7667
www.msaa.com

American Health Care Association (AHCA)
(202) 842-4444
www.ahca.org

Conill Institute for Chronic Illness
(215) 746-7267
www.conillinst.org

Family Care America
www.familycareamerica.com
(Website presently experiencing technical difficulties; please check again later if site does not connect)
Family Caregiver Alliance
(415) 434-3388 or (800) 445-8106
www.caregiver.org

National Alliance for Caregiving
www.caregiving.org

National Center for Assisted Living
(202) 842-4444
www.ncal.org

National Family Caregivers Association
(301) 942-6430
www.nfcacares.org

WellSpouse Foundation
(800) 838-0879
www.wellspouse.org
Caregiver Magazine
www.caregiver.com

Caregiving Guide
www.careguide.com

List of References

DeGraff A.H., *Caregivers and Personal Assistants*, revised third edition, Saratoga Access Publications, Fort Collins, CO, 2002.

Family Care America

Kalb R.C., *Multiple Sclerosis: A Guide for Families*, Demos Vermande, New York, 1998.

Meyer M.M., Derr P., *The Comfort of Home*, CareTrust Publications LLC, Portland, Oregon, 1998.

Schonhoff S., Speaker J., *Family Caregiver Guide*, Simon & Kolz Publishing, Dubuque, IA, 1999.

Web MD

Many special thanks to Lara Krawchuk, MSW, LSW, MPH, a therapist who specializes in chronic and life-threatening illnesses. She has been of great help to MSAA and our readers by providing valuable information and insight, not only for this article, but also for a previous article on depression (appearing in the fall 2003 issue).

Staying Well Connected.

Our free ms*dialogue*® teleconference/chat series is hosted live by leading multiple sclerosis (MS) experts and advocates to help you gain a greater understanding of today's MS issues.

REGISTER TODAY
CALL 1-800-938-1912

	Teleconference:	*Online chat:*
Total Health Management Effective MS treatment is more than just taking your therapy. Learn how good communication, conserving your energy, and staying well informed can all play a part in helping to manage your MS.	**April 13** 8 PM ET (5 PM PT) **April 14** 9 PM ET (6 PM PT)	**April 15** 8 PM ET (5 PM PT) @www.msdialogue.com
	Patricia Kennedy Registered Nurse, Certified Nurse Practitioner, MS-certified Nurse at the Rocky Mountain MS Center **Linda C.** MS advocate	
Exercise It can improve stamina, increase energy, and help you cope with stress. Find out why exercise is so essential to good overall health and how to get started on a training program of your own.	**May 18** 8 PM ET (5 PM PT) **May 19** 9 PM ET (6 PM PT)	**May 20** 8 PM ET (5 PM PT) @www.msdialogue.com
	Dr. Randall Schapiro Founder and Director of the Fairview MS Center, Clinical Professor of Neurology at the University of Minnesota **Susan C.** MS advocate	
Relapses – What to Know Keeping relapses under control is one of the more important goals of MS management. We'll discuss the benefits of long-term therapy and provide the answers that may help reduce your chances of having a flare-up.	**June 8** 8 PM ET (5 PM PT) **June 9** 9 PM ET (6 PM PT)	**June 10** 9 PM ET (6 PM PT) @www.msdialogue.com
	Dr. Timothy Vollmer Chairman, Division of Neurology and Director of Barrow MS Program at Barrow Neurological Institute, Phoenix, AZ **Ginger H.** MS advocate	

Each ms*dialogue*® teleconference features a live Q&A session. For a current schedule and/or to read transcripts and supplements on previous teleconferences, visit www.msdialogue.com.

 04260003/0243B4

For information on events and newly formed support groups, please call the phone numbers listed. When specific numbers are not given, please contact the MSAA Regional Office appearing below each listing. Established support groups are held in many other cities; please call the nearest MSAA Regional Office for details. All activities are free of charge unless otherwise noted.

