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## Whitaker Abstracts

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### **(W01) Multiple Sclerosis Response: Introducing a One-Stop Online Multiple Sclerosis Information Database**

Whether someone is newly diagnosed with multiple sclerosis (MS), a family member, a health professional, or a community front-line service provider, finding reliable information about MS is the key to empowerment and moving forward. However, a significant increase in MS research over the past decades has resulted in a deluge of studies, journals, and extensive topical MS articles. This often adds to the confusion and frustration of those seeking basic and current information. Providing access to standardized MS information for front-line service providers became a priority in Alberta because maintaining reliable files posed a tremendous challenge. After setting up a catalog of questions people have about MS, students skilled in library sciences and information systems took on the tedious task of compiling basic MS articles and adding links to appropriate topical information and resources. The result of this 2-year project is a user-friendly, searchable information database highlighting more than 500 MS topics and 2500 links. Cross-references connect users to ASK MS, an MS Society of Canada database with more than 2000 comprehensive educational articles available through a toll-free information line. To further inspire user confidence, an Alberta medical review committee is being established to harness the expertise available through MS professional networking in various multidisciplinary fields. The database is currently under review by services providers. Our goal is to place the database on the Alberta Division Web page for universal access, at a significant and welcome savings to a nonprofit budget. The real advantage, however, is a reliable and current MS information resource on your desktop and at your fingertips.

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### **(W02) Inspired Fitness: Individualized Fitness Program for People Living With Multiple Sclerosis**

The impetus for creating the Inspired Fitness program is based on the overall philosophy Inspire Health embraces. Physical therapists play a valuable and necessary role through a continuum of services, from rehabilitation to fitness and prevention. This is particularly apparent in the multiple sclerosis (MS) population because of the general course of the disease process. We know addressing the fitness needs of those with MS during relatively stable times of the disease process is important for overall health and fitness, and it minimizes the impact an exacerbation may have on future functional status. The objective of our program is to create individualized fitness plans that address impairments related to the MS disease process while emphasizing the importance of exercise and fitness for general health benefits. We created a 12-visit program that includes an initial assessment, an exit interview, and phone/email follow-up. The initial assessment consists of objective measures of flexibility, strength, endurance, balance, and posture. The following 11 sessions consist of specific exercise instruction based on client goals, likes/dislikes, and objective limitations to create a home-

based fitness program the client will continue independently. Various exercise options such as Pilates, Theraband exercises, stability ball exercises, free weights, and stretching are used, depending on the client's needs and goals. Phone or email consultation for 1 month after the last visit keeps motivation high and encourages compliance. Before the initial assessment, health information and disability status are gathered from the referring physician. The program is a platform for numerous research topics. As Pilates's influence on the health care community grows, evidence-based physical therapy practice demands that we show its efficacy. No current or past studies have looked at its benefits in people with MS. Research investigating the efficacy of Pilates exercise to improve overall fitness, flexibility, balance, endurance, and posture is a natural progression from the implementation of the Inspired Fitness program.

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### **(W04) Assessing Assessments: Selecting Appropriate Home Assessment for Individuals With Multiple Sclerosis**

Home modifications can improve performance of routine household activities, facilitate caregiving, improve safety, and reduce the need for personal care services for individuals with MS. However, individuals with multiple sclerosis (MS) encounter different physical barriers and have different problems with routine activities and tasks from people with other types of disabilities. As a result, the same modifications that work for people with other types of disabilities are not likely to work for people with MS. Clearly, selecting appropriate modifications for people with MS depends on identifying MS-specific barriers and problems. On the positive side, a wide variety of assessment instruments for identifying problems and barriers are readily available, ranging from self-report checklists of function or safety to detailed environmental-based assessments to evaluations of functional performance. On the negative side, not all assessments are created equal. Few are MS specific and therefore are not equally applicable to people with MS and other conditions. As a result, they are unlikely to provide positive home-modification outcomes for people with MS. This presentation outlines an analytical process for using appropriate assessment approaches that will meet the needs of a specific client with MS. Based on an analysis of more than 60 assessment tools, a conceptual framework was developed that demonstrates the relationship between the key assessment activities (ie, investigation, interpretation, and intervention) and the key factors to be assessed (ie, person, place, and performance). The framework not only provides a mechanism for understanding the goals, strengths, and weaknesses of the wide array of commonly used assessment instruments but is also critical for guiding practitioner-driven assessments for people with MS. As a result, the framework serves as a diagnostic tool that will enable practitioners to identify and select an assessment instrument that best meets the needs of each client and each situation.

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## (W05) Neurorehabilitation in Progressive Multiple Sclerosis

**Introduction:** Progressive multiple sclerosis (P-MS) is associated with greater impairment, disability, and handicap and a poorer quality of life (QOL) than other forms of MS. The disease-modifying therapies have shown little benefit in P-MS. Recent clinical trials have suggested an improvement in people with P-MS subjected to neurorehabilitation programs.

