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Winter 2010

Volume 6, Number 4

## Assessing and Addressing Disability in MS



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

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# Counseling Points™

## Assessing and Addressing Disability in MS

# Continuing Education Information

### Target Audience

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

### Purpose

To provide MS nurses with current strategies for assessing disability in the patient with MS and treatment solutions emphasizing the patient's individual abilities.

### Learning Objectives

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

- Define disability in general and in the context of multiple sclerosis (MS)
- Describe the pros and cons of standard disability measures in MS
- Discuss the benefits of physical therapy and exercise on disability in MS
- Discuss the effects of disease-modifying therapies (DMTs) on disability in MS

### Continuing Education Credit

This continuing nursing education activity is cosponsored by Delaware Media Group and NP Alternatives.

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

Laurie Scudder, DNP, NP, served as nurse planner for this activity. She has no significant financial relationships to declare.

This activity has been approved for 1.0 contact hours (0.0 contact hours are in the area of pharmacology). Code: MSCP010410

Approximate time to complete this activity is 60 minutes.

This program expires December 31, 2012.

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# welcome

Dear Colleague,

The availability of new medications and therapies for multiple sclerosis (MS) has the potential to attract new groups of patients, including those who may have declined to use or previously given up on disease-modifying therapies (DMTs). Whether or not these patients are candidates for newer therapies, much can be gained by an updated evaluation of their condition.

Our emphasis has shifted toward maximizing what the person *can do*, rather than dwelling on what he or she cannot do. Measuring an individual's abilities and disease status in MS goes well beyond the categories of the Expanded Disability Status Scale (EDSS). Though commonly used in clinical trials, this scoring system has significant drawbacks in the "real world," as we will discuss in this issue.

There are many other tools for screening and evaluation that offer useful information and can be performed in the office setting. Some situations will warrant referral to a professional with specialized knowledge, such as a physical therapist or neuropsychologist, especially when a disability claim is being presented for insurance or Social Security Disability Insurance (SSDI) purposes.

Although we strive to be positive and upbeat for our patients, it's important that MS nurses be truthful and thorough in documenting the effects of MS in the medical record. These points are stressed in this issue as we evaluate current strategies for assessing and addressing disability in MS.



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# Assessing and Addressing Disability in MS

**D**isability, according to the World Health Organization (WHO), is an umbrella term encompassing *impairments* (problems in body function or structure), *activity limitations* (difficulty executing a task or action), and *participation restrictions* (problems experienced in life situations).<sup>1</sup> The WHO definition refers to disability as “a complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she lives.”<sup>1</sup>

It can be useful to view these definitions in a broader context: “Impairment” is an abnormality of structure or function (e.g., muscle weakness); “disability” is a consequence of the impairment (e.g., limited walking ability); and “handicap” is the social consequence of the impairment (e.g., loss of a job).

One of the difficulties in defining and measuring disability in multiple sclerosis (MS) is that this experience can be highly subjective and individual.<sup>2</sup> Disability means different things to different people. To some, numbness of the foot may be seen as very disabling, while others may view it as an inconvenience. Many patients tolerate conditions that would seem to be extremely limiting, yet don’t regard themselves as “disabled.” Fear of impending disability can also have an impact on how a particular MS symptom is regarded. For example, new onset of paresthesia may not cause significant change in function for a particular patient, but to her it may be terrifying because it represents future disability. Likewise, in the course of MS, a person’s perspective of what he or she regards as disabling changes over time.

## Assessing the Patient

An important role of the MS nurse is to examine the patient’s history to determine what measures of disability have been performed in the past, what may have changed since the previous evaluations, and what assessments need to be repeated.

