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Complimentary Continuing Education Credit for Nurses **Counseling Points**

Enhancing Patient Communication for the MS Nurse

Managing **Patient and Family Expectations in MS**

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Counseling Points™ Managing Patient and Family Expectations in MS 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 provide nurses with information and practice advice related to patient counseling on up-to-date issues in multiple sclerosis management and daily living.

Learning Objectives

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

- Discuss current findings affecting patients' expectations for therapeutic outcomes
- Describe how patient expectations influence adherence to MS therapies
- Develop counseling strategies to help patients manage expectations specific to their individual disease course and health status

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welcome

Dear Colleague,

Patients' and family members' expectations for treatment of multiple sclerosis (MS) are higher than ever before, and there are many good reasons for this. The disease-modifying agents available for MS can be highly effective at suppressing central nervous system (CNS) inflammation, especially in the early and active inflammatory stages of the disease. There is some hope that newer therapies for MS may be successful in slowing disease worsening in progressive forms of MS as well.

However, people whose lives are affected by MS usually do not view their condition as a percent change in T2 lesion volume, or stability in Expanded Disability Status Scale (EDSS) score over time. They want to feel better. They want to be able to keep their jobs and care for their families. Most want to know how the much-hyped advances in MS management apply to them specifically.

As nurses in MS research and clinical settings, our job is often to help patients strike a balance between maintaining hope and realistic expectations. Many patients in our care are living longer, more productive lives with limited need for mobility devices. But we must be aware of the significant burden of disease our patients face, with multiple drug regimens, side effects, and symptoms that may arise without warning and disrupt daily activities, as well as the need for diligent follow-up and ongoing medical monitoring.

To best help patients with MS and their families, we need to actively partner with them to learn about their expectations and goals for treatment, as our faculty discusses in this issue of *MS Counseling Points*.

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Managing Patient and Family Expectations in MS

nsuring that patients and families are well informed is one of the most important steps we can take as nurses. Patients who are well educated about their condition and who feel empowered to take charge of their own care are more likely to stay on a disease-modifying therapy (DMT), follow through with appointments and monitoring, and report concerning symptoms or side effects.^{1,2} Educating people about a serious and complex condition like multiple sclerosis (MS)—and keeping up with ongoing changes—is a job that doesn't always fit into the time allotted for patient visits. Some of the common challenges faced by nurses who treat MS include:

- Trying to remain positive and hopeful while providing realistic and accurate information;
- Presenting a realistic assessment of whether the patient is a candidate for a particular therapy, or whether he or she is benefitting from the current therapy;
- Giving education that is balanced and unbiased amidst a barrage of print materials, Internet information, and social media; and
- Finding time to answer questions that arise over the phone or email while attending to patient care, paperwork, and other responsibilities.

Establishing Open Lines of Communication With the Patient

When counseling patients and their families, it is essential to establish a line of communication that is non-judgmental and promotes trust. The patient should feel that he or she is not bothering the nurse by asking questions, even if the questions may seem to be uninformed or excessive. Patients who feel they are a "burden" to the practice will likely reach out for help only when a situation has become serious, rather than early on when more options are available for intervention. Having a strong, open relationship with the patient in place is a good way to anticipate and pre-empt potential problems. Patients are also more likely to take an active part in managing their disease if they feel empowered and trusted rather than "told what to do."

Patient Expectations at Diagnosis and in Early MS

Receiving a diagnosis of MS is frightening and confusing for anyone. This initial stage is a time when people seek support and a voice of reason amidst an avalanche of information—some of it relevant to them, some irrelevant or inaccurate. The time of diagnosis and soon afterward is a critical point for answering patients' questions honestly and accurately, since the steps taken at this point can set the stage for the clinical course over the long term.³⁻⁵ Because there is so much hopeful news in the field of MS right now, it's possible to lose sight of the need to balance this news with realistic expectations for the patient.

People who are newly diagnosed may anticipate that treatment with a DMT may erase their MS symptoms (rather than preventing further damage) or eliminate the possibility of further relapses. In reality, the patient usually continues to experience some symptoms of MS. In addition, the therapies used to treat MS may bring on side effects that require management and adjustment as well. The National Multiple Sclerosis Society (NMSS) recommends providing patient with a "contract," that encourages them to communicate their needs and states what is expected of them in terms of communication and follow-up with their healthcare providers. This patient "bill of rights and responsibilities" can be found on the NMSS website under the heading "Making the Most of Your Doctor Visits."⁶

What Therapy Should I Start With?

