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Fall 2014
Volume 10, Number 2

Counseling Points™

Enhancing Patient Communication for the MS Nurse

Making the Most of MS Support Organizations



Series Editor

Amy Perrin Ross, APN, MSN, CNRN, MSCN

Faculty Panel

Kathleen Costello, MS, ANP-BC, MSCN

Theresa LaRocca, RN, BSN, MSCN

Dorothea Cassidy Pfohl, RN, BS, MSCN

This continuing education publication is supported by an educational grant from Teva CNS.

FACULTY:

Series Editor

Amy Perrin Ross, APN, MSN, CNRN, MSCN
Neuroscience Program Coordinator
Loyola University Medical Center
Maywood, IL

Faculty Panel

Kathleen Costello, MS, ANP-BC, MSCN
Associate Vice President
Advocacy Services and Research
National Multiple Sclerosis Society

Theresa LaRocca, RN, BSN, MSCN

Clinical Nurse Specialist
Linda Morgante Multiple Sclerosis Care Center
Maimonides Medical Center
Brooklyn, NY

Dorothea Cassidy Pfohl, DNP, MSN, RN, MSCN

Clinical Coordinator
University of Pennsylvania Multiple
Sclerosis Center
Philadelphia, PA

Faculty Disclosure Statements

Amy Perrin Ross has received honoraria for consulting and participating on the Speakers' Bureaus for Acorda Therapeutics, Bayer HealthCare, Inc., Biogen Idec, EMD Serono, Genzyme, Novartis, Questcor, Pfizer Inc, and Teva CNS.

Kathleen Costello has disclosed no relevant financial relationships.

Theresa LaRocca has received honoraria for consulting and participating on the Speakers' Bureaus for Acorda Therapeutics and Questcor.

Dorothea Cassidy Pfohl has received honoraria for consulting and participating on the Speakers' Bureaus for Acorda Therapeutics, Genzyme, Novartis, and Questcor.

Planners and Managers

The following planners and managers have declared no relevant financial relationships: Joseph J. D'Onofrio, Frank Marino, Katherine Wandersee.

PUBLISHING INFORMATION:

Publishers

Joseph J. D'Onofrio
Frank M. Marino
Delaware Media Group
66 South Maple Avenue
Ridgewood, NJ 07450
Tel: 201-612-7676
Fax: 201-612-8282
Websites: www.delmedgroup.com
www.counselingpoints.com

Medical Writer

Katherine Wandersee

Art Director

James Ticchio

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Counseling Points™

Making the Most of MS Support Organizations

Continuing Education Information

Target Audience

This educational activity is designed to meet the needs of nurses who treat or who have an interest in patients with multiple sclerosis (MS).

Purpose

To assist nurses who treat patients with MS to advocate for patients, families, and themselves by utilizing the services of MS support organizations.

Learning Objectives

Upon completion of this educational activity, the participant should be able to:

- Recognize the barriers that prevent people with MS from accessing support organizations
- Identify key sources for medical information, connection with counselors and peer advisors, financial assistance, and other MS support services
- Discuss sources for nurses to receive advocacy and peer interaction to support their professional development and personal well-being

Continuing Education Credit

This continuing nursing education activity is developed under the joint providership of Delaware Media Group and NP Alternatives.

NP Alternatives is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation.

Laurie Scudder, DNP, NP, served as nurse planner and reviewer for this activity. She has declared no relevant financial relationships.

This activity has been awarded 1.0 contact hours (0.0 contact hours are in the area of pharmacology). Code: MSCP11014.

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Disclaimer

Participants have an implied responsibility to use the newly acquired information to enhance patient outcomes and their own professional development. The information presented in this activity is not meant to serve as a guideline for patient management. Any medications, diagnostic procedures, or treatments discussed in this publication should not be used by clinicians or other health care professionals without first evaluating their patients' conditions, considering possible contraindications or risks, reviewing any applicable manufacturer's product information, and comparing any therapeutic approach with the recommendations of other authorities.

welcome

Dear Colleague,

As MS nurses we often feel pulled in many directions—trying to get more done in less time, and trying to help patients achieve improved outcomes with lower costs of care. Many nurses feel overwhelmed at times with the multiple responsibilities of providing care in this challenging and rapidly advancing area of healthcare.

When the idea was presented to do a special issue of *MS Counseling Points* on MS support organizations, the response among our panel was unanimously positive. All of our faculty serve important roles in key MS organizations. We all recognize how much these groups do to provide patient care services, professional support, ideas for improving care, or just a shoulder to lean on.

The organizations discussed in this issue include peer support for patients, financial resources, caregiver services, and many others. Our goal was to provide an organized and updated resource, but also to explain how these groups can benefit patients and others involved in the care of MS.