Comprehensive assessment in MS usually incorporates components of multiple body systems, including

the sensory, neuromuscular, cognitive/affective, and bladder/bowel systems. Planning a comprehensive evaluation of a person with MS, particularly someone who is not regularly followed in the practice, should include careful consideration of the circumstances and the patient’s current mental and physical state. Because some people with MS tire easily and may be particularly susceptible to fatigue as the day progresses, planning an exhaustive battery of neurologic, physical, and cognitive tests for the same day (possibly after a long wait or travel time) is often counterproductive. However, some professionals prefer early afternoon as a time for a reasonable range of tests rather than selecting only the patient’s “best” time of day. This may give a more accurate view of the challenges the patient faces in combating fatigue and its effects on endurance, coordination, and range of motion.

In addition to neurologic testing, a standard physical evaluation of a person with MS includes some or all of the components listed in **Table 1**.

Many of these tools provide an objective way to measure and document physical changes, while others rely on the subjective observation of the evalu-

**Table 1. Physical Assessments Used in MS**

Strength	Manual muscle testing, hand-held or computer-assisted myometry, dynamometry
Range of motion	Goniometer used to measure angle of a joint through its range
Spasticity	Modified Ashworth Scale, Tardieu Scale
Balance	Berg Balance Scale, Dynamic Gait Index
Ambulation	Timed up and go (TUG) test (and visual inspection for deviations), 25-foot walk test,* 6-minute walk test
Pain	Palpation for areas of tenderness, 5 components of pain (location, character, intensity, frequency, duration)
Coordination	Finger to nose, forearm pronation and supination, 9-hole peg test*

\*Components of the Multiple Sclerosis Functional Composite.  
Source: Matthew Sutliff, PT

ator. The patient interview is a critical part of this process, as it allows any functional changes to be put into the context of the patient’s life circumstances. It may involve questions such as, “How is your function today versus 6 months ago?” or “What are the symptoms that most interfere with your life?”

A number of tools and instruments have been developed to measure and quantify disability in MS. Some are mainly intended for research; others are quite useful in clinical practice. The newer, disease-specific instruments attempt to evaluate disability across the spectrum of physical, cognitive, and psychosocial symptoms that are part of MS.

## Tools for Measuring Disability and Impact of MS

### Expanded Disability Status Scale (EDSS)

When discussing disability in MS, the EDSS immediately comes to mind. This scale breaks down disability among eight functional systems (FS) and allows the rater to assign a subscore in each area (**Table 2**).<sup>3</sup> EDSS scores ranging from 1.0 to 4.5 focus on the ambulatory stages of MS, while scores of 5.0 to 9.5 are defined mainly by ambulatory limitations.<sup>3</sup>

**Table 2. Functional Systems in the EDSS<sup>3</sup>**

- |              |                     |
|--------------|---------------------|
| • Pyramidal  | • Bowel and bladder |
| • Cerebellar | • Visual            |
| • Brainstem  | • Cerebral          |
| • Sensory    | • Other             |

EDSS=Expanded Disability Status Scale.

From clinical trial reports in the MS literature, it would seem that the EDSS is the gold standard for evaluating disability and disability progression. In the “real world” of clinical practice, however, this is far from the case. Developed nearly 30 years ago, the EDSS has a number of detractors that limit its usefulness in clinical practice (**Table 3**).<sup>4,5</sup>

When the EDSS is used in a clinical setting, it is important to remember that an individual patient’s outcomes often vary from one evaluation to the next based on factors such as time of day, relapse status, and

**Table 3. Clinical Limitations of EDSS**

- Heavy focus on ambulation
- Less sensitivity for cognitive functioning
- Time-consuming to perform and difficult to score
- Result may depend on skill of evaluator
- Progression is typically non-linear; patients may “jump” back and forth on the scale
- Certain incremental changes can be highly significant for patient functionality (e.g., the transition from EDSS 5 to 7, which signifies loss of ambulation), while similar increments (e.g., 1 to 3) are less monumental

EDSS=Expanded Disability Status Scale.