Presenting a patient who is newly diagnosed with MS with too many DMT choices is very likely to be confusing or overwhelming. A better way to initiate this discussion may be to start with a general overview and then narrow the options down to 2 or 3 that appear to be most appropriate for that individual. This allows the person and his or her family or support system to go home, absorb the information, and think about the options more concretely. Although a DMT should be started as soon after diagnosis as is realistically possible, rushing into an initial choice before the person is truly ready may be counterproductive in the long run. Patients who start treatment before they have considered their options carefully are much more likely to stop therapy or to have adherence difficulties early in the course of treatment.⁷

While information about the wide range of available treatment options is readily available on the Web, determining which of the available options is right for any individual is a much more daunting task that requires communication and personalized attention. Some of the questions to consider are outlined in **Table 1**.

Preauthorization of therapies

Even with an ideal give-and-take process there are typically some limitations on what therapies an individual patient can use, based on contraindications or safety issues. Furthermore, it may be necessary to determine initially which therapeutic choices are covered under the patient's health

Table 1. Considerations for TherapeuticSelection in MS

- How severe does the initial presentation appear to be? Some people with a particularly aggressive onset may respond better to an escalated course of therapy.
- What does the person's insurance coverage (if available) allow, and how does this influence the selection of therapy?
- Are there comorbidities, such as liver dysfunction or heart rhythm abnormalities, that could influence the selection of therapies?
- What previous treatments (including immunosuppression with steroids or chemotherapy) might influence selection of therapy?
- How important is future fertility to the patient (male or female)?
- Is the person likely to adhere to pre-therapy testing and ongoing monitoring required for treatment with some DMTs?
- How important is the route of administration (oral, injection, infusion)?
- Does the patient understand the overall risks and benefits of these choices, including potential side effects and adverse events balanced against the potential reduction in disease progression?
- Is the person a risk-taker who will assume the risks of potential serious adverse events, or someone who wants to take a more balanced approach between safety and efficacy?
- What support systems are available to help the person administer medications correctly and ensure adherence to DMT regimens and monitoring?

DMT=disease-modifying therapy.

insurance or other medical plan. This can help to streamline the initial approval process. If certain DMTs are ruled out because of coverage or contraindications, it is always helpful for the patient to be aware of these reasons up front.⁸ In addition, payers such as insurance companies often require an extensive precertification process, so it may take 3 or more months before a person can realistically start the prescribed therapy. Patients should be warned that many MS agents require preliminary laboratory and medical testing, ongoing monitoring, and/or participation in a risk evaluation and management (REMS) program.

Many payers require patients to start with a trial of a medication that falls within preferred formulary categories and to have a documented "failure" on one or more of these therapies before switching to one on a second tier. The nurse may need to document the presence of intolerable adverse effects or adverse laboratory findings to justify a switch to a second-tier medication.

The Challenges of Surfing

Studies have established that most patients with MS want to be part of shared decision-making process in therapeutic selection.⁹ People who feel they have a "say" in their therapeutic decisions are more likely to adhere to therapy.¹⁰⁻¹² Shared decision-making involves the exchange of information, in which the healthcare provider contributes experience and information, and the patient communicates details about values, risk tolerance, and goals for treatment.¹³

It is probably unrealistic to tell patients and families to "stay off the Internet." Many people who are newly diagnosed with MS are likely to surf the Web and arrive armed with information (some accurate, some not) and ideas about the disease and their own preferences for management. There is a huge range in the level of sophistication and complexity of information that patients and families desire and are able to absorb. Some prefer a simple overview, while others are ready for complex scientific explanations and examination of the data. Some basic "starter" kits and collections of web materials are recommended in **Table 2**.

With About Patients With Progressive MS?