There is much to gain from partnering with MS medical and advocacy groups. In addition, it's important to remember that these groups grow and thrive because of the time and efforts that nurses contribute along with many other dedicated individuals. Through this issue, we acknowledge our united goals of improving healthcare and quality of life for people with MS and their families.



Amy Perrin Ross, APN, MSN, CNRN, MSCN (series editor)
Neuroscience Program Coordinator
Loyola University Medical Center
Maywood, IL

Making the Most of MS Support Organizations

Introduction

One of the most important services that a nurse can provide for people with multiple sclerosis (MS) is connecting them with valuable resources to help manage their condition. The goal of this issue of *MS Counseling Points* is to provide an updated and useful resource, but also to emphasize how people with MS, MS nurses, and others can benefit by reaching out to these groups.

Most of us have access to plenty of websites and phone numbers of MS organizations. However, it may not be clear to the patient and family how these resources can help to address their needs or just help them to feel less alone. Patients with MS may mistakenly believe that support services are mainly for “joiner” types of people, or that they need to become members, send money, or participate in a fundraiser to access services and information.

Many MS service organizations are also in place to help address the needs of caregivers and health-care providers. If you are a nurse involved in the care of patients with MS, you may want to review this issue with your own needs and goals in mind as well. You may find ideas for your practice or ways to expand your circle of supporters and colleagues, locally or nationally.

National/International MS Organizations

For many patients, the large national or international organizations are the best place to start for information, resources, and support. However, because an initial diagnosis of MS can be so overwhelming, some people might feel intimidated to call a “big organization.” Others may have come to the impression that the organization

exists mainly for fundraising or medical research. Patients may feel that they are being “pushed off” onto someone else if the nurse simply hands them a list of organizations to call. Or they may believe they will be expected to pay for certain services. Thus, the MS nurse should stress that there is individual and very personal support to be had, even from a large national group, and that this support is closely connected to (not in place of) the support available from medical providers. A common theme among many people who have benefitted from national MS organizations is, “If only I had reached out sooner.”

National MS Society (NMSS)

The NMSS offers a huge wealth of resources for patients, family members/caregivers, and health-care providers through its national office and state/local chapters. Some services patients may want to check out:

MS Navigator® service: This program, whose theme is “*Because No One Should Have to Face MS Alone*,” offers personal support (via phone or email) for individuals with MS. MS Navigators are trained to help callers access the specific resources they need, including connecting with other people living with MS, maintaining independence, or finding medical information and answers. Contact NMSS through its toll-free number (see **Table 1**) during business hours Monday through Friday. A brochure for the MS Navigator service can be found on the NMSS main website.

Knowledge is Power program: Patients who are newly diagnosed with MS often feel bombarded by too much information. Knowledge Is Power is a free, at-home educational series for people newly diagnosed with MS that paces the information in smaller doses so the person has

Table 1. National/International MS Organizations

Organization	About	Contact Information
National Multiple Sclerosis Society (NMSS)	The largest MS advocacy group in the U.S., with the vision of “A World Free of MS.”	nationalmssociety.org contactusnmss@nmss.org (800) 344-4867
Multiple Sclerosis Association of America (MSAA)	A national nonprofit organization dedicated to improving lives through vital services and support.	General Information email: webmaster@mymyaa.org MS questions email: MSquestions@mymyaa.org Phone: (856) 488-4500 Helpline: (800)-532-7667 ext. 154
Multiple Sclerosis Foundation (MSF)	A national nonprofit organization offering support groups and grant-based assistance.	Email: support@msfocus.org (888) 673-6287
North American Research Committee on Multiple Sclerosis (NARCOMS)	An international patient registry service to collect information about living with MS that can be utilized by researchers to further the advancement of MS care.	Email: MSregistry@narcoms.org (800) 253-7884

time to absorb the ideas. Written by Dr. Rosalind Kalb, the program provides up-to-date facts about many aspects of MS. Patients who register will receive an informational packet approximately once per week over 6 weeks, on topics such as Taking the First Steps, Treating Yourself Well, and Working With Your Doctor.

MS Friends: A peer support group connecting people with volunteers who also have MS. This hotline is available 15 hours per day, 7 days a week. Callers can pick from a list of trained peer support volunteers and connect via email or telephone. (peerconnections@nmss.org)

Local and State chapters: The regional and state chapters of NMSS are the best way for people with MS to find support groups, local activities and community-specific resources for MS. The NMSS currently has a 50-state network of chapters. A person with MS might explore the national website to get information about MS and then reach out to the local chapter if he or she is ready to find out about local services or participate in a group.

Multiple Sclerosis Association of America (MSAA)

MSAA is another national MS organization that offers a wealth of resources for patients, families,

and others interested in MS. Some notable services:

Toll-Free Helpline: The MSAA toll-free Helpline allows individuals with MS, family members, and care partners to speak directly with a specialist in counseling/social services with specialized knowledge of MS. This service is available business days between 8:30 am and 5:00 pm Eastern time, or via email as shown in Table 1.