**Objective:** Evaluation of the efficacy of neurorehabilitation in people with P-MS.

**Methods:** We reviewed the results from controlled clinical trials that have evaluated the efficacy of neurorehabilitation in P-MS.

**Results:** Treatment of spasticity suggests that a combination of physical therapy and medication is needed. Interventions for equilibrium and balance with exercise have shown a favorable result. Strength can also be improved with exercise. Conversely, there is no proof of effectiveness of neurorehabilitation treatment for tremor. The efficacy of educational courses on energy conservation by occupational therapy has been demonstrated, having a positive impact on fatigue and on some aspects of QOL. Moderate improvement in the coordination of the upper limbs with exercise has been shown. In speech-language therapy, rehabilitation interventions in dysarthria has preliminarily shown improvement in precision of articulation, vocal acuity, naturalness of language, acoustics, sonority, and duration in maintaining phonation (and in QOL). Studies of dysphagia note the need for complete evaluation of swallowing function. Dysphagia treatment can allow for better nutrition and avoid respiratory complications. Respiratory muscle exercises have a beneficial effect on the strength of inspiration. Currently, there is no confirmation of the efficacy of cognitive rehabilitation programs in P-MS. Yoga exercises improved fatigue, and reflexology influenced motor and urinary dysfunction in one study. We have found that pulsed magnetic field therapy has been efficacious in the treatment of fatigue, improved QOL, and seemed to diminish spasticity. On the contrary, hyperbaric oxygen therapy was not useful in MS.

**Conclusions:** Neurorehabilitation in P-MS does not improve the impairment yet has a positive effect on many symptoms, disability, handicap, and many aspects of QOL. The neurological rehabilitation process in P-MS should be continuous throughout the evolution of the disease.

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## (W06) Evaluation of Caregiver's Wellness Day Event

Primary caregivers of individuals with spinal cord injuries (SCIs) are often spouses or other family members. These caregivers must adjust to a new role within the family. This new role affects the quality of their life as well as the individual with SCI. The effects on the caregiver are often negative. Depression, health problems, increased stress, emotional distress, and strain of caregiving have been reported in many studies. Coping skills and social support systems can affect the caregiver's stress and quality of life. The Caregiver's Well-

ness Day Event was developed to provide coping strategies and social support to caregivers of individuals with SCI. The aim of this study was to evaluate the Caregiver's Wellness Day Event, view the stressors that are brought on from caregiving, and determine whether the Wellness Day was beneficial in the caregiver's quality of life. A qualitative research method will be used. A quality-of-life questionnaire will be given to all participants of the Caregiver's Wellness Day Event from the past 3 years. This event will be evaluated on the feedback from the participants via the questionnaire to determine the impact of the event on their lives and their overall wellness. The results of this study will promote awareness of the stressors and quality-of-life issues for caregivers.

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## (W07) Clinical and Research Applications of a Comprehensive Psychology Database

Patients with multiple sclerosis (MS) present with significant psychological issues such as depression, coping difficulties, and stress-related problems. For this reason, there is a compelling need to evaluate their psychological status for the purposes of diagnosis and treatment planning. To address this need, all consecutive patients with a diagnosis of MS referred to Health Psychology at the Mellen Center for Research and Treatment from 2003 to 2006 have participated in an evaluation that included chart review for demographic and disease-related information; clinical interview concerning current and past psychological status, stressors, and relationships; and self-report measures of mood, coping, and fatigue. Of the 397 individuals in the database, 75.3% were women, 80.1% were white, and 74.6% had relapsing-remitting MS with an average MS duration of 5.4 years. Moreover, 72.7% were on an ABCR drug, and 48.4% were employed at least part time, whereas 26.7% were on disability. Historically, 58.4% had taken psychotropic medications, and 63.3% had participated in mental health treatment. Individuals identified their most problematic MS symptoms as fatigue (17.6%), pain (14.0%), and other sensory symptoms (14.5%). The mean score on the Beck Depression Inventory-II (BDI-II) was 20.5, and 67.5% demonstrated clinically significant depressive symptoms with a BDI-II score of >14. We present a detailed description of the psychological characteristics (eg, coping patterns) of these individuals, relevant IRB-related issues in the development of the database (eg, informed consent requirement), potential clinical uses of the database (eg, recruiting for psychotherapy groups and educational programs), and current studies (eg, the relationship between depression and coping).

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## (W08) Postmortem Tissue Is Important Component of Multiple Sclerosis (MS) Research: Critical Role of MS Tissue Banks

**Goal:** Because of the need for accurate characterization of MS pathology, it is important to increase the quality and amount of postmortem MS tissue available for research.