With the excitement over new advances in relapsing-remitting MS (RRMS), progressive forms of MS are often viewed as being ignored or woefully overlooked.¹⁴ In reality, progressive MS is more misunderstood than ignored. We don't know why some patients develop the non-relapsing, fast-pro-

Table 2. Web Resources for Patients

For Patients Who Are Newly Diagnosed

- National Multiple Sclerosis Society (www.nationalMSsociety.org)
 Knowledge is Power educational series
 Register online at NMSS website, or call 800-FIGHTMS (800-344-4867)
- The Multiple Sclerosis Association of America (www.myMSAA.org) Information for Newly Diagnosed
- Multiple Sclerosis Foundation (www.MSfocus.org) Coping with MS – Newly Diagnosed
- Consortium of Multiple Sclerosis Centers (CMSC) CMSC Essential Elements program (www.MSpatientcare.com)

General MS Web Resources

- National Multiple Sclerosis Society (www.nationalMSsociety.org)
 Resources & Support page (http://www.nationalmssociety.org/Resources-Support)
- Multiple Sclerosis Foundation Get Educated (https://msfocus.org/Get-Educated/Overview)
- Multiple Sclerosis Association of America (MSAA) Living With MS (http://mymsaa.org)
- Blogs: Healthline provides a listing of MS patient blogs, brief descriptions, and links: The Best MS Blogs (http://www.healthline.com/ health/multiple-sclerosis/blog)
- Chatrooms and Facebook pages: Positive Living With MS (https://www.facebook.com/PositiveLivingWithMs) MS World (http://www.msworld.org/)

gressing presentation known as primary progressive MS (PPMS). In this form, neurodegeneration with early axonal loss and brain atrophy are the cardinal features, while in RRMS inflammation and demyelination are predominant.¹⁵

There is much buzz surrounding promising treatments for PPMS following recent research reports in 2016.^{17,18} What encouragement can we offer our patients with progressive MS? First, the potential benefits of rehabilitation, exercise, and other therapies should not be overlooked. Rehabilitation has been shown to improve function in many aspects of progressive MS.¹⁹ Second, many patients with PPMS and secondary progressive MS (SPMS) begin or remain on a DMT with the goal of suppressing disease activity. Those patients with progressive MS who respond best to treatment seem to have some underlying inflammatory activity.^{20,21} Because existing DMTs have not proved as effective in progressive forms of MS as in RRMS, the management of symptoms is paramount.¹⁹ MS clinicians should explore the range of therapeutic options for these patients and set appropriate expectations about symptomatic treatments.

People with progressive forms of MS as well as RRMS often respond to extended-release dalfampridine, which has been shown in clinical trials to improve walking speed in a subset of patients with MS who have ambulatory impairment.²² Dalfampridine is believed to work by restoring conduction by way of blocking certain potassium channels in demyelinated axons.²² Because this drug does not treat the underlying disease, the patient's disability may progress despite improvements in gait.²³

While patients may believe that progressive forms of MS have been neglected in research, more hope for people with progressive MS is on the horizon. Many current and ongoing research studies are exploring novel therapeutic options specifically for this population, including stem cell therapies, monoclonal antibodies, oral medications, and combination therapies.⁸

Expectations and the Risk-Benefit Analysis

People vary widely in terms of how much risk they are willing to accept based on personality traits, personal preferences, family priorities, and other issues. Some patients want the newest or "strongest" therapy regardless of risk, while others prefer approaches with a milder side effect profile. The nurse's role is to present the information and guide the patient in determining his or her own risk tolerance related to a particular treatment option. It's important to help patients remember that MS in itself is a dangerous and debilitating condition that progresses silently. Despite the presence of risks seen with newer MS therapies, the benefits of treatment with a DMT are believed to outweigh the risks in most cases.

Setting realistic expectations is particularly complicated in today's environment, with all of the "noise" about breakthrough treatments for MS. At times nurses may feel they are "bursting the patient's bubble" by bringing up the limitations of a particular treatment approach. It's important for people with MS to understand that results from large clinical trials can be applied to groups, but do not really predict the response of any one individual.²⁴ When viewing the latest data on MS therapies, patients should also recognize that relapse rate reductions from trials of newer treatments for MS may not be directly comparable with data from earlier treatments (such as older injectable drugs) because of differences in trial designs. Due to advances in MRI and early diagnosis the study populations in the early trials had more advanced disease, for the most part, than those in placebo-controlled trials of newer agents.²⁴ If a person has what the healthcare

provider believes to be an excessive number of relapses or an unstable pattern of lesions on MRI, a change in therapy may be recommended.^{25,26}

Talking with colleagues and sharing ideas may help MS nurses to understand that their challenges are not unique. While we want our patients to remain hopeful and optimistic, nurses must be careful to present information in a positive and yet realistic light.