Cooling, Assistive Equipment, MRI funding assistance: These programs provide cooling vests and accessories for adults and children with MS, as well as various safety equipment (shower chairs, grab bars, and mobility devices such as canes, walkers, and wheelchairs). Distribution requires a physician’s prescription confirming a diagnosis of MS, and completion of the application form available on the MSAA website. MSAA provides products at no charge and ships directly to the client. The MRI Diagnostic Fund and MRI Institute provide advocacy and funding for patients who need assistance paying for these services.

My MS Journey (<http://myMSAA.org/journey>): The “My MS Journey” portion of the MSAA website helps people with MS to navigate the vast amount of information on MS, organized according to stage: “Just Starting Out” (newly

diagnosed); “Staying on Course” (day to day MS management); and “The Seasoned Traveler” (mobility, independence, and caregiving needs).

Shared-Management tools: This program fosters joint decision-making between patients and MS healthcare providers by providing tools to help them organize and share information. Current components are:

- My MS Resource Locator[®], an online database offering targeted information and unique support services, including detailed guides
- My MS Manager[™], a mobile-phone app for iPhone/iPad and Android devices which allows patients to track disease activity, store medical information, generate reports, and assist with treatment planning
- S.E.A.R.C.H.[™], a multisponsored toolkit to help guide in learning about available disease-modifying therapies for MS

Multiple Sclerosis Foundation (MSF)

This organization, which operates from a centralized office in Fort Lauderdale, FL, sponsors fundraising programs as well as information services, support groups, and special programs to help people with MS maintain their health and well-being. All services provided by the MSF are free of charge. Highlights of MSF programs include:

Independent Support Group Program: The MSF has a network of more than 100 independent support groups nationwide for patients and family members. Those interested in starting a support group will receive training from MSF’s program. Email contact for information: Alissa Ayden (MSF Support Group Coordinator), alissa@msfocus.org, or main number: 888-673-6287.

Assistive technology and cooling equipment: Information about assistive technology and cooling products, financial assistance, and logistical help in obtaining devices is available through programs offered by the MSF. Applications can be completed via mail or online.

Homecare, Brighter Tomorrow, and computer grants: For home care services such as therapy visits, respite care, and hospital transition, this MSF service functions as a liaison between the patient and the local resources or, if local resources are unavailable, temporary grant support may be provided. Selected individuals with MS may be eligible for a Brighter Tomorrow grant to help improve their quality of life, or grants for computer equipment. Applications are available on the MSF website under Programs & Activities.

North American Research Committee on Multiple Sclerosis (NARCOMS)

NARCOMS is a global registry for MS research, treatment, and patient education that maintains an active database of over 37,000 people with MS. Enrollment involves completion of an initial MS/health history survey. Participants are then asked to complete 2 update surveys each year. Enrollment is free and confidential (personal data are coded with a secure ID number). Participants receive NARCOMS *Now* magazine (also available online) which discusses findings based on NARCOMS research and other topics of interest to persons with MS and families. NARCOMS surveys and information are available in English and Spanish.

Online Communities

A number of online communities have cropped up in the Internet age, many of which are helpful and supportive for patients with MS. It can be confusing to patients to discern which online sites provide medically sound information, and which have an “agenda” such as promotion of a product or particular disease-modifying approach. Patients interested in online communities should start with the major MS organizations and MS care centers (one tip is to look for those with web addresses ending in “.org” or “.edu” rather than “.com”). However, there are some reliable and well-run consumer-based sites as well. Many of the latter

offer “real-world” information and interaction from people who can relate to what the patient is feeling. When discussing online communities and information with patients, MS nurses should caution them to:

- Remember that much of the medical information may not apply to their own situation. Just because another patient has a relapse after 1 month on a particular agent, or has intolerable side effects on another, does not necessarily mean that your patient will have that same experience.
- Beware of fraud or potential quackery—miracle cures that the “doctors don’t want you to know about,” or that seem too good to be true (and therefore probably aren’t true). There are always multiple ways to check out and verify information by turning to a reliable source, so patients should be reminded to try to keep an open mind and bounce questionable information off of a reliable source such as the MS nurse, neurologist, or personnel from a trusted group such as the NMSS.

[MSConnection.org](#)

MSConnection.org is the online community run by the NMSS. There are blogs, online interest groups, and discussion groups on topics such as MS symptoms, research, employment, health insurance, and daily living with MS.

[MSWorld.org](#)

This nonprofit site started as a small chat room in 1996 and continues to be run by volunteers who are either individuals with MS or caregivers of those with MS. This site has a large variety of chat rooms and message boards, as well as other online resources.