**Background:** The animal model of MS, experimental allergic encephalomyelitis (EAE), is increasingly recognized as being an inadequate pathological model of the disease and an unreliable indicator of the effectiveness of experimental MS therapies. One essential component to understanding the disease process in MS is to study human tissue. Although this tissue is not generally obtainable from living people, it can be obtained postmortem.

**Methods:** The Rocky Mountain Multiple Sclerosis Center, one of the few tissue banks in the world dedicated solely to collecting and processing tissue for MS research, and the Human Brain and Spinal Fluid Resource Center at UCLA, one of the largest and most highly regarded neurological tissue banks in the world, have been collecting tissue for MS research for a combined total of 75 years. To improve the quality, quantity, and variety of neurological tissue available, these two banks, with the support of the National MS Society (NMSS), have established a collaboration. MS-specific dissection and tissue-preparation methods have been developed to optimize tissue for research. Efforts are being made to increase the amount of control tissue. To maximize the impact of this tissue for MS research, tissue is made available to all interested investigators.

**Results:** Through this collaboration, there are nearly 800 samples and 2435 potential donors. Tissue from the banks has contributed to 15 publications in the past year. Recent postmortem studies of brain and spinal cord tissue have produced major discoveries in understanding MS.

**Conclusion:** Donated neurological tissue is an essential contribution for understanding MS pathology and for advancing MS therapies. New donations are critical, because modern research methods may benefit from the most up-to-date banking techniques.

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### **(W09) Feasibility of Home Telerehabilitation in Multiple Sclerosis**

In this study, we seek to assess feasibility and patient acceptance of a home telerehabilitation system in patients with multiple sclerosis (MS). The trial will use simple randomization to compare the effect of home telerehabilitation versus routine care. Our goal is to enroll 25 patients per group for a total of 50 patients who will be followed for 6 months. In both groups, the patients will receive a comprehensive baseline evaluation conducted by physical therapists specialized in the treatment of MS patients. Based on this evaluation, each patient will receive an individualized exercise plan and will be trained to perform exercises. After the baseline evaluation, all patients will be followed by their physical therapists and receive physical therapy treatment consistent with the current standard of care. In addition, the patients in the intervention group will receive computer-mediated support in following their individualized exercise plans at their homes on a daily basis. Daily exercise logs from the patients in the intervention group will be transmitted from their homes to a central server. Exercise safety and compliance will be monitored and analyzed by the server in real time. If a patient is non-

compliant or the patient symptom score is higher than a pre-defined individualized threshold, the system will alert the study case manager/physical therapist. The patient will then be contacted and counseled by clinical staff, and possible treatment issues will be addressed in a timely manner. If necessary, the exercise plan will be revised during the follow-up period, and all changes will be uploaded to the patient unit. The clinical impact of telerehabilitation will be estimated in three major domains: functional status, symptom activity, and behavioral and psychosocial domain. The primary outcome will be the difference between groups in scores assessing patient functional status.

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### **(W10) Fall-Prevention Education Program for Older Adults With Multiple Sclerosis**

**Background:** Numerous fall-prevention programs have been developed and tested over the past 10–15 years targeting older community-dwelling adults. Few of these programs accommodate the needs of frail older adults or those with physical disabilities such as multiple sclerosis (MS).

**Methods:** Through telephone interviews with 354 individuals with MS aged  $\geq 55$  years, data were collected on fall risk factors, as well as interest in and preferences for fall-prevention education. These data, together with the expertise and input of an international work group, were used to design a group-based fall-prevention program for older adults with MS. The work group consisted of occupational and physical therapists, a physician, and a nurse. Theories of cognitive behavioral therapy and psychoeducational group development were used to guide the structure, organization, and teaching methods used in the program. The program is being pilot tested throughout 2006.

**Results:** The resulting fall-prevention education program involves six 90-minute sessions addressing the identification and management of fall risks. The content of the sessions is organized around four key topics: 1) behaviors and attitudes influencing fall risk and management, 2) understanding how activity modification can reduce fall risk, 3) the importance of MS symptom management in reducing fall risks, and 4) reducing environmental hazards to manage fall risks at home and in the community. This poster describes the contents of each of the individual sessions of the program. In addition, the inclusion criteria, outcome tools, and overall evaluation plan for the program are shared.

**Conclusions:** Falls are common and frequent among older adults with MS, and many factors contribute to these events. This work in progress illustrates how a combination of empirical data and multidisciplinary clinical expertise have been used to develop and test a fall-prevention education program specifically for this population.