Road Blocks Ahead: Discontinuing Therapy

Helping patients with MS set and understand their own expectations is not a one-time event, but an ongoing process that needs to be adapted with changes to the person's life and disease state. Over time, expectations must be refocused and new strategies tried. Common barriers that MS nurses encounter when helping patients to manage their MS are summarized in **Table 3**.

Table 3. Common Barriers to EffectiveTreatment of MS

- Fear of the negative aspects of treatment or risks of therapy;
- Desire to try alternative treatments, dietary and lifestyle changes;
- Lack of belief in the diagnosis (searching for alternative diagnoses);
- Feeling he or she is not sick enough to initiate a strong and possibly risky treatment;
- Concern about receiving injections or infusions;
- Unwillingness to undergo necessary monitoring or MRI testing;
- A decline in interest after a few months or a year on treatment (especially if the person is in remission and does not want to be "reminded" about the MS);
- Lack of insurance coverage/financial reimbursement for therapy; and
- Lack of money for insurance copays and non-covered treatment-related costs.

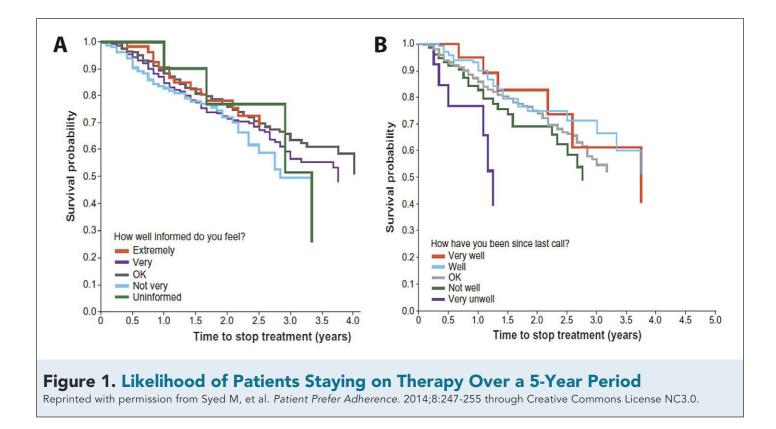
Data show that between 17% and 41% of patients with MS ultimately discontinue DMT and most do so in the first 1 to 2 years of treatment.^{7,27-30} Among the most common reasons for patients with MS to discontinue therapy is because they feel the treatment is not working for them.^{12,27,28,31-33} Patients typically start off well with a new therapy, and then begin to miss doses or discontinue treatment as more time progresses.^{2,34}

Unrealistic expectations about therapy can influence rates of discontinuation. In an older study, 57% of patients beginning an interferon regimen were shown to have unrealistic expectations about their reduction in relapse rates.³³ Even after participating in an educational program, 36% of patients continued to have unrealistic expectations of therapy, and most of those who discontinued treatment had unrealistic expectations.³³

A more recent study of treatment benefits on adherence to initial treatment with interferon beta-1b was conducted from a United Kingdom database of 2,390 patients with MS.³⁵ In all, 24% of new interferon patients (not previously treated) discontinued therapy during the study period. The investigators found that whether the patients believed they had received high-quality information, and how well they felt on treatment were the main factors associated with discontinuation, as shown in **Figure 1** (A and B).³⁵

A study comparing patient's reasons for nonadherence with physicians' perceptions showed that the top reasons for both parties were side effects in general, the sense that the disease was showing no signs of decline, injection-site reactions, and patients' being fed up with or emotionally drained from having to take the drug.³⁶