[PositiveLivingWithMS Facebook community](#)

For patients who prefer to chat via Facebook, this site offers uplifting and encouraging information exchange among interested parties.

[WebMD MS Community \(exchanges.webmd.com/multiple-sclerosis-exchange\)](#)

This online community, run by the widely known “WebMD” service, is moderated by Neil S. Lava, MD, director of the MS clinic at Emory University in Atlanta. Dr. Lava will answer medical questions about MS submitted by readers.

[This is MS \(www.thisisms.com/forum\)](#)

This message-board-based site provides an “unbiased” community dedicated to MS. Topic categories include drug pipeline, treatment regimens, life with MS, and a section for people who are undiagnosed and wondering if they have MS.

[MS Blueprint \(www.MSblueprint.com\)](#)

This site, sponsored by Biogen Idec, provides a template or “blueprint” for personal goal setting using a positive mental attitude, coached by *Happiness Project* author Gretchen Rubin.

Legal/Financial Assistance

Managing the high costs associated with MS treatment is a challenge for virtually all patients and their families. The NMSS is an excellent place to start for information about local and national resources to help with financial needs. In addition to the NMSS, **Table 2** lists other charitable organizations that provide financial assistance to help cover the cost of medication, replace lost income, or provide home healthcare services. **Table 3** lists pharmaceutical manufacturer-sponsored programs that provide assistance for drug co-pays or funding assistance for uninsured patients. **Table 4** is a list of directories that offer quick access to links and contact information for many financial assistance programs.

Caregiver Support

Caregivers are increasingly recognized as people who need support and assistance for themselves in order to maintain the care they provide for others. A substantial proportion of people with MS (at

Table 2. Financial Assistance Organizations

Organization	About	Contact Information
Americans with Disabilities Act	Federal organization under US Department of Justice. Offers guidelines and support for legal rights/privileges under ADA.	www.ADA.gov 800-514-0301
Chronic Disease Fund (Also known as Good Days from CDF®)	This organization provides copay assistance for patients with chronic diseases who meet eligibility requirements. Many of the MS disease-modifying therapies are on the CDF formulary. (New enrollment for some disease states closes temporarily when funds are diminished.)	Email: info@cdfund.org 877-968-7233
Healthwell Foundation	A nonprofit organization that offers copay, coinsurance, and premium assistance.	Email: info@healthwellfoundation.org Web: www.healthwellfoundation.org 800-675-8416
National MS Society Financial Assistance Program	Provides assistance with respite services (short-term home care); medical equipment, accessibility modifications, transportation to medical appointments, critical short-term needs. NMSS also offers financial planning services for people with MS (including an online class) and scholarship programs.	Website: nationalmssociety.org 800-344-4867
Patient Advocate Foundation Co-Pay Relief Program	Direct copay and coinsurance for insured patients (including Medicare Part D) whose income is below 400% of Federal Poverty Guideline (household expenses are considered). Patients must be insured with coverage for medication for which the patient seeks assistance.	www.copays.org 866-512-3861
Patient Access Network Foundation	Copayment assistance from \$500 to \$15,000 per year depending on diagnosis. Patient must be insured with coverage for medication, and meet financial criteria.	www.PANfoundation.org 866-316-7263

least 30%) require supportive assistance at home.¹⁻³ About 80% of such care is provided by informal or unpaid caregivers—usually a family member such as the person’s spouse, parent, or adult son or daughter. Although caregiving for people with acute and chronic diseases usually falls to women, research shows that just over half of the caregivers for people with MS are males.⁴ Buchanan and colleagues found that caregiver burden in MS is increased with the number of hours per week devoted to care and higher degree of illness, as well as presence of bladder or bowel dysfunction. Lower cognitive abilities on the part of the caregiver also increased caregiver burden.⁴ The physical, emotional, and time-intensive nature of caregiving in MS often impairs the caregiver’s own physical and emotional health.⁵ Organizations that focus on caregiver support for a variety of conditions and MS specifically are shown in

Table 5. In addition to traditional in-person support groups, there are online community sections for caregivers. This list is not all-inclusive; many local hospitals and community centers hold support groups specifically for caregivers.

Pharmaceutical Company-Sponsored Nurse and Care Support Programs

Pharmaceutical organizations offer a variety of useful resources available for patients including peer-to-peer support and counseling with clinicians. Among the most valuable services are the ongoing nursing support programs offered in association with many of the MS disease-modifying treatments. These services can function as a source of significant assistance and comfort to the patient and supplement the care provided by the patient’s regular healthcare provider (**Table 6**). As Halper observed in the *Journal of Neuroscience Nursing*,