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## (W11) Hypothermia in Multiple Sclerosis

A 53-year-old woman with a 25-year history of secondary progressive multiple sclerosis (MS) was admitted to the hospital after she was found to have a rectal temperature of 32°C. Her husband had stated that she seemed more confused for the past 3–4 days but was otherwise asymptomatic. She also had a neurogenic bladder and paraplegia for many years resulting from MS. Two months before the current admission, she had urosepsis and hypothermia. She was treated at the time, and her temperature returned to normal. On one other occasion, she had asymptomatic hypothermia with no identifiable cause (temperature 33.8°C). On exam, blood pressure and heart rate were normal. The extremities were warm to touch. On neurological exam, she was noted to have right lateral visual field deficit, disconjugate eye movements, and right nystagmus with right lateral gaze. The vibratory sensation in both lower extremities was decreased; all other sensations were intact. There was decreased strength in all her extremities, with 0/5 strength in the lower extremities. Reflexes were normal in the upper extremities and increased in the lower extremities. Babinski sign was positive bilaterally. Her electrocardiogram showed a suggestion of Osborne wave in the inferior leads and V4–5. The thyroid, adrenal, and pituitary gland functions were all within normal range. Her magnetic resonance imaging (MRI) scan was read as chronic-appearing MS with no plaques identified in the hypothalamic region. There were no clinical signs of sepsis and no identifiable sources of infection. During her hospital stay, the patient was passively rewarmed. She remained stable and normotensive. Her temperature at the time of discharge was 36°C. Three months later at a follow-up visit, her temperature was 36.1°C. Hypothermia is characterized by a decrease in temperature to below 35°C. Hypothermia secondary to hypothalamic dysfunction, which is suspected in this patient, is uncommon. Human thermoregulation is a complex process that involves afferent peripheral and central thermoreceptors that sense changes in blood temperature. These afferent thermoreceptors synapse in the hypothalamus; the anterior and posterior have different roles in regulating body temperature. When the hypothalamus senses a change in body temperature, reflex efferent and behavioral responses occur to cause the body to either lose heat or gain heat. In this case, it was suspected that the patient had a lesion in the hypothalamus (not identified on the MRI) that caused an inability to mount an adequate response to cold temperatures, thus causing the patient to become hypothermic.

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## (W12) Renewal: Resources, Networking, Well-Being, and Learning for Caregivers of Veterans With Multiple Sclerosis

**Background:** Multiple sclerosis (MS) centers and advocacy groups have directed efforts toward educating and empowering individuals affected by the disease. Less effort has been directed toward meeting the needs of caregivers, most of whom are women. To assist veterans with MS and optimize their health care, the Veterans Health Administration (VHA) must also address the needs of their caregivers.

**Objective:** Establish a pilot customized program for caregivers of veterans, and then modify and disseminate that program to other MS centers.

**Setting:** US Department of Veterans Affairs Puget Sound Healthcare System (VAPSHCS) and the VHA MS Center of Excellence West.

**Methods:** Phase I consisted of a written survey completed by a convenience sample of 40 caregivers who prioritized their top six educational needs. Phase II consisted of the development of learning modules based on the results of the survey. Phase III is under way and includes a 6-week, 2-hour-per-week pilot education program. Four hundred caregivers of veterans treated at VAPSHCS were invited to participate in this program. Caregivers who attend the series will be asked to provide program feedback and may participate in a research study about their personal changes over the course of the educational series.

**Findings:** Phase I: the top educational needs of caregivers of veterans with MS were identified. Phase II: a 6-week educational program was developed using a problem-solving format with the goal of empowering caregivers to be proactive problem solvers. Phase III: 400 caregivers of veterans with MS treated at VAPSHCS have been invited to participate in the 6-week pilot program. This poster presents feedback from caregivers about both the course and their personal well-being.

**Conclusions:** We anticipate a positive response to this program with helpful feedback that will assist in tailoring the program for future caregiver needs.

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## (W13) International Organization of Multiple Sclerosis Nurses Mentorship Program in Multiple Sclerosis Nursing

**Background:** Sponsored by the International Organization of Multiple Sclerosis Nurses (IOMSN), the Mentorship Program in MS Nursing is a training opportunity for nurses to familiarize themselves with the skills and knowledge necessary to provide the highest quality of specialized MS nursing care. IOMSN supports the professional development and training of nurses in the comprehensive care of people affected by MS. This program offers the nurse apprentice the opportunity to practice under the tutelage of an MS nursing expert in a specialized MS clinical setting. The experience is designed to result in the initial acquisition of skills and knowledge necessary to practice as an MS nurse specialist.

**Objectives:** After completing the mentorship program, the trainee will be a nurse specialist who will 1) identify aspects of comprehensive nursing care to those affected by MS, 2) become an active participant in the MS clinical community, and 3) describe future learning needs for other educational opportunities.

**Mentorship:** Components of mentorship include 1) collaborative nursing care of MS patients/families and care partners, 2) involvement with the interdisciplinary health care team, and 3) identification of opportunities for participation in activities such as self-study, lectures, professional meetings,

seminars, or workshops. A registered nurse license or approved equivalent in other countries and at least 12 months of clinical experience in nursing was required. The length of the mentorship was 2 days. On completion of the mentorship, documentation was provided to the apprentice acknowledging his or her participation in and completion of the program.