Northeast Region

Upcoming Events:

- Wednesday, June 16th, MS Awareness Conference, Marriott Baltimore Inner Harbor, Baltimore, Maryland

Newly Formed Support Groups:

- University of Pittsburgh, Pennsylvania Department of Rehab, Sciences and Technology; contact Joseph Ruffling at (412) 383-6599 or (412) 965-7780
- Pasadena, Maryland; contact Liberty Kinnie at (410) 360-7912
- Camden, New Jersey; contact Kathy Nolan at (856) 964-7531

Support Groups Coming Soon:

- Lake Carmel, New York
- Springfield, Vermont
- Parkville, Maryland

MSAA Northeast Regional Office:
Susan Freund, Director
706 Haddonfield Road
Cherry Hill, New Jersey 08002
(856) 488-4500
(800) 532-7667, ext. 106
MSAA Connecticut Field Office:
Marcia Williams
Client Services Coordinator
7 Richelieu Street
Norwalk, Connecticut
(203) 855-7988
(800) 532-7667, ext.151

Midwest Region

Upcoming Events:

- Saturday, June 19th, Intercontinental Hotel and Conference Center, MS Awareness Conference, Cleveland, Ohio. Dr. Howard Schecht, MD of the Toledo Clinic will the main speaker; a speaker from Twin Pines Retreat Care Center of Stow, Ohio, will talk about occupational and physical therapies; Chris Verich of Ohio Consumer Counsel will talk about "Assistance Programs That Can Lower Your Utility Costs;" and a representative from Holden Arboretum will talk about "Tips for Gardeners with MS"
- Sunday, July 18th, MSAA Day at the Zoo, Columbus, Ohio
- Saturday, August 14th, MSAA Day at the Zoo, Cleveland, Ohio
- Wednesday, September 22nd, MSAA at the Comedy Club, Cleveland, Ohio
- Saturday, October 30th, MSAA's Halloween Ball, Cleveland, Ohio

To pre-register for events, please call the Midwest Regional Office Event Line at (800) 532-7667, ext. 121.

Newly Formed Support Groups:

- Crawfordsville, Indiana; contact Wendy Harrington at (765) 798-5178
- Chicago, Illinois; contact Estell Buckner at (773) 978-4106
- Chicago, Illinois; contact Sharon Elliot at (773) 821-0907

MSAA Midwest Regional Office:
Renée Williams, Director
13938A Cedar Road, #243
University Heights, Ohio 44118
(216) 320-1838
(800) 532-7667, ext. 140

MSAA Chicago Area Field Office:
Scott McDonald
Client Services Coordinator
3013 S. Wolf Road #215
Westchester, Illinois 60154-5639
(708) 223-0734
(800) 532-7667, ext. 150

Northwest Region

Upcoming Events:

- Saturday, June 12th, MS Public Awareness Event, "Living with MS," Yakima Convention Center, Yakima, Washington; neurologist James Bowen and Jan Shilling, CRRN, will be speaking; both are from the University of Washington MS Clinical Center
- Sunday, September 12th, "Celebration Picnic in the Park," Great Falls, Montana, 1:00 to 4:00 pm
- Saturday, September 25th and Sunday, September 26th, "Parade of Homes," Great Falls, Montana; volunteers needed

New Exercise Class

- Missoula, Montana (Tai Chi class)

Support Groups Coming Soon:

- Harlem, Montana
- Spokane, Washington

MSAA Northwest Regional Office:
Sue Pencoske, Director
600 Central Plaza, Suite #13
Great Falls, Montana 59401
(406) 454-2758
(800) 532-7667, ext. 131

Southeast Region

Upcoming Events:

- Tuesday, July 13th, "Keep Cool," held in Largo, Florida

New Support Groups:

- Deltona, Florida; contact Nayda Cuevas at (386) 789-0332 or nayda824@earthlink.net
- Port St. Lucie, Florida; contact Bonnie Cotrell at (772) 344-6110 or chazgirl824@bellsouth.net
- West Palm Beach, Florida; contact: Jeanie Zeis at (561) 683-8163 or jzmsldr@aol.com or Vicky and Jim Stanfield at (561) 793-7189

MSAA Southeast Regional Office:
Linda Chaney, Director
PO Box 66565
St. Petersburg, Florida 33736
(800) 532-7667, ext. 154

Mid-South Region

Upcoming Events:

- Saturday, June 5th, 9:30 am to noon, "Taking Charge of Your MS" conference, Fort Worth Zoo, Fort Worth, Texas
- Saturday, September 11th, MSAA Health Fair, Baton Rouge, Louisiana
- Saturday, October 9th, 9:30 am to noon, "Taking Charge of Your MS" conference, Holiday Inn Select Memphis – Downtown (Beale Street), 160 Union Avenue, Memphis, Tennessee

Newly Formed Support Groups:

- Oklahoma City, Oklahoma; contact Michael Bast at (405) 942-1969
- Texarkana, Arkansas/Texas; contact Karen Coker at (870) 653-2255

Support Groups Coming Soon:

- El Dorado, Arkansas
- Edmond, Oklahoma
- Dallas, Texas

MSAA Mid-South Regional Office:
Adam Roberts, Regional Director
1515 N. Town E Boulevard
Suite 138, Box 320
Mesquite, Texas 75150
(817) 480-2125
(800) 532-7667, ext. 153

MSAA Arkansas Field Office:
Judith Bennie, Client Services Coordinator
107 Avonshire Terrace
Hot Springs, Arkansas 71913
(501) 262-9380
(800) 532-7667, ext. 137 ◆

Continued from page 30

cities in less urban settings to host the Fairs. This helps to reach clients in potentially underserved populations who may not have the opportunity to meet with top MS experts in the country. By June 2004 two more Health Fairs will have been held. Please see schedule below for upcoming Fairs. Seating is limited; to reserve your space, please call Anne Negrin, MSAA's health fair coordinator, at (800) 532-7667, ext. 105. ◆

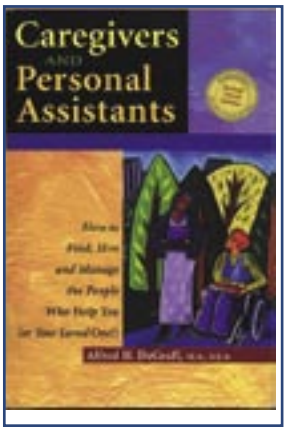
— *Peter Damiri*

Upcoming MSAA Health Fairs

July 24th:	Madison, Wisconsin
August 14th:	Chicago, Illinois Area
September 11th:	Baton Rouge, Louisiana
September 18th:	Columbus, Ohio
October 16th:	Portsmouth, New Hampshire
November 6th:	Dover, Delaware

Hippotherapy Note:

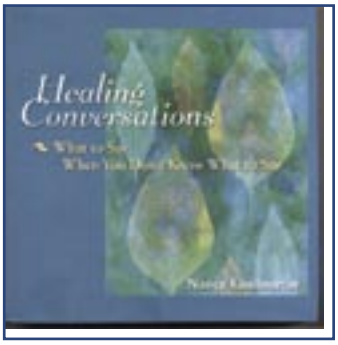
As a follow-up to our recent article on rehabilitation, we wanted to clarify that hippotherapy falls under the classification of "physical therapy." Hippotherapy is a treatment approach that uses activities on the horse to provide a foundation of improved neuromotor function and sensory processing, and may also promote a positive effect on psychological, cognitive, behavioral, and communication outcomes. We hope this clarification will be helpful.



Caregivers and Personal Assistants

Edited by Alfred H. DeGraff, MA, SEA
Published by Saratoga Access Publications
MSAA Book #236

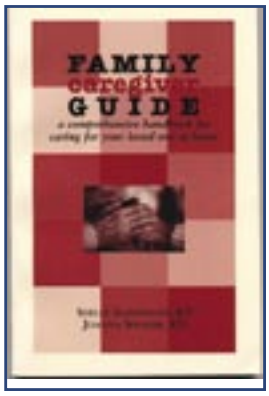
This extensive publication provides a wealth of information on the many issues involved with finding, hiring, and managing people to care for someone in need. The writer is an inspiring individual who was paralyzed from the chest down following a diving accident at the age of 18. Among other topics, specific examples are given on: how to interact with an aide; strategies for being a good manager; providing direction and training; salaries, tax obligations, and legal matters; medical monitoring; and privacy issues.



Healing Conversations

Written by Nance Guilmartin
Published by Jossey-Bass
MSAA Book #229

Personal stories, healing dialogue, and advice on how to provide comfort to a friend or family member, are given on a variety of difficult situations. Examples of topics include changes or loss in areas of health, career, and personal relationships.