Table 3. Pharmaceutical Manufacturer-Sponsored Patient Assistance Programs

Drug Name/ Company	Aubagio/ Genzyme	Avonex/ Biogen	Betaseron/ Bayer	Copaxone/ Teva	Extavia/ Novartis
Program Name	MS One 2 One	MS ActiveSource	BetaPlus	SharedSolutions	Patient Services Program
Contact	855-676-6326 www.aubagio.com	800-456-2255 www.avonex.com	800-788-1467 www.betaseron.com	800-887-8100 www.copaxone.com	866-398-2842 www.extavia.com
Uninsured	PAP for U.S. residents (SS#) w household income <\$100,000.	PAP available; criteria not disclosed	PAP, 3-month supply for variable fee; undisclosed criteria.	Shared Solutions partners with AssistRx; eligible patients may receive free medication for 1 year.	Novartis Patient Assistance Foundation covers medication cost if qualified (< 5x Federal Poverty Level).
Private insurance	Copay assistance: 3 months no charge; \$35 thereafter.	Copay assistance program.	Copay assistance up to \$14,500/year. No household income restrictions. Bridge program for patients with insurance that does not cover the drug (up to 1 year no charge)	Copay Solutions program offered on sliding scale.	Copay assistance for eligible patients.
Impact of Federal coverage	Medicare Part A and B may apply for PAP. Medicare Part D participants not eligible for PAP.	Medicare enrollees may be ineligible for copay assistance or PAP	Medicare Part D can apply for PAP.	Medicare patients may be able to receive gap coverage.	Medicare gap coverage may be available.
Re-enrollment requirements	After 1 year	After 1 year	After 1 year	After 1 year	After 1 year

Table Continued

these services “employ nurses who offer valuable emotional, educational, and technical support to MS patients, ensuring that their needs are met throughout the course of therapy.”⁶

Professional Support and Development for Nurses

Professional burnout has been defined as “a state of physical and psychological exhaustion due to prolonged involvement in emotional conditions,” as well as “a phenomenon in which the cumulative effect of a stressful environment ultimately overcomes defense mechanisms of workers.”⁷ Job stress and burnout are common problems in the healthcare field, and have been reported to be

more prevalent among nurses than other members of the healthcare team.⁸ Because of the unique stressors in the MS care environment, nurses who work in this area of care delivery are at high risk for burnout. As Engel stated: “Time constraints, a health care system in flux, and political agendas, combined with the stress of overwork and high-pressure work environments ... can lead to compassion fatigue, mistakes, and burnout.”⁹

Being part of a larger organization and interacting with a group of peers can help MS nurses to feel less alone and better understood and supported. By becoming part of a nursing or MS professional organization, nurses can gain men-

Table 3. Continued

Drug Name/ Company	Gilenya/ Novartis	Plegridy/ Biogen	Rebif/ EMD Serono	Tecfidera/ Biogen	Tysabri/ Biogen
Program Name	Patient Services Program	MS Active Source	MS Lifelines	MS Active Source	MS Active Source
Contact	800-445-3692 www.gilenya.com	800-456-2255 www.plegridy.com	877-447-3243 www.rebif.com	800-456-2255 www.tecfidera.com	800-456-2255 www.tysabri.com
Uninsured	Novartis Patient Assistance Foundation covers medication cost if qualified (< 5x Federal Poverty Level).	PAP available; criteria not disclosed.	Free medication under Access Made Simple program.	PAP available; criteria not disclosed.	PAP available; criteria not disclosed.
Private insurance	Up to \$12,000/year under Pharmacy Copay Support program. Also, Go Program may assist with costs of testing to initiate treatment (up to \$600).	\$0 copay assistance program, no income requirements.	Copay assistance, no cost for 3 months and \$50/month thereafter (no reapplication required).	\$0 copay assistance program, no income requirements but there may be a cap if out of network.	Copay assistance program.
Impact of Federal coverage	Medicare/Medicaid patients may be ineligible for copay assistance. Also, residents of certain states are not covered.	Medicare/Medicaid recipients may be ineligible for copay assistance or PAP.	Medicare coverage gap assistance available if qualified.	Medicare/Medicaid recipients may be ineligible for copay assistance or PAP.	Medicare/Medicaid recipients may be ineligible for copay assistance or PAP.
Re-enrollment requirements	After 1 year	After 1 year	After 1 year for some programs	After 1 year	After 1 year

Patient assistance programs (PAPs) are also available for other medications used to treat MS symptoms and complications. A directory of these services is available on the MSAA website (www.mysaa.org) under About MS; Prescription Assistance Programs.