inter-rater variability. *Sustained* change in functionality is necessary before a score should be adjusted on the EDSS. By definition, confirmed disability progression is “EDSS worsening that persists on two consecutive visits, separated by [3] or [6] months.”<sup>3</sup> However, some studies have shown that EDSS worsening may revert back to baseline even after a 3- to 6-month period.<sup>6</sup>

### MS Functional Composite (MSFC)

The MSFC is a combined assessment of cognitive and upper limb function and gait disorders.<sup>7-9</sup> This three-part instrument was developed in the mid-1990s by a task force convened by the National Multiple Sclerosis Society (NMSS). Like the EDSS, it is used extensively in clinical studies to measure changes in response to therapy.<sup>9</sup> The NMSS offers a handbook (available online) guiding the evaluator through all aspects of conducting the MSFC, which takes approximately 20 to 30 minutes to perform.<sup>10</sup> Each component of the MSFC can be scored individually, or a composite can be developed. The three components of the MSFC are:

- Timed 25-foot walk test, a gait analysis;
- 9-hole peg test, a measure of arm and hand function; and
- Paced Auditory Serial Addition Test (PASAT), a cognitive measure focusing on auditory information processing speed and flexibility.<sup>10</sup>

Advantages of the MSFC over the EDSS include the ability to evaluate patients at various levels of disability—for example, to evaluate ambulation at lower

EDSS disability levels, arm function at higher disability levels, and cognitive function at all levels.<sup>10</sup>

## International Classification of Functioning, Disability and Health (ICF)

ICF is a non-disease-specific classification system from WHO that views disability as “a universal human experience.”<sup>11</sup> A key component of the ICF is the Disability Assessment Schedule II (DAS II), which assesses the effect of disability on six lifestyle “domains” within the past 30 days. Questionnaires range from 12 questions to 36 questions, with either self-administered or guided interviews. An example of the 12-question self-administered DAS II is shown in **Figure 1**.<sup>11</sup>

The ICF is an extremely broad and comprehensive scale, but it has been validated in MS.<sup>12,13</sup> Data presented at the 2010 Consortium of Multiple Sclerosis Centers’ meeting describe a 2-year prospective study using physical functioning measures in the ICF to evaluate early decline among 120 ambulatory Finnish patients with MS.<sup>13</sup> The investigators found that lower initial scores on the Box and Block test and Berg Balance Scale and poorer results on the 10-meter walk and 6-minute walk tests predicted greater ICF change over the 2-year follow-up. They concluded that minor decrements in functioning could precede and possibly predict the onset of detectable dependence in performance.<sup>13</sup>

## 36-item Short Form Health Survey Questionnaire (SF-36)

One of the most widely used generic measures of health status is the SF-36, a pared down version of the Medical Outcomes Survey. The SF-36 is divided according to physical health and mental health summaries.<sup>14</sup>

Studies have shown that the SF-36 can offer valid information in the setting of MS. A recent literature review revealed seven studies using the SF-36 to measure disability and perceived health status in MS.<sup>15</sup> Not surprisingly, longer disease duration and more severe disease constituted lower scores in perceived health status. The lowest SF-36 scores were observed among patients with more disability, more depression, and older age.<sup>15</sup> In addition, an adaptation of this survey

has been developed specifically for MS (the 54-item Multiple Sclerosis Quality of Life Scale or MSQOL-54), which uses five unchanged SF-36 scales, three altered SF-36 scales, and five new scales incorporating 15 additional items.<sup>16</sup>

## Six-Step Spot Test

This test is a quantitative method for evaluating lower-limb function over time.<sup>17</sup> It is valuable for use in MS because patient performance on the test reflects the complexity of sensory-motor function, including lower limb strength, spasticity, coordination, and balance. The test requires the subject to walk on alternating sides of a field and push a wooden cylinder block outside of a circle using either the medial or lateral sides of each foot. The test is repeated using both the dominant and non-dominant leg to move the blocks. When conducting the test, it’s a good idea to demonstrate the procedure for the participant in addition to offering a verbal explanation.

