

IOMSN UPDATE

How the IOMSN Helps Promote the Concept of "Comprehensive Care" in MS

We're all looking forward to visiting Denver and attending the 22nd Consortium of Multiple Sclerosis Centers (CMSC) Annual Meeting. The theme of this year's meeting is "Comprehensive Approaches to Complex Challenges in Multiple Sclerosis." As nurses, this is a concept near and dear to all our hearts.

In the last issue of *MS Exchange*, June Halper wrote an article about the benefits of the comprehensive care model in MS (available online at www.ms-care.org). Although there were only a few comprehensive centers in existence when the Consortium was first founded, those of us involved in all disciplines related to MS knew we needed to pull together to provide better care for our patients.

Not all of us are fortunate enough to work at a comprehensive MS center, and we can learn a lot from those who do. Using the same model, we can establish "centers without walls." We can familiarize ourselves with available resources in our communities, establish relationships with them, and refer our patients to

them. We can offer to teach other professionals about MS, our patients, and how to be part of an interdisciplinary team. As MS nurses, we are often expected to fill the role of team leader, and it is a natural extension for us to provide professional education as well as patient education.

At this year's CMSC meeting, you'll have a wide array of lectures, workshops, and seminars from which to choose. Pick a few that will teach you more about the different

specialists we refer patients to, as this will enhance your discussions with your patients. Interact with other professionals and ask them how they manage scheduling and patient-related issues in their practices. At the close of the meeting, you will be richer from your experience and you will be practicing a more "comprehensive" model in your care of patients with MS.



*Patricia Kennedy, RN, CNP, MSCN
Director,
Editorial Board
MS Exchange*

Congratulations to the following candidates who passed the examination for certification in the United States as MS Nurses in February 2008:

Tammy M. Bell
Thomas L. Bennett
Rachel A. Bierschbach
Stephanie N. Breland
Andrew D. Brown
Cathy H. Ciolek
Christy M. Dittmar

Kincaid B. Early
Alicia M. Hudson
Donald W. Jordan
Heidi M. Knutson
Ruth Ann Lackey
Kristen L. Levine
Angela M. Martino

Jeanne M. Maslar
Lisa M. Mccurdy
Gretchen T. Michaelson
Lesley A. Murray
Suzan I. Noori
Melissa Sai-Yin Pei
Michelle D. Prichard

Amie Sowe-Jallow
Daniel J. Storey
Sandra L. Swanson
Amy Lee Trottier
Thomas S. Vnuk

Patient Advocacy: An Invaluable Service to Patients

Patients with multiple sclerosis (MS) have a broad range of needs that go far beyond medical treatment. The physiological changes caused by MS and the decisions that have to be made require support in all facets of a patient's life, including work, finances, and family. Marie Namey, RN, MSN, MSCN, an Advanced Practice Nurse at the Cleveland Clinic Mellen Center in Cleveland, Ohio, and Chair of the Consortium of Multiple Sclerosis Centers (CMSC) Advocacy Committee, offers her insights on patient advocacy for MS.

Patient advocacy is one of the major aspects of the comprehensive care model for patients with MS. The key issues in advocating for patients are education and communication. Initially, it's important to help patients start with a good understanding of their disease and what to expect, and beyond that, to educate them about MS organizations and other resources that can provide many answers to them throughout their lifetime with this disease.

The National Multiple Sclerosis Society, the Multiple Sclerosis Society of America, and the Multiple Sclerosis Foundation all provide good resources to help patients find available services in their area. "All three of the MS societies have a broad geographic basis, so they can help patients find some of the things they need," says Ms. Namey, adding that these organizations have informative websites where people can obtain balanced information. They also produce useful publications (see box, page 7).

Good educational websites for patients are also being developed by some major MS treatment centers, including the Rocky Mountain Center in Englewood, Colorado and the University of Maryland. These sites offer general information on MS and its treatment, national links to organizations and research, and local resources for patients.

Helping Patients to Self-Advocate

Once patients have visited various websites for information, they should then discuss their questions with someone who is specifically familiar with their case. Ms. Namey recommends that patients plan the agenda for their office visit, to get the most out of their time with their health care professionals. "I think nurses can help by teaching patients to be succinct about what's important to them," she says. "Patients need to realize that they're the consumers, and they are the ones who should be guiding the visit."

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Patients have increasingly become proactive and self-advocating. As Ms. Namey points out, "With MS, we have a lot of younger patients who are quite savvy about speaking up for themselves or managing the Internet." Older patients, however, who may have had the disease for a while, sometimes come to believe there is nothing new that can be done for them. These patients need coaching to make their office visits more productive and to fully understand the level of disease management they can achieve. Physicians often hear a litany of nonspecific complaints that can make it difficult to provide real relief for patients. Ms. Namey suggests that nurses educate their patients to focus on one or two particular issues that can realistically be addressed in a single visit, and to plan follow-up visits to discuss other issues, creating an ongoing system of patient/clinician interaction.

In addition to the importance of understanding their treatment options and the medical aspects of their therapy, patients with MS have a range of changing needs that require counseling. Physical limitations, as well as cognitive symptoms, may inevitably lead to strains on their family and work lives, and create additional financial costs and logistical issues to be overcome. MS nurses, social workers, and psychologists are the best sources to provide counseling and advocacy throughout these challenges.

The Range of Advocacy Issues

One of the most pervasive difficulties MS patients have is with insurance companies that try to "manage their care." Health care providers work together to provide

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therapies that are most effective with the least amount of side effects, but these may not be the therapies covered by insurance companies. MS nurses are frequently called upon to advocate for patients with insurance companies that deny claims for medications they do not have on their formulary, and who make unrealistic requests to change to less expensive medications or therapies other than the one the clinician selected for a particular patient.