Family Caregiver Guide

Written by Shelly Schonhoff, RN and Joanna Speaker, RN
Published by Simon & Kolz Publishing
MSAA Book #80

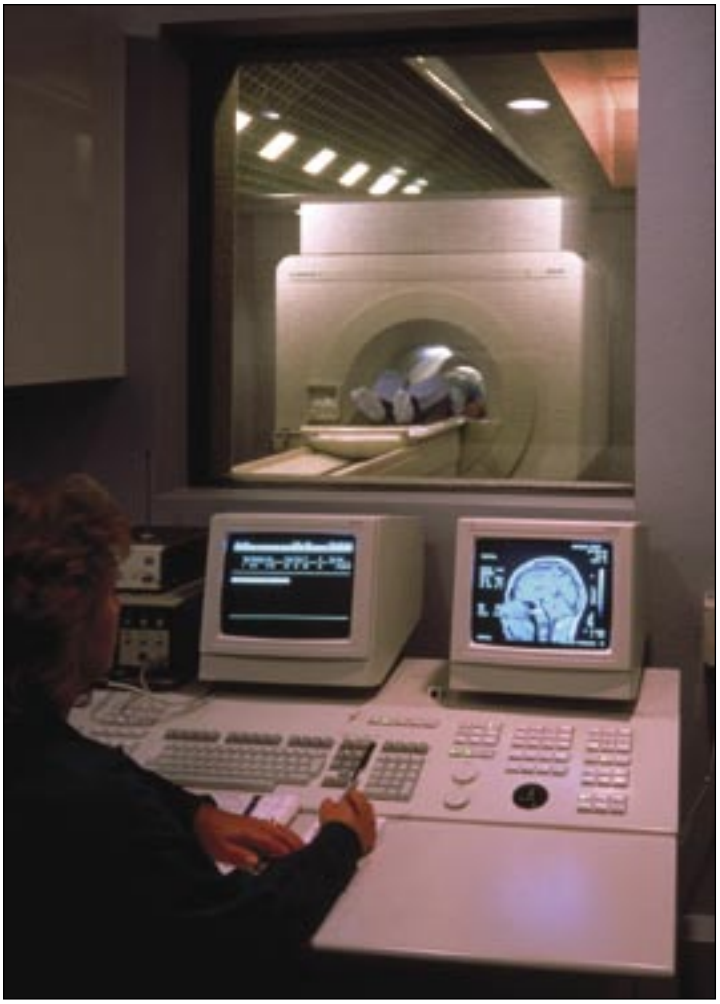
Self-described as "a comprehensive handbook for caring for your loved one at home," this resource provides a clear and concise listing of the issues and instruction necessary to provide a full range of assistance to someone who is ill or disabled. Chapters include information on everything from safety, personal care, medical skills, and diet, to communication, emotional interactions, legal and financial issues, and resourc

MSAA Lending Library

If you would like to borrow any of the books featured in this column or any other book in MSAA's Lending Library, please send us your name and address. We will send you an application and a list of books for the Lending Library. MSAA and its clients greatly appreciate any donations made to help build the Lending Library. If you would like to donate a book to the Lending Library you need only send it to us at the address below. Please address all correspondence to:

MSAA Lending Library
Attn: Woody Dyer
706 Haddonfield Road
Cherry Hill, NJ 08002
(Please reference book number)

MSAA Offers Financial Assistance For Follow-up MRIs



- A follow-up MRI exam can help you and your neurologist keep pace with the ever-changing course of MS
- New information can assist in evaluating disease progression and help find the best treatment options to meet your needs

The MSAA MRI Institute provides financial assistance in securing MRI's of the brain for uninsured, under-insured or financially challenged MS clients.

To learn more about the MRI Institute, please contact MSAA at (800) 532-7667, ext. 120 or mriinstitute@msaa.com.

The MSAA MRI Institute is funded by a grant from Serono/Pfizer.

Multiple Sclerosis Association of America
706 Haddonfield Road
Cherry Hill, NJ 08002 USA

CHANGE SERVICE REQUESTED

Non-Profit Org.
U.S. Postage
PAID
Rockville, MD
Permit No. 800