Table 4. Directory Services to Find Financial Assistance

Organization	About	Contact Information
NeedyMeds.org	Nonprofit organization provides a directory of pharmaceutical-company sponsored patient assistance programs (PAPs), coupons and rebates, as well as Drug Discount Cards. Subscriptions are available at no charge.	www.Needymeds.org Helpline: 800-503-6897
RxAssist	This site contains a current and comprehensive directory of pharmaceutical company-sponsored PAPs. Also provides Drug Discount Cards for medications, some with moderate enrollment fees.	www.Rxassist.org email: info@Rxassist.org
CareConnect USA	This website provides contact information for organizations to assist with bankruptcy advice, tax relief, child support and collection, mortgage and debt relief (including medical debt).	www.careconnectUSA.org info@careconnectusa.org 800-291-1068

Table 5. Caregiver Support Organizations

Organization	About	Contact Information
National Multiple Sclerosis Society (NMSS) Family Matters program	Website contains guides for families and caregivers. MS Navigators can answer family questions/concerns via phone or email.	800-344-4867 www.nationalmssociety.org/Resources-support/family-matters
NMSS MS Connection support services	Online community for people with MS also includes support groups specifically for families. Search under “Caregiver support” on website.	www.msconnection.org
Well Spouse Association	Support and information for individuals caring for a spouse with a chronic illness.	www.wellspouse.org 732-577-8899
National Alliance for Caregiving	National nonprofit advocacy service for caregivers. Online and print resources, searchable database of reviewed and rated caregiving organizations.	www.caregiving.org 301-718-8444
Caregiver Action Network (CAN)	Major family caregiver organization (formerly called the National Family Caregivers Association) offers peer networking, resources, support.	www.caregiveraction.org 202-772-5050

torship, patient care advice and ideas, continuing education opportunities, and friendship and camaraderie. Members are often encouraged to get involved at a higher level by participating on committees or taking on other leadership roles.

While taking on such responsibilities is clearly time-consuming, there may be a greater reward in the form of tighter connections with the group and wider networking opportunities with MS professionals around the country as well as abroad.

Table 6. Pharmaceutical Company-Sponsored Support Programs

Service	About	Contact Information
MS Active Source (Biogen) Avonex, Plegridy, Tecfidera, Tysabri	In-person injection training services; in home follow-up visits; phone counseling available 24/7.	800-456-2255 www.msactivesource.com
Beta Plus Program (Bayer) Betaseron	Phone counseling available 24/7; individual injection training, in-person nurse visits.	800-788-1467 www.betaseron.com
MS Lifelines (EMD Serono) Rebif	Call center available 27/7; nurse support available 7 days a week (till 10 pm ET weekdays and till 5 pm ET weekends). In-home injection training services.	877-447-3243 www.mslifelines.com
Shared Solutions (Teva) Copaxone	Call center M–F 8 am to 8 pm Central Time; after-hours nursing support available if needed. In-person injection training, refresher training, nurse support.	800-887-8100 www.copaxone.com
MS One to One (Genzyme) Aubagio	24/7 access to on-call nurse; regularly appointed nurse available during business hours; no in-person visits.	855-676-6326 www.msOnetoOne.com
Go Program (Novartis) (Extavia, Gilenya)	Call center available 8 am – 9 pm Eastern M–F. Nurse support for injection training and case management.	866-398-2842 (Extavia) www.extavia.com 800-445-3992 (Gilenya) www.gilenya.com

Career and emotional support is available for any MS nurse working in the field through organizations like those listed in **Table 7**. These groups provide resources like partnering and mentorship programs, continuing education opportunities, and research grants. Some programs require membership to the organization, while others can be utilized by anyone who reaches out.

Conclusion

This resources document is by no means an exhaustive list of all that is available in the MS community. At times, the volume of information and resources might seem overwhelming or confusing, for both patients and healthcare professionals alike. Nurses who care for people with MS can begin with some of these services, but may also develop a stable of local resources by checking into what is available in the community. Some MS nurses have found excellent and reliable support services within local womens' organizations, health departments, hospitals and rehabilitation facilities, universities, and other groups that foster

health and well being in the community. Within this wide and very active advocacy community for MS, there is really no reason for an MS healthcare professional or a person with MS to feel alone or isolated in their fight against this disease.

References

1. Aronson KJ, Cleghorn G, Goldenberg E. Assistance arrangements and use of services among persons with multiple sclerosis and their caregivers. *Disabil Rehabil.* Jul 1996;18(7):354-361.
2. Carton H, Loos R, Pacolet J, Versieck K, Vlietinck R. A quantitative study of unpaid caregiving in multiple sclerosis. *Mult Scler.* Aug 2000;6(4):274-279.
3. Minden SL, Frankel D, Hadden LS, Srinath KP, Perloff JN. Disability in elderly people with multiple sclerosis: An analysis of baseline data from the Sonya Slifka Longitudinal Multiple Sclerosis Study. *NeuroRehabilitation.* 2004;19(1):55-67.
4. Buchanan RJ, Radin D, Huang C. Caregiver burden among informal caregivers assisting people with multiple sclerosis. *Int J MS Care.* 2011;13:76-83.
5. Hillman L. Caregiving in multiple sclerosis. *Phys Med Rehabil Clin N Am.* Nov 2013;24(4):619-627.
6. Halper J. The evolving role of the nurse in the treatment of multiple sclerosis. *J Neurosci Nurs.* 2009;41(4):E1-E3.
7. Ahmadi O, Azizkhani R, Basravi M. Correlation between workplace and occupational burnout syndrome in nurses. *Adv Biomed Res.* 2014;3:44.
8. Khamisa N, Peltzer K, Oldenburg B. Burnout in relation to specific contributing factors and health outcomes among nurses: a systematic review. *Int J Environ Res Public Health.* Jun 2013;10(6):2214-2240.
9. Engel M. "I'm here": the words that started a movement. *Creat Nurs.* 2014;20(3):149-152.