**Evaluation:** The apprentice evaluated the program via a written evaluation. In addition, IOMSN will conduct follow-up surveys during the next 2 years with the apprentice to determine long-term outcomes of the program. This poster presents data about the number of participants in this program, results of the evaluations, and other outcomes of this important training effort in MS nursing. Apprentice nurses were encouraged to sit for MS nursing certification, and data will be compiled about outcomes for these participants. Data will include number of mentors and apprentices, practice locations, professional backgrounds of participants, and other information relevant to this program.

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### **(W14) Training Multiple Sclerosis Nurses for Advanced Practice Models of Care: International Organization of Multiple Sclerosis Nurses**

Greater insights into the pathophysiology of multiple sclerosis (MS) have led to the availability of disease-modifying agents. The growing array of treatment options and management strategies has seen the emergence of advanced practice nurses (APNs) as pivotal members of the MS health care team. In a chronic disease with a variable course, such as MS, patient care can be extremely complex. The specialized knowledge and skills of APNs contribute to structuring management plans that synthesize evidence-based practices and hands-on experience to ensure optimal outcomes. APNs typically fill several roles within an MS center, clinic, or private practice, including administrator, consultant, researcher, advocate, and clinician. These roles are derived and adapted from models of advanced practice nursing developed in the 1980s and 1990s. Because APNs can have a significant effect on the well-being of patients with MS, it is essential that they embody a core set of competencies delineated by domains specific to MS care. This project provides training and ongoing advice and support for APNs, either in the clinical setting or within the area of MS nursing research.

**Clinical Objectives:** Clinical objectives include defining essential components of the APN clinical educator role, identifying domains of MS APN practice, identifying key components of MS physical assessment, discussing strategies for MS symptom management, describing the role of the APN in initiation and maintenance of individuals on disease-modifying agents, and critically analyzing the role of the MS APN as part of the multidisciplinary health care team.

**Research Objectives:** Discuss the essential components of MS nursing research, engage in an MS nursing research activity of choice, and establish a network of collaboration with other nurse researchers.

**Methodology:** This poster presents the full scope of this initiative to include didactic and hands-on learning, the selec-

tion process for learners and advisors, and the evaluation process.

**Conclusions:** We present short-term and long-term outcomes for this project. The International Organization of Multiple Sclerosis Nurses summarizes implications for nursing practice in North America and globally.

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### **(W15) Standards of Care: What Clinicians Need to Know to Care for End-Stage Multiple Sclerosis Patients in Long-Term Care Facility**

People with multiple sclerosis (MS) may require nursing home care at a much younger age. According to statistics from the Center for Medicare and Medicaid Services (CMS), approximately 15,000 people with MS reside in nursing homes nationally. Because of the lack of specialized settings, most of these adults are residents of generic (geriatric) long-term care facilities. Although the National MS Society (NMSS) chapters do try to educate staff and work with skilled nursing facilities to help establish separate units for younger people with disabilities, these efforts have been only partially successful in improving care and quality of life. NMSS established a long-term-care advisory panel to oversee initiatives including the challenge of skilled nursing home care. A resource guide for nursing home staff, *Nursing Home Care of Individuals With MS: Guidelines & Recommendations for Quality Care*, was published under the guidance of an NMSS task force. The John Dystel Nursing Fellow and her mentor, clinicians practicing at The Boston Home, have used evidence-based practice, clinical guidelines, and the knowledge of experts in the field to create detailed standards of care for geriatric long-term-care facilities interested in serving this population. The four core areas include elimination, nutrition/hydration, pain, and cognition.

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### **(W16) Participation: Comparison of Frequency, Importance, and Self-Efficacy**

Rehabilitation care in multiple sclerosis (MS) is typically dedicated to enhancing participation in various settings, including the home, community, workplace, and educational environments. The purpose of this study was to compare how people living with MS rank order participation in various activities with respect to three domains: frequency, importance, and self-efficacy. One hundred ten individuals with MS completed a mail survey in which they rated the frequency, importance, and self-efficacy of a range of activities. Items were rank ordered according to the mean responses to the importance dimension, and this rank order was compared to rankings for frequency and self-efficacy (ie, Can I do it?). The results suggested that importance of an activity is not necessarily reflected in the frequency with which individuals engage in valued activities. For example, managing finances, interacting socially with family face to face, and sexual activity were ranked relatively higher for importance than they were for frequency. Conversely, cooking and quiet leisure were activities that occurred frequently but were not ranked high in importance.

Respondents reported that they were not able to engage in certain activities that were important to them as often as they wanted. These activities included working, getting to and from regular activities, and engaging in sexual activities. Results suggest that each dimension measured provided unique information about participation, and caution is warranted when interpreting scales of participation that only measure one dimension.