The authors of a study validating this test in people with MS suggest that it is a more sensitive instrument for evaluating gait than the lower-limb portion of the MSFC, and therefore might be added to the MFSC.<sup>17</sup> Other advantages noted are low cost, reproducibility, and ease of interpretation.

## Multiple Sclerosis Impact Scale (MSIS-29)

This instrument was developed to provide a disease-specific measure of patients’ perspectives on the physical and psychological impact of MS.<sup>18</sup> The patient questionnaire consists of 29 items on physical and psychological concepts, inquiring about whether MS affects their ability to do physically demanding tasks, grip things tightly, maintain balance, move without difficulty or limitation, as well as how it affects them psychologically. In a study measuring correlation of the MSIS-29 with EDSS scores in MS over a 6-month period, the MSIS-29 was significantly responsive to change in terms of both self-reported change and EDSS worsening.<sup>19</sup> MSIS-29 physical scores remained stable when the EDSS was also stable, but increased significantly in proportion to EDSS deterioration.

## Modified Fatigue Impact Scale (MFIS)

In assessing disability in MS, the importance of fatigue cannot be overlooked. Fatigue is the most common symptom of MS and a significant contributor to disability. More than two-thirds of people who have MS experience significant fatigue, and almost half describe fatigue as *the most disabling feature* of the disease.<sup>20-23</sup>

A simple and effective way to determine the effects of fatigue in MS is through the MFIS, a modified form of the Fatigue Impact Scale.<sup>24</sup> The MFIS assesses the impact of fatigue according to physical, cognitive, and psychosocial functioning. It consists of a structured questionnaire that patients can generally complete on their own. The full version has 21 items and the short version has five items. The full version is estimated to take only 5 to 10 minutes to complete. Individual subscale scores for physical, cognitive, and psychosocial functioning can be generated.<sup>25</sup>

Scoring of the short version, or MFIS-5, involves adding the sum of the points for each question (score 0 if almost never; 1 if rarely; 2 if sometimes; 3 if often; and 4 if always). The patient answers how fatigue has affected his or her life during the past 4 weeks in regard to five items:

- I have been less alert.
- I have been limited in my ability to do things away from home.
- I have had trouble maintaining physical effort for long periods.
- I have been less able to complete tasks that require physical effort.
- I have had trouble concentrating.

## Practical Applications of Disability Information

Although the MFIS-5 and the full 21-question MFIS are practical and easy to conduct, in reality these and many other measures of disability are not routinely performed in MS clinics or neurology practices. Nurses are frequently required to complete insurance disability forms, and yet may find themselves with little practical information to go on. Standardized “Func-

tional Capacity Assessments” used on insurance forms are often not well-suited for the impairments seen in MS, especially because of the degree of variability that can occur day to day. In this way, fatigue can be a particularly frustrating aspect of MS disability. A person may *appear* normal, with little or no outward impairments, yet struggle to maintain performance throughout an 8-hour workday. Stress and anxiety about poor work performance can serve to exacerbate the fatigue and other impairments.


To aid in preparation for future needs, the nurse should attempt to capture on the medical record how the patient is doing in his or her own words, using practical descriptions that relate to the person’s life. This may include questions such as, “How long can you stand? Sit comfortably? Manipulate small items? Dial the phone?” Questions about caring for children may be applicable to a parent with MS, while an older person would have different circumstances to address.

## Benefits of Physical Therapy in MS

Many of the tests of disability described in this issue are part of the standard procedures performed by physical therapists (PTs) and other specialized professionals such as occupational therapists. Thus, referral to a qualified PT for a baseline measure of disability can be valuable for the ongoing management and documentation of the patient’s course.