Table 7. Professional Support Organizations

Organization	About	Contact Information
Consortium of Multiple Sclerosis Centers (CMSC)	Preeminent organization of MS healthcare providers, the CMSC serves as the umbrella organization for a number of professional groups (including IOMSN and IOMS-RT).	www.ms-care.org 201-487-1050
International Organization of MS Nurses (IOMSN)	International organization focused solely on the needs and goals of nurses who care for patients with MS. The IOMSN offers mentoring, educational programs, networking, MS specialty certification, and professional support.	www.iomsn.org 201-487-1050
American Association of Neuroscience Nurses (AANN)	Professional organization for advancement of neuroscience nursing as a specialty	www.aan.org 847-375-4733
American Association of Nurse Practitioners (AANP)	Professional organization for NPs; eNPnetwork online service allows NPs to connect with groups, colleagues, support, and research	www.enpnetwork.com
Multiple Sclerosis International Federation (MSIF)	A global network of 44 MS organizations representing 90 countries; with a goal to further global cooperation in MS research, funding, and care delivery.	www.msif.org +4-420-7260-1911
Association of Rehabilitation Nurses (ARN)	Certifying organization for rehab nurses, offering continuing education, networking opportunities	www.rehabnurse.org 800-229-7530

CP Counseling Points™

Making the Most of MS Support Organizations

- Multiple sclerosis (MS) support organizations and other advocacy groups provide education, expert and peer counseling, forums for sharing ideas, financial support, and many other valuable services for patients with MS, their families, and nurses working in the field of MS care.
- Patients with MS may be aware of MS advocacy organizations but may be hesitant to contact these organizations because of a variety of personal barriers, including mistaken impressions about how these services work.
- National MS support organizations include the National Multiple Sclerosis Society (NMSS), Multiple Sclerosis Association of America (MSAA), and Multiple Sclerosis Foundation (MSF), all of which offer a variety of programs for financial, educational, and peer support.
- Patients who cannot afford their medications or their copayments can contact the manufacturer's patient support program or other organizations such as the Chronic Disease Fund or the Patient Advocate Foundation.
- Financial support services are not just for disease-modifying agents: patients may receive help paying for cooling devices, adaptive equipment, and other services through the NMSS, MSAA, and others.
- The needs of caregivers in MS should not be overlooked. A number of programs have been established to address the support needs of caregivers, including the NMSS Family Matters program, Well Spouse Association, and Caregiver Action Network.
- Many people with MS have gained education and guidance from the nurse support programs offered through pharmaceutical manufacturers. These professionals can function as valuable adjuncts to the patient's regular healthcare team.
- MS nurses can gain tremendous levels of professional support by participating in organizations such as the International Organization of MS Nurses (IOMSN). Nurses who are active in these groups not only give back to the profession, but also gain support for their careers and daily patient care activities.

Counseling Points™

Making the Most of MS Support Organizations

Continuing Education Post-test

To receive contact hours, please read the program in its entirety, answer the following post-test questions, and complete the program evaluation. A certificate will be awarded for a score of 80% (8 correct) or better. A certificate will be mailed within 4 to 6 weeks. There is no charge for CNE credit.

By Mail: Delaware Media Group, 66 S. Maple Ave., Ridgewood, NJ 07450

By Fax: (201) 612-8282

Via the Web: Applicants can access this program at the International Organization of MS Nurses' website, www.IOMSN.org. Click on *Counseling Points* and follow the instructions to complete the online post-test and application forms.