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### **(W17) DDAVP: Meeting the Challenge of Dehydration in Clinical Drug Trials**

**Background:** Patients involved in clinical drug trials undergo frequent lengthy clinic visits. Bladder dysfunction with accompanying urgency and incontinence has a significant effect on the ability of the patient to manage these visits. To cope with this problem, patients tend to limit fluids before clinic visits, making procedures such as phlebotomy and intravenous initiation difficult and uncomfortable. In this case study, the effect of desmopressin (DDAVP) was evaluated in one patient with multiple sclerosis (MS) currently involved in a clinical drug trial. DDAVP is recognized as a safe, effective treatment for nocturia, and many people with MS alternatively use it for occasional social situations where improved bladder control is needed.

**Methods:** A 50-year-old woman enrolled in a clinical trial previously presented for intravenous (IV) drug/placebo administration in a state of dehydration and suffered a hypotensive episode during drug/placebo administration. To prevent further hypotensive situations, DDAVP along with oral hydration was offered in an attempt to increase the patient's intravascular fluid volume, decrease difficulty and discomfort with phlebotomy and IV initiation, and decrease the chance of incontinence and urgency during the clinical trial visit. The patient hydrated orally for 24 hours preinfusion. Oral DDAVP 0.2 mg, followed by oral and IV hydration, was administered 1 hour before phlebotomy and drug/placebo infusion.

**Results:** Phlebotomy and IV insertion were much easier, and the patient experienced no hypotension. Also, the patient had better bladder control during the study visit.

**Conclusions:** Pretreatment with oral DDAVP permitted hydration while preventing urinary urgency and incontinence. This improved the experience and safety of trial procedures. DDAVP should be considered an effective strategy for use in patients who self-dehydrate to control bladder dysfunction in the clinical trial setting and for treatment of nocturia or urinary frequency that interrupts social outings.

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### **(W18) Importance of Family in Neuropsychological Rehabilitation Program to Treat Patients With Multiple Sclerosis**

**Introduction:** Multiple sclerosis (MS) is a disease that affects not only the patient's life but also the life of everyone that

lives with the patient, such as family members. Therefore, it is important to involve family members in treatment, as we have done in the neuropsychological rehabilitation program (NRP) at the Brazilian MS Society (ABEM). The program includes neuropsychologists, occupational therapists, and a speech therapist.

**Objectives:** Involve patients' families by giving them orientation, information, and support to help them better comprehend the patient's cognitive and behavior impairments; help the patient and family to cope and understand these impairments and improve quality of life; and increase the patient's autonomy.

**Methods:** Psychoeducation of the patients and their families about MS, neuropsychological rehabilitation, the functioning of NRP, and cognitive function; family interviews to get more information about the patient, the familiar dynamics, and daily routines; home visits to analyze the environment, suggest adaptations and strategies, and improve the patient's routine and mobility.

**Results:** The family members became more participative in treatment and had a better understanding about the patients, their disease, and their cognitive impairments. When family members supported and helped patients with their homework (practicing compensatory strategies and making environment modifications), improved neuropsychological function seemed more likely and less stressful.

**Conclusion:** The inclusion of the family in treatment is important during the process of the neuropsychological rehabilitation, whether in the institution or at home. It is hoped that this approach will improve patients' and relatives' quality of life.

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### **(W19) Improved Walking Endurance in 57-Year-Old Man With Multiple Sclerosis After Intermittent Exercise: Case Report**

Fatigue is one of the most common multiple sclerosis (MS) symptoms. Although exercise has been shown to be beneficial for people with MS, fatigue can limit the ability to engage in an exercise program and therefore gain exercise's benefits. A means of exercise that limits fatigue but still allows for exercise gains to accrue would therefore give an individual with MS the opportunity to gain greater fitness. Intermittent exercise, where periods of exercise are interspersed with periods of rest, is one possible venue where people with MS could make exercise gains with a minimum of fatigue. This case report describes a successful intermittent exercise program for a 57-year-old man with moderate disability (Expanded Disability Status Scale score 5.0) because of MS. At baseline, the patient showed limited endurance in walking tasks. His 6-minute walk test was 734 feet. He was unable to walk farther than 2 city blocks (~500 feet) without fatigue and requiring a rest. He had no spasticity, significant muscle weakness, or range limitations. There was mild central vestibulopathy and balance loss. His score on the Fatigue Severity Scale (FSS) was 44/63. As a training program, the patient was instructed to walk every other day at a fast but

comfortable pace for 2 minutes. At the end of 2 minutes (before onset of fatigue), he was instructed to take a seated rest for 1 minute, then walk again for 2 minutes. This process was repeated until the subject noted significant fatigue. The training was done every other day for 6 weeks. Initially, the subject could perform four 2-minute walks. By 6 weeks he could complete eight 2-minute walks without significant fatigue. His 6-minute walk score improved to 1056 feet, and he could walk up to 6 blocks without noting significant fatigue. His FSS was unchanged. Fatigue often limits exercise in MS. This case illustrates a program where a man with significant fatigue was able to improve his walking endurance through an exercise program where fatigue was minimized.