PTs can also perform a comprehensive disability evaluation. Such an evaluation can be particularly valuable when documenting the person’s need for disability benefits or to suggest reasonable accommodations that may allow a person to continue working (for example, assistive devices, handicapped parking placards, or workplace modifications). However, a PT who handles mainly sports-related injuries or cardiopulmonary rehabilitation may not have the expertise necessary to be sensitive to the issues that are unique to MS. For this reason, it is important for the patient (or the MS nurse) to investigate the experience and qualifications of the specialists who are performing these services and consult with a PT who specializes in MS.

**Figure 1. 12-question self-administered Disability Assessment Schedule II (DAS II).**



**World Health Organization**  
**Disability Assessment Schedule II**

**Phase 2 Field Trials – Health Services Research**  
**12-Item Self-Administered Version**

For Office Use Only:

Center#    Subject # - Time #

\_\_\_\_/\_\_\_\_/\_\_\_\_  
Day / Month / Year

Pop:                      Dwelling:

Gen                       Independent

Drg                       Assisted

Alc                       Hospitalized

Mnh

Phys

Other

H1	How do you rate your <u>overall health in the past 30 days</u> ?	Very good	Good	Moderate	Bad	Very Bad
----	------------------------------------------------------------------	-----------	------	----------	-----	----------

This questionnaire asks about difficulties due to health conditions. Health conditions include diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs.

Think back over the last 30 days and answer these questions thinking about how much difficulty you had doing the following activities. For each question, please circle only one response.

In the last <u>30 days</u> , how much <u>difficulty</u> did you have in:						
S1	Standing for <u>long periods</u> such as <u>30 minutes</u> ?	None	Mild	Moderate	Severe	Extreme /Cannot Do
S2	Taking care of your <u>household responsibilities</u> ?	None	Mild	Moderate	Severe	Extreme /Cannot Do
S3	<u>Learning a new task</u> , for example, learning how to get to a new place?	None	Mild	Moderate	Severe	Extreme /Cannot Do
S4	How much of a problem did you have <u>joining in community activities</u> (for example, festivities, religious or other activities) in the same way as anyone else can?	None	Mild	Moderate	Severe	Extreme /Cannot Do
S5	How much have <u>you</u> been <u>emotionally affected</u> by your health problems?	None	Mild	Moderate	Severe	Extreme /Cannot Do

*Please continue to the next page ...*

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In the last <u>30 days</u> , how much <u>difficulty</u> did you have in:						
S6	<u>Concentrating</u> on doing something for <u>ten minutes</u> ?	None	Mild	Moderate	Severe	Extreme /Cannot Do
S7	<u>Walking a long distance</u> such as a <u>kilometre</u> [or equivalent]?	None	Mild	Moderate	Severe	Extreme /Cannot Do
S8	<u>Washing your whole body</u> ?	None	Mild	Moderate	Severe	Extreme /Cannot Do
S9	Getting <u>dressed</u> ?	None	Mild	Moderate	Severe	Extreme /Cannot Do
S10	<u>Dealing with people you do not know</u> ?	None	Mild	Moderate	Severe	Extreme /Cannot Do
S11	<u>Maintaining a friendship</u> ?	None	Mild	Moderate	Severe	Extreme /Cannot Do
S12	Your day to day <u>work</u> ?	None	Mild	Moderate	Severe	Extreme /Cannot Do

H2	Overall, how much did these difficulties <u>interfere</u> with your life?	Not at all	Mildly	Moderately	Severely	Extremely
H3	Overall, in the past 30 days, <u>how many days</u> were these difficulties present?	RECORD NUMBER OF DAYS ___/___				
H4	In the past 30 days, for how many days were you <u>totally unable</u> to carry out your usual activities or work because of any health condition?	RECORD NUMBER OF DAYS ___/___				
H5	In the past 30 days, not counting the days that you were totally unable, for how many days did you <u>cut back</u> or <u>reduce</u> your usual activities or work because of any health condition?	RECORD NUMBER OF DAYS ___/___				

*This completes the questionnaire. Thank you.*

In general, the goal of a PT program is to improve the patient's independence and quality of life by assisting with movement, functioning, and pain relief.<sup>26</sup> Effective PT techniques can augment the patient's other MS treatments and may include:

- personalized exercise programs;
- addressing balance and coordination problems;
- bracing;
- spasticity management;
- fatigue management;
- pain relief approaches; and
- assistance with weakness or immobility.