Nurses often take on unusual responsibilities to help patients navigate their everyday lives. "I had a patient who joined a health club," Ms. Namey recalls, "and because of his MS he couldn't continue his membership in the health club. He actually fell off the treadmill and it caused him some problems and he didn't want to go back. Well, of course, there's a clause in that contract saying that you have to continue to pay for the health club for the next 18 months, unless for medical reasons you can opt out. So I wrote a letter saying he could not benefit from continuing at the health club.

"Advocacy takes time if you want to do it right," says Ms. Namey. She explains that common requests include asking nurses to fill out forms or write medical excuse letters for patients who are unable to perform jury duty due to accessibility issues, experience transportation problems with work or appointments, or need to get handicapped parking permits. "It helps if patients understand that it's going to take time to handle these kinds of requests," she notes. "During a brief follow-up visit, you don't have time to address their issues *and* fill out a form."

RESOURCES FOR PATIENTS

MS Organizations

National MS Society

www.nationalmssociety.org

Multiple Sclerosis Association of America (MSAA)

www.msassociation.org

Multiple Sclerosis Foundation

www.msfocus.org

Treatment Centers with Educational Websites

Rocky Mountain MS Center, Englewood CO

www.mscenter.org

University of Maryland

http://www.umm.edu/ms/multiple_sclerosis_resources.htm

While the state disability parking forms can usually be completed during a single visit, many other requests require mining the patient's record for information to fill in a multipage form. Patients can help by scheduling a special visit to complete such forms, and by filling in much of the information beforehand. Patients also need to help nurses understand their needs and preferences about how to present information. In some cases, they may prefer to be fully excused from a commitment, while in other cases they are asking for special assistance or compensation to continue.

Advocating with Patient Employers

Employment situations present a number of potential difficulties for MS patients. Nurses often perform a key function by simply helping employers understand what kinds of limitations people with MS might have that will affect their work. Some problems can be relatively easily rectified. "A number of my patients are school teachers," Ms. Namey says. "They often have problems with their bladders, and they need to have easy access to a bathroom. I've written many letters recommending that they have a classroom close to the bathroom so that they can manage this symptom effectively."

"In truth, the patient is our client, but we also have to listen to reasonable concerns that the family may bring to the table," says Ms. Namey.

Part of the job of advocacy is helping patients with different levels of disclosure. Patients should talk to their human resource department and their employers to let them know what their concerns are, and what their diagnosis is if they want some reasonable accommodation. While it's not legally required that patients disclose their MS, it is difficult to ask an employer to make concessions without such information. Ms. Namey recalled a patient who was asked to work a night shift by her supervisor, but felt she couldn't work nights because of issues with fatigue. Since the patient hadn't told anyone but her supervisor about her MS diagnosis, Ms. Namey suggested she talk first with her employer, after which Ms. Namey wrote a letter in support of her contention that night work was not a reasonable expectation for her.

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Nurses, social workers, and occupational therapists can be invaluable in helping patients to function in their work environments—or to recognize when they can no longer work. Some patients will need extra counseling to understand when they have reached the point where they are physically unable to perform their jobs, and to make the difficult transition to a less demanding job or not working at all.

Help From the Family

The family can certainly help with advocacy by talking with patients about those things that are important to accomplish in a single visit. Some patients may have problems with their thinking and memory, and forget to report important symptoms or changes; others may experience anxiety when they come to the doctor's office. In both instances, family members can be of assistance.

Sometimes, however, health care professionals may need to mediate between the patient and the family, when there is disparity between what the patient wants and what the family thinks the patient needs. "In truth, the patient is our client, but we also have to listen to reasonable concerns that the family may bring to the table," says Ms. Namey. "One thing that comes to mind is driving. Many patients think that they can continue to drive while family members are shaking their heads. The patient may have had a fender bender or two, maybe because of vision problems or leg weakness. We understand how hard it is to give up your driver's license. For many people it means giving up their independence."

The nurse or social worker will initiate a discussion between the patient and the family about what's going to be best, with the goal of reaching a compromise, such as having the patient undergo a formal driving evaluation.

Counseling for Major Life Changes

Unfortunately, patients may reach a point where they can no longer function in the home environment, which requires that major decisions be made about their care. This is where home care agencies can be very helpful in assessing the safety concerns in the home, and initiating discussions with patients about whether it is reasonable for them to remain in the home.

Social workers, occupational therapists, and psychologists generally assist patients and families with this decision, as it is a complex issue that needs to be discussed many times over a number of visits. "It's a big enough step when a patient goes from walking independently to using a cane—a lot of discussion goes into that, with not only the physician, but also the nurse, the physical therapist, and family members. When you're talking about patients moving out of their home situation and into a structured environment, that's a really big transition," Ms. Namey says.

When a patient needs to move to a full-care facility, social workers can be invaluable, as they are generally the most knowledgeable about the resources available. "The MS societies and organizations can be helpful in providing this kind of counseling, because they have a lot of social workers on their staff who can focus more on that element," Ms Namey explains.

Ultimately, health care professionals can offer a great deal of support that can protect patients' rights and enhance the quality of their lives with MS. Patients should be encouraged to seek out individuals they feel comfortable with to provide additional support with the many challenges they will face with this disease.

DON'T FORGET TO REGISTER FOR THE NEXT EXAMINATION SITTINGS!

2008 Multiple Sclerosis Certified Nurse (MSCN) Examination Schedule

Exam Date	Location	App. Deadline
May 28, 2008	Denver, CO (onsite at CMSC Meeting)	April 15, 2008
May 31, 2008	Multisite—USA Nationwide	April 15, 2008
Nov. 2, 2008	England and Australia	Sept. 15, 2008
Nov. 8, 2008	Multisite—USA Nationwide	Sept. 15, 2008



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