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### **(W20) iMed Patient Management System: Improving Care Through Information Exchange**

The chronic, progressive nature of multiple sclerosis (MS) necessitates many years of careful monitoring of disease parameters, such as relapses, cognitive examinations, disability measures, laboratory tests, magnetic resonance imaging (MRI) results, and medication history. The limited natural history data do not provide a sufficient basis to evaluate the efficacy of treatments over the long term or to assess an individual patient's response to treatment relative to a comparable cohort. Additionally, extracting relevant information from medical records that have accumulated over many years can be challenging. The iMed patient management system ([www.imed.org/](http://www.imed.org/)) is an electronic, clinic-oriented monitoring tool designed for storing, standardizing, and organizing medical information about MS patients. The iMed system can store information on medical history, neurological status, relapses, treatments, neurological rating scores on various scales, and results from MRI, cerebrospinal fluid, and evoked-potential tests in a single database. iMed is available to all clinicians involved in MS treatment and can be customized to capture information pertaining to safety, tolerance, or nearly any field that the clinician may consider valuable. The secure multiple-user support function enables clinicians within a local internal network to share patient files. Furthermore, the Web-based electronic nature of iMed facilitates information sharing among centers worldwide, thereby enabling research that would be impossible with the patient population of a single center. The MSBase International Patient Registry ([www.msbase.org](http://www.msbase.org)) is one such external database by which clinicians using iMed can share anonymous patient information through an encrypted Internet connection. Currently, several hundred centers worldwide use the iMed system in eight languages to monitor MS patients, and an increasing number of centers within the United States are beginning to adopt the system. Through such extended use, the iMed system enables and fosters international collaboration, which ultimately will help to optimize the care physicians can provide to MS patients.

**Tom Leist, MD**

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### **(W21) Multiple Sclerosis Support Staff Guide**

**Background:** Information for nonclinical support staff in multiple sclerosis (MS) centers regarding the presentation of the disease process is frequently suboptimal. Basic understanding of the disease, progression, associated symptomatology, and where to go to get additional information can assist support staff in their communication with patients, caregivers, and health care professionals.

**Objective:** Provide knowledge and resources to support staff members servicing patients with MS.

**Methods:** Structured questionnaires were sent out to 103 Consortium for Multiple Sclerosis Centers sites with full-membership status, including 58 US Department of Veterans Affairs MS Centers and 654 patients at the Indiana Center for MS. The site questionnaire was designed as a tool to gather information about the sizes of centers and their knowledge of their patients. The questionnaire sent to the patients of Indiana Center for MS was designed to gather information about their knowledge of MS and explore how MS center nonclinical staff members can better help communication among physicians, caregivers, and patients.

**Discussion:** This project was designed to be used as an educational tool for support staff. Additionally, information gathered from these surveys may help to emphasize the significance of timely intervention, recognition, and management of potential side effects of the initiated treatment and provide necessary support to maintain compliance with the ongoing therapy.

**Conclusion:** This information will assist the support staff in MS centers in their interactions with patients, caregivers, and other health care professionals. The study will hopefully provide the support staff with improved knowledge to assist more efficiently, better understand the disease process, and increase compliance with the ongoing medications.

**J. Ellen Looney, BSM; Teri Sanford**

Indiana Center for MS, Indianapolis, IN, USA

### **(W22) Addressing Sexual Health Needs Through Various Educational Programs**

**Introduction:** Sexual health concerns may be overlooked when addressing symptoms during routine health visits. The Allegheny District Chapter in conjunction with the University of Pittsburgh has offered many types of sexual health programs to address the many types of needs clients within the chapter may experience.

**Methods:** The following types of programs have been offered through the chapter. *Couples retreat:* during a 2-day and -night stay at a local resort, several hours were spent discussing sexuality and sexual function with experts within the field. *Sassy Sensation Party for Women:* women were instructed by a physical therapist, nurse, and vendor regarding sexual items for enhancing pleasure. As a result of its success, the venue was repeated for both individuals and couples. *Teleconference—Sexual Function and MS:* sexual health for men and women was discussed, followed by a question-and-answer session. *Love Boat Luncheon:* sexual and bladder health was discussed during a riverboat cruise. *Sex in the City Program:* a 2-night program series that featured physicians, nurses, and sexual health counselors. Issues related to emo-

tional/sexual abuse. An expert within this field was available onsite for clients and clinic staff at the two National Multiple Sclerosis Society-affiliated clinics within the city.