Another reason to select a therapist familiar with MS, if possible, is to calibrate exercise levels appropriately, given the significant impact of factors such as heat, fatigue, and muscle weakness in this disease. The days of discouraging people with MS from exercising are long gone. A now-classic study by Petajan showed that regular aerobic exercise (sufficient to elevate pulse and respiration rates) has the potential to raise fitness and workout capacity, increase arm and leg strength, and improve bowel and bladder control.<sup>27</sup> Subjects also reported reduced depression, fatigue, and anger as a result of exercising.

Because MS is a lifelong disease, assisting people with MS to embrace exercise as a regular, enjoyable, and accessible lifestyle enhancement is an important goal toward minimizing further disability. Organizations such as the National Multiple Sclerosis Society, Multiple Sclerosis Association of America, and Multiple Sclerosis Foundation can provide excellent resources to help people with MS find exercise classes, videos, and information.

## Impact of Pharmacologic Management on Disability in MS

The effect of DMTs for MS on disability has been established in a large number of well-designed, controlled clinical trials. Some of these studies have followed a group of patients since the early pivotal trials and tracked disability over time.<sup>28-30</sup> Most of these studies have evaluated changes in EDSS and/or MFSC

scores over time; overall, disability progression has been significantly delayed among people whose disease is responsive to these therapies.

## Effects of Long-term Treatment With Glatiramer Acetate on Disability

The US Glatiramer Acetate Trial is the longest evaluation of continuous immunomodulatory therapy in relapsing-remitting MS (RRMS).<sup>28</sup> This 15-year study followed patients who remained on glatiramer acetate (Copaxone<sup>®</sup>) therapy as their sole immunomodulating agent, without switching to other drugs or going off therapy. Participants were evaluated every 6 months using the EDSS as the primary measure of disease activity. One hundred patients (43%) remained on the study drug (the “ongoing” cohort) during an average of 13.6 years of continuous treatment. Although these patients had a mean disease duration of 22 years and a mean age of 50 years, 57% had stable or improved EDSS scores, and 82% remained ambulatory without the need for mobility aids.<sup>28</sup> The investigators concluded that long-term treatment with glatiramer acetate delays accumulation of disability in people with relapsing MS as measured by the EDSS and that patients remaining on this therapy appear to do better compared with the withdrawn cohort. Forty percent of the ongoing cohort reached an EDSS score of 4.0 or higher and 23% reached an EDSS score of 6.0 or higher during the trial period.<sup>28</sup>

## Effects of Long-term Treatment With Interferon Beta-1b on Disability

Long-term studies of interferon beta-1b (Betaseron<sup>®</sup>) have followed the original pivotal trial participants for as long as 16 years after randomization.<sup>29</sup> A follow-up study stratified patients according to their original dose in the pivotal trial (250 mcg, 50 mcg, or placebo) and by the length of time they were exposed to the study drug (<10%, 10% to 80%, or >80% of the time since the start of the trial). Of 253 participants in the follow-up study, almost 50% had reached an EDSS score of 6.0 or higher. Those with >80% exposure to the interferon had a slower progression to an EDSS score

of 6.0 (13 years from time of diagnosis) compared with those who had low exposure to the drug (7 years from time of diagnosis to an EDSS score of 6.0).