PLEASE SELECT THE BEST ANSWER

1. **Barriers that may prevent a patient from contacting an MS support organization include:**
 - a. overwhelmed by diagnosis and information volume
 - b. impression that organizations are mainly for fundraising
 - c. concern about possible charges for services
 - d. all of the above
2. **A patient who is newly diagnosed with MS wants to find out how the National Multiple Sclerosis Society (NMSS) might connect him with other people who understand what he's going through. You refer this patient to:**
 - a. NMSS local chapter
 - b. MS Friends program
 - c. MS Navigator program
 - d. all of the above
3. **A patient in your practice wants help selecting an adaptive device for ambulation, but admits that she cannot afford very much. You encourage her to contact:**
 - a. Multiple Sclerosis Society of America (MSAA)
 - b. Multiple Sclerosis Foundation (MSF)
 - c. MSAA and MSF
 - d. the medical equipment company manufacturers directly
4. **NARCOMS is:**
 - a. a program that collects and assembles data from controlled clinical trials in MS
 - b. a registry service that collects data from individuals with MS
 - c. a program that collects and communicates risk information about MS medications
 - d. a European organization equivalent to the National MS Society
5. **Your patient has been spending a lot of time on MS blogs and chat rooms and comes to her appointment with questions about whether she is on the right disease-modifying agent for her. You respond that:**
 - a. she shouldn't listen to what she reads/hears on the Internet
 - b. blogs are sometimes the best way to get the latest information about MS
 - c. you can discuss what she read, but be aware that it may not be relevant to her particular situation
 - d. you can give the other drug a try to see if she has the same response as the people she chatted with
6. **A patient who is receiving Medicare Part D wants information about how to obtain assistance with drug copayments. You advise that:**
 - a. the manufacturer-sponsored programs won't provide additional help if the person receives Medicare Part D
 - b. most national assistance programs do not assist people who receive drug benefits through Medicare Part D
 - c. he contact Medicare Part D directly for more assistance
 - d. he contact the manufacturer support service for his MS DMT, as well as other patient advocacy programs
7. **Patient assistance programs supported by MS drug manufacturers provide:**
 - a. copayment assistance for patients who have insurance coverage
 - b. gap coverage for patients who have private or government-sponsored insurance
 - c. free medication for patients who qualify financially
 - d. all of the above
8. **True or False: Women make up the majority of the family caregivers of people with MS.**
 - a. True
 - b. False
9. **Job stress and burnout have been reported to be more prevalent in which group of healthcare professionals?**
 - a. nurses
 - b. surgeons and hospital-based physicians
 - c. private practice physicians
 - d. emergency medical technicians (EMTs)
10. **An organization dedicated to providing professional support for nurses who practice in the field of MS is:**
 - a. the Multiple Sclerosis Nurses Foundation
 - b. the Consortium of MS Nurses
 - c. the International Organization of MS Nurses
 - d. the National MS Nurse Society

Counseling Points™: Program Evaluation Form

Making the Most of MS Support Organizations

Using the scale provided (Strongly Agree = 5 and Strongly Disagree = 1) please complete the program evaluation so that we may continue to provide you with high-quality educational programming. Please fax this form to **(201)612-8282** or complete it online as instructed below.

5 = Strongly Agree 4 = Agree 3 = Neutral 2 = Disagree 1 = Strongly Disagree

At the end of this program, I was able to: *(Please circle the appropriate number on the scale.)*

- 1) Recognize the barriers that prevent people with MS from accessing support organizations 5 4 3 2 1
- 2) Identify key sources for medical information, connection with counselors and peer advisors, financial assistance, and other MS support services 5 4 3 2 1
- 3) Discuss sources for nurses to receive advocacy and peer interaction to support their professional development and personal well-being 5 4 3 2 1

To what extent was the content:

- 4) Well-organized and clearly presented 5 4 3 2 1
- 5) Current and relevant to your area of professional interest 5 4 3 2 1
- 6) Free of commercial bias 5 4 3 2 1
- 7) Clear in providing disclosure information..... 5 4 3 2 1

General Comments

- 8) As a result of this continuing education activity (check only one):
 - I will modify my practice. (If you checked this box, how do you plan to modify your practice?) _____
 - I will wait for more information before modifying my practice.
 - The program reinforces my current practice.
- 9) Please indicate any barriers you perceive in implementing these changes (check all that apply):
 - Cost Lack of opportunity (patients) Patient adherence issues Other (please specify) _____
 - Lack of administrative support Reimbursement/insurance Lack of professional guidelines _____
 - Lack of experience Lack of time to assess/counsel patients No barriers _____
- 10) Will you attempt to address these barriers in order to implement changes in your knowledge, skills, and/or patients' outcomes?
 - Yes. How? _____
 - Not applicable
 - No. Why not? _____

Suggestions for future topics/additional comments: _____

Follow-up

As part of our continuous quality-improvement effort, we conduct postactivity follow-up surveys to assess the impact of our educational interventions on professional practice. Please check one:

- Yes, I would be interested in participating in a follow-up survey.
- No, I would not be interested in participating in a follow-up survey.

There is no fee for this educational activity.

Post-test Answer Key	1	2	3	4	5	6	7	8	9	10

Request for Credit *(Please print clearly)*

Name _____ Degree _____
 Organization _____ Specialty _____
 Address _____
 City _____ State _____ ZIP _____
 Phone _____ Fax _____ E-mail _____
 Signature _____ Date _____

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