Adverse effects are high on the list given by both patients and physicians as reasons for stopping therapy. If a patient discontinues due to adverse effects, this tends to occur soon after treat-



ment initiation.³⁷ Often patients who discontinue therapy for any reason do so without seeking medical advice. An analysis of 396 people with MS who stopped their immunomodulatory treatment showed that 75% of patients made this decision on their own.³⁸ Perceived lack of efficacy was the reason for withdrawal for about half of those who discontinued **(Table 4)**.³⁸ Of those who withdrew, approximately half of patients said they wanted to restart therapy, but 200 patients did not want to restart a DMT.³⁸

The unpredictable nature of the MS disease course makes it particularly difficult for patients to recognize why they need to adhere to therapy. People with MS may not "feel" the effects of the disease they are treating, and they do not necessarily notice beneficial effects on their health and well-being when they take a DMT.³⁹ And, it is still not possible to predict how any individual's MS disease might progress if he or she were not receiving treatment.³²

Counseling Patients About Adherence to Therapy

Even the best medications do no good for the patient sitting in the medicine cabinet. It is often said that the best MS therapy is the one that the individual will use consistently. Problems with tolerability or worries about adverse effects are

Table 4. Reasons for Discontinuingand Staying Off Disease-modifyingTherapy38

Reasons for discontinuing Proven or putative lack of efficacy Side effects	(n=396) 51.4% 58%
Reasons for not restarting therapy	(n=200)
Lack of conviction that therapy influences	
the disease	29.4%
Fear of injection	18.7%
Fear of bringing disease to mind regularly	17.9%
Doubts about the diagnosis	11.2%

Data adapted from Bischoff C, et al. *J Neurol.* 2012;259(11): 2347-2353.

another chief reason for patients to skip doses or discontinue therapy.⁴⁰ The MS nurse's role is often that of monitoring adherence to therapy. Nurses need to ask patients how often they are taking their medications-but the manner in which this subject is broached might make the difference between whether a person is truthful or just says what they think the nurse "wants to hear."38 An understanding and nonjudgmental approach often works best. For example, the nurse might acknowledge that it's normal for people to exaggerate their extent of adherence in order to avoid confrontation or the appearance of being uncooperative. If the patient admits to exaggerating adherence rates, this can be a turning point for a more honest dialogue.

In addition, some patients have "creative" ways of altering their dosage regimens, which they may believe still constitutes appropriate adherence. Once the conversation has been started, the nurse should attempt to identify any barriers that can be overcome, potentially with an adjustment in medication delivery or therapeutic approach. These barriers and solutions are summarized in **Table 5**.¹

A basic tenet of adherence is that a person's perceived need for a medication must outweigh the downsides, such as inconvenience, cost, and possible adverse effects.⁴⁸ This is truer in MS now than ever before, with a greater variety of therapies available and a greater need to balance the risks and benefits of these therapies. MS nurses must be aware of the importance of adherence in making therapeutic decisions, considering safety risks, and evaluating the potential efficacy of DMTs, and gain the skills to effectively counsel patients with MS about these issues.

A number of reminder systems are available to help increase patient adherence to medication therapies. Studies in other health conditions such as diabetes, smoking cessation, and hypertension have shown that cell-phone text messaging

Table 5. What Factors AffectAdherence?

Factors that positively influence adherence

- Patient is better informed about the disease and the purpose of treatment⁴¹
- Patient receives care at a specialized MS care center²⁸
- Efforts are made to increase the convenience of dosing (e.g., autoinjector use)⁴²
- Patient receives sponsor support and self-injection training⁴³

Factors that negatively influence adherence

- Stable disease status (patients do not believe their condition requires treatment)⁴⁴
- Depression^{12,45}
- Alcohol use⁴⁶
- Secondary-progressive MS²⁸
- Adverse effects and injection-site reactions⁴²

Barriers to adherence^{1,47}

- Unrealistic expectations about the impact of therapy on MS
- Lack of belief in the benefits of therapy
- Fear of or intolerance to injection (with injectable agents)
- Adverse effects/tolerability problems
- Complacency, "treatment fatigue"
- Cognitive decline or declining motor skills
- Change in family or financial circumstances

systems that prompt patients with reminders are effective at increasing adherence.⁴⁹⁻⁵¹ Some MSspecific Web-based and smart-phone technologies are available, some of which include medication reminders. These include TrackMyShots and the Multiple Sclerosis Association of America's mobile phone app, "Multiple Sclerosis Self-Care Manager." Even a simple electronic alert programmed into a smartphone may be helpful to signal the time for taking a medication. However, one must bear in mind that these "novelty factor" of these technologies may wear off over time for some patients.