This trial also showed that baseline EDSS scores at the start of treatment were predictive of disability in the long-term study—participants with lower initial EDSS scores had lower scores at the long-term follow-up and vice versa.<sup>29</sup>

### Effect of EDSS Changes on Longer-term Disability

Although the EDSS score is relied upon heavily in drug trials as a sign of treatment effect, it is not clear how these short-term changes affect clinically relevant disability over time. A recent study by Rudick and colleagues retrospectively examined EDSS score changes during a 2-year pivotal trial of intramuscular (IM) interferon beta-1a (Avonex<sup>®</sup>) to determine how these fluctuations affected disability 8 years later.<sup>30</sup> The study also examined how disability at the 8-year follow-up was influenced by treatment group (active versus placebo), baseline EDSS score, and relapses occurring during the 2-year study period. These investigators found that worsening by 1 point or more on the EDSS from baseline during the trial was the strongest predictor of clinically significant disability 8 years after randomization into the clinical trial. Patients receiving placebo, those with two or more relapses during the trial, and patients with EDSS scores of 2.0 or higher at baseline were more likely to have significant disability at 8 years.<sup>30</sup>

The authors concluded that “results from this study suggest that [the EDSS] can be used to meaningfully identify disability progression in an RRMS population and to determine the effect of a disease-modifying therapy on disability progression at this early stage of MS.”<sup>30</sup>

### Effect of Natalizumab on Disability in MS

Patients who receive treatment with natalizumab (Tysabri<sup>®</sup>) often constitute those who have had a poor response to other therapies and/or those with particularly aggressive disease. While long-term data are not

yet available, shorter-term studies of natalizumab have examined its effects on disability in MS.

A recent study examined the effects of natalizumab treatment on disability status and ambulation among 45 people with MS switched from other DMTs.<sup>31</sup> EDSS scoring and walking tests were performed every 4 weeks during 44 weeks of natalizumab treatment. At the conclusion of the study, 29% of patients showed confirmed EDSS improvement over 44 weeks of natalizumab therapy. Patients with improvement on the EDSS had similar baseline EDSS scores and number of active lesions. However, the group that responded best had a significantly higher number of relapses and 92% of them had experienced relapse-mediated sustained EDSS worsening in the previous year. The investigators suggested that the effect of natalizumab on EDSS may have been due to a delayed recovery from relapses in patients who had high levels of disease activity on other therapies.<sup>31</sup>

### Conclusion

Today’s emphasis has shifted toward maximizing what a person with multiple sclerosis (MS) *can do*, rather than dwelling on what he or she cannot do. A comprehensive care team can enable clients to improve their ability to perform daily tasks, supporting the *can do* approach. At the same time, disability must be assessed and documented to assist patients in getting the treatments and social/financial support services they need. As a result of new therapies being introduced for MS, some clinical centers may encounter people with MS who have not been on active treatment. For these patients, a thorough assessment of their disease status is warranted. Disability assessment can include the EDSS if resources allow, but many other instruments are better suited for use in the office setting, as described in this issue. More comprehensive testing by a PT or other specialized professional is recommended for baseline assessment and in cases where a disability claim is sought. Because disability progression is slowed in most patients with the use of DMTs, early treatment and active follow-up are encouraged to optimize these therapies for the patient.

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# CP Counseling Points™

## Assessing and Addressing Disability in MS

- Today's emphasis has shifted toward maximizing what a person with multiple sclerosis (MS) *can do*, rather than dwelling on what he or she cannot do.
- While the best-known test of disability status in MS is the Expanded Disability Status Scale (EDSS), a number of disadvantages limit its use in clinical practice.
- MS-specific instruments to assess disability include the Multiple Sclerosis Functional Composite (MFSC), a combined assessment of cognitive and upper limb function and gait disorders, and the MSIS-29, a survey for measuring the physical and psychological impact of disability.
- Some generic health status instruments are also valid for use in MS, including the ICF (World Health Organization) and the SF-36 (part of the Medical Outcomes Survey).
- Many symptom-focused scales are available, including the Six-step Spot Test for gait and balance disturbance, and the Modified Fatigue Impact Scale for evaluating fatigue within the context of MS.
- Physical therapists (PTs) with expertise in MS are among the professionals qualified to perform a comprehensive evaluation of disability, which may be useful if an individual applies for disability insurance.
- Part of the PT's role is to design an exercise program individualized for the person with MS, to encourage regular activity at any level of disability.
- The effect of disease-modifying therapies (DMTs) for MS on disability has now been established in a large number of well-designed, controlled clinical trials.
- Most of these studies have evaluated change in EDSS and/or MFSC scores over time; overall, disability progression has been significantly delayed for patients on active treatment with a DMT such as glatiramer acetate, interferon beta, or natalizumab.