Finding Time to Communicate

The time slot designated for the patient's appointment is rarely realistic for answering all of a person's questions about MS. How do MS nurses find the time to educate, advocate, comfort, and reassure?

Email or no email? Some nurses feel strongly

that email is not an appropriate method for answering patient questions-and others say they couldn't live without it. The decision about whether to answer treatmentrelated questions via email may come down to an institutional directive and what the administration will allow. Those who do use email should set appropriate expectations: Some patients may want to fire off a question and expect an exchange every few minutes, but if a nurse is busy seeing other patients he or she

is unlikely to be sitting in front of the computer. Clinicians who use email may want to consider setting a time frame for answering emails (e.g., "Email will be answered between 4:00 and 4:30 daily—if the matter is more urgent please contact the office via phone.")

The phone. Friend or foe? Some MS nurses feel that a question about treatment has subtle nuances that only a phone or face-to-face conversation can pick up. Again, it can be helpful for people—particularly those newly diagnosed with MS—to be aware of the best times to call with questions and what options are available for any after-hours concerns. Support services provided by the manufacturers of MS therapies can be especially helpful in providing information about administration, side

effects, and daily medication management. Many of these services have 24-hour helplines available.

Electronic medical record systems. Some institutions are turning to electronic systems to provide a limited amount of medical information (such as lab results) to patients. The systems may provide a link to allow emailing the organization, and some

Rule of 3's for Switching MS Medications

 Is the administration form something the patient is willing and able to take? (e.g. injection, oral, infusion)
 Is the patient's current therapy working to control the disease?
 Is the patient tolerating the adverse effects associated with the medication? patients may use this as an avenue for inquiries related to their care. Organizations using these systems should be aware of the level of patient communication that is occurring and determine up front on a system to best handle such inquiries.

Conclusion

The MS nurse's role often involves helping the patient set expectations about therapy. That does not mean promising that they will no longer have relapses or that the disease will not eventually worsen.

However, we can provide insight from our own experiences and from the overall progress made in this disease. Many clinicians can remember how different patient outcomes were when DMTs were not available for MS. With the presently available therapies, we do not yet know the "end game"-that is, at what point the therapy may no longer be effective for treating relapsing or progressive forms of disease.⁵² Many clinicians elect to keep patients on DMT until the person's condition has progressed to a point where they are no longer having relapses and do not appear to derive benefit from the treatment. With no cure available at present, the "end" of DMT is not something to look forward to, but something to be delayed to the greatest extent possible.

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Counseling Points[™]

Managing Patient and Family Expectations in MS

- •Discussing patient and family expectations is an essential part of shared decisionmaking and patient communication in MS care.
- Patients may view the goals of therapy differently than clinicians, who often think in terms of MRI results or in-office tests. People with MS tend to describe goals relating to feeling better, keeping their jobs, and caring for their families.
- Most patients want to know how the current advances in MS management apply to them. The MS nurse needs to remain positive and hopeful while providing realistic and accurate information about available therapies and clinical trial findings.
- Although a disease-modifying treatment (DMT) should be started soon after diagnosis, it is best to avoid rushing into an initial choice before the person is ready. The patient should be allowed to absorb the information with his or her family or support system and think about the options more concretely.
- With the excitement over advances in RRMS, progressive MS may seem overlooked. Many ongoing research studies are exploring novel therapeutic options specifically for this population. Symptomatic and rehabilitation therapies should be pursued for these patients.
- Unrealistic expectations about therapy are a major cause of medication discontinuation and nonadherence. Nurses should explore reasons for nonadherence using a nonjudgmental, collaborative approach.
- Nurses who treat patients with MS need updated knowledge of MS therapies and issues relating to balance of safety and efficacy in order to effectively counsel patients and manage patient/family expectations.

Counseling Points[™]

Managing Patient and Family Expectations in MS

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% (5 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 Educational Materials > Publications > *Counseling Points* and follow the instructions to complete the online post-test and application forms.

PLEASE SELECT THE BEST ANSWER

- 1. Kate, who is newly diagnosed with relapsing-remitting multiple sclerosis (RRMS), is eager to start on a disease-modifying therapy (DMT) because she wants the numbness and weakness in her lower limbs to go away. You advise:
 - a. Most people with MS feel a lot better after going on a DMT
 - b. The newer DMTs can produce a significant change in lower extremity weakness
 - c. We hope the DMT will slow or stabilize progression of your MS and prevent relapses, but it will probably not have an effect on the existing symptoms
 - d. We don't have any medications that will alleviate these symptoms.
- 2. When discussing DMT options for Kate, the best initial approach is:
 - a. Give her a printed table with all of the current DMT options, their mechanisms of action, and methods of administration
 - b. Provide her with a brief overview of 3 agents that seem to best fit her clinical and lifestyle profile
 - c. Select the optimal DMT for her based on your experience in similar patients
 - d. Discuss clinical trials of newer therapies
- 3. Kate elects to begin on an oral therapy, and she completes all pre-dose monitoring requirements. Can she start therapy immediately?
 - a. Yes, the sooner the better.
 - b. Maybe. There may be a delay related to preauthorization of the treatment by the payer (e.g., health insurance)
 - c. No. Most payers require that patients start with an injectable therapy and switch to oral only if they fail on the injectable.
 - d. Maybe. She may want to delay the start of treatment to see if she has another relapse, in case the disease course turns out to be relatively benign.

4. Investigative research shows that disease-modifying treatment for progressive MS (PMS):

- a. has not been proven to be effective
- b. is slightly less effective in PMS than it is in RRMS
- c. may be effective in patients with PMS who have underlying inflammatory activity
- d. is effective in secondary-progressive but not primary progressive MS

- 5. Data have shown that approximately ____% of patients with MS discontinue their DMT, most within the first 1 to 2 years.
 - a. 10% to 15%
 - b. 20% to 40%
 - c. 50%
 - d. 60% to 80%
- 6. Which of the following reasons are associated with discontinuation of MS therapy?
 - a. patients believe the drug is not working for them
 - b. patients dislike adverse effects of drug
 - c. patients feel they are not well informed about the drug or disease
 - d. all of the above
- 7. At a clinic follow-up visit, MS patient John says he is taking his injectable DMT exactly as directed. You suspect this may not be accurate, given his past adherence patterns. You respond:
 - a. Why don't you tell me the truth? How often are you really taking it?
 - b. Your blood test results suggest this information is not accurate. Let's try again.
 - c. Since you say you're taking it every day, I believe you.
 - d. There are a lot of reasons why people miss doses of this drug. I'd like to find out whether you have experienced any of these issues.
- 8. Your patient Anna has read that some of the newer therapies can "completely wipe out" MS. She wants to switch to a treatment that will do that for her. To manage her expectations, you:
 - a. have a discussion with her about what she has read and how she would define "wipes out"
 - b. tell her that no therapy will wipe out her MS so she should stay on her current agent
 - c. refer her to a neurologist who can put her on some experimental therapies
 - d. try switching her to a "stronger" immunomodulatory agent

Counseling Points[™]: Program Evaluation Form Managing Patient and Family Expectations in MS

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	
	erapeutic outcomes5 4 3 2 1
	S therapies
	ations specific to their individual disease course and health status 5 4 3 2 1
To what extent was the content:	5.4.0.0.4
	5 4 3 2 1
General Comments	
 8) As a result of this continuing education activity (check on □ I will modify my practice. (If you checked this box, h 	ly one): ow do you plan to modify your practice?)
I will wait for more information before modifying my	⁷ practice.
□ The program reinforces my current practice.	•
9) Please indicate any barriers you perceive in implementing	
□ Cost □ Lack of opportunity (patients)	· · · · · ·
11	Lack of professional guidelines
□ Lack of experience □ Lack of time to assess/counsel	-
TYes. How?	plement changes in your knowledge, skills, and/or patients' outcomes?
□ Not applicable	
□ No. Why not?	
Suggestions for future topics/additional comments:	
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As part of our continuous quality-improvement effort, we contional interventions on professional practice. Please check on Yes, I would be interested in participating in a follow- No, I would not be interested in participating in a follow-	up survey.
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