# Counseling Points™

## Assessing and Addressing Disability in MS

### Continuing Education Posttest

To receive contact hours, please read the program in its entirety, answer the following posttest 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 the 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](http://www.IOMSN.org). Click on Counseling Points and follow the instructions to complete the online posttest and application forms.

#### PLEASE SELECT THE BEST ANSWER

- The experience of disability has been described as a(n) \_\_\_\_\_ phenomenon:**
  - subjective
  - objective
  - unmeasurable
  - normal
- An appropriate test for evaluating spasticity in multiple sclerosis (MS) is the:**
  - Timed Up and Go (TUG) test
  - Expanded Disability Status Scale (EDSS)
  - Modified Ashworth Scale
  - MSIS-29
- Which of the following is not a functional system included in the EDSS?**
  - pyramidal
  - extrapyramidal
  - bowel and bladder
  - sensory
- A patient with an EDSS score of 4.5:**
  - is fully ambulatory
  - uses a walker or cane on occasion for ambulation
  - needs a walker or cane most of the time for ambulation
  - uses a wheelchair
- Among the disadvantages of the EDSS in clinical practice is:**
  - its heavy focus on ambulation
  - the difficulty in conducting and scoring the evaluation
  - patients' nonlinear progression on the scale
  - all of the above
- Which of the following is NOT one of the three components of the MS Functional Composite (MSFC)?**
  - Timed 25-foot walk
  - Timed 6-meter walk
  - 9-hole peg test
  - Paced Auditory Serial Addition Test (PASAT)
- The SF-36 is too nonspecific to measure disability in MS.**
  - True; this study is best used for other medical conditions
  - False; this instrument has been validated in MS
- The MSIS-29 examines:**
  - physical and psychological disability from the patient's perspective
  - cognitive dysfunction
  - pain and spasticity in MS
  - none of the above
- With respect to disability in MS, fatigue is best described as:**
  - a major contributor to disability in MS
  - a separate phenomenon from disability
  - having a modest impact on disability in MS
  - not a measurable aspect of disability
- The Modified Fatigue Impact Scale (MFIS) measures the effect of fatigue during the previous \_\_\_\_:**
  - 3 days
  - 1 week
  - 4 weeks
  - 6 months
- The unique effects of fatigue, heat, and muscle weakness in MS would be rationale for:**
  - people with MS to avoid exercise
  - people with MS to limit exercise to non-aerobic activities
  - design of individualized exercise programs in MS
  - limiting exercise to supervised sessions
- Approved disease-modifying therapies (DMTs) in MS have been shown to significantly reduce disability in terms of EDSS progression and other measures of disability (e.g., the MSFC).**
  - True
  - False

# Counseling Points™: Program Evaluation Form

## Assessing and Addressing Disability 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**.

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. Define disability in general and in the context of multiple sclerosis (MS) ..... 5 4 3 2 1
- 2. Describe the pros and cons of standard disability measures in MS..... 5 4 3 2 1
- 3. Discuss the benefits of physical therapy and exercise on disability in MS..... 5 4 3 2 1
- 4. Discuss the effects of disease-modifying therapies (DMTs) on disability in MS..... 5 4 3 2 1

**To what extent was the content:**

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

**General Comments**

9. 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.

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.

Posttest Answer Key	1	2	3	4	5	6	7	8	9	10	11	12

**Request for Credit** *(Please print clearly)*

Name \_\_\_\_\_ Type of Degree \_\_\_\_\_

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