**Results:** Based on attendance and positive evaluations, these health programs were viewed as successful and will continue to be used in future programming. We have also increased our number of referrals to agencies caring for women who have experienced abuse.

**Conclusions:** Sexual health needs in people with MS must include information to manage sexual symptoms and ways to handle dysfunctional relationships. By raising awareness, we are able to reduce isolation that may be experienced when sexual health problems exist.

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### (W23) Multiple Sclerosis and Employment in Europe

Early published studies of the employment situation of people with multiple sclerosis (MS) have focused on identifying factors that differentiate the employed from the unemployed for predicting which individuals are at risk for leaving the workforce, including disease and demographic characteristics, premorbid personality, coping style, workplace characteristics, and social support. In a resolution adopted by the European Parliament in December 2003, specific priorities were delineated that directly pertain to Europeans with MS (an estimated 400,000), including improving the employment situation of these individuals through implementing legislation that encourages autonomy and job security. Currently, there are no comprehensive data available on the employment situation of people with MS in Europe. A comprehensive, self-administered questionnaire, formatted as a checklist of factors that can either facilitate or hinder job maintenance, divided into three major categories (personal, MS related, work related) with six subcategories, is currently being administered in 15 European countries to approximately 1000 people with MS. Subjects are stratified by employment status and according to whether they require assistance to walk. Final results will be available in summer 2006. The results of this study, commissioned by the European Multiple Sclerosis Platform, will be used to promote the rights of people with MS to obtain and maintain employment, without discrimination, architectural barriers, or other cultural, social, psychological, or physical obstacles. It will also be used as a lobbying tool, at the European Union (EU) level, to help guarantee appropriate interpretation and application of the EU directives on employment of disabled people in member states.

Michele Messmer Uccelli, BA, MSCS\*; Deborah Miller, LISW, PhD; Anssi Kemppi; Mario Alberto Battaglia, MD

\*Italian MS Society, Genoa, Italy

### (W24) COMPARE: Comparing MusiQol and MSQOL-54 in Multiple Sclerosis Patients on Long-Term Rebif Therapy

Multiple sclerosis (MS) can have diverse effects on the lives of patients and their families. Quality of life (QOL) is becoming increasingly important to neurologists treating MS patients.

The Multiple Sclerosis International Quality of Life (MusiQoL) questionnaire is a self-administered, MS-specific multidimensional QOL instrument uniquely constructed from the MS patients' perspective. The questionnaire was codeveloped and validated globally in 14 languages and 20 countries by an independent steering committee composed of neurologists, MS patients, and health economists and is endorsed by the International MS Federation. Placebo-controlled clinical trials have demonstrated the efficacy of Rebif in relapsing-remitting MS with reduction in relapse rate, delay in disability progression, and reduction in magnetic resonance imaging activity and accumulation of lesion burden. The objectives of this observational, one-arm multicenter study are to assess the utility of the MusiQoL instrument in clinical practice compared with a disease-specific QOL instrument (MSQOL-54) in subjects with relapsing forms of MS (RMS) on Rebif therapy and evaluate the effectiveness of Rebif therapy with respect to health-related QOL longitudinally. This COMPARE study will enroll approximately 200 RMS subjects. Data from the MusiQoL and MSQOL-54 instruments as well as physical (Expanded Disability Status Scale [EDSS]) and psychological (Folstein Mini-Mental Status Examination; Frontal Assessment Battery; Hospital Anxiety and Depression Rating Scale) health outcomes will be collected biannually for a 2-year period. The relative utility and acceptance of the two questionnaires will be captured through a separate evaluation questionnaire and an analysis of missing items. Pearson's correlation coefficients between QOL scores derived from both questionnaires and EDSS measures over the 2-year study period will be calculated. The relationship between overall QOL and MusiQoL and/or MSQOL-54 and clinical neurological measures will be assessed.

Fraser Moore, MD, FRCPC; Liesly Lee, MD, FRCPC; Mary Lou Myles, MCLSc, MD, FRCPC; Richard Leckey, MD, FRCPC; Anthony Feinstein, MD, PhD, FRCPC; Sun Cheung, MD, PhD

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### (W25) Zanaflex Capsules for Treatment of Spasticity in Multiple Sclerosis: Case Report

**Objective:** Determine whether Zanaflex capsules are an effective treatment for spasticity in patients with multiple sclerosis (MS).

**Methods:** A male patient with MS and severe spasticity was seen in a clinic for a routine follow-up visit. This patient's spasticity was being managed with daily stretching and exercise, baclofen 20 mg tid, and Zanaflex tablets 12 mg tid. He had used tizanidine in the past for his spasticity and did not find it to be as effective as the Zanaflex tablets. He reported ongoing spasticity despite his current regimen and was switched to Zanaflex capsules 12 mg tid and asked to take the capsules with food so that the half-life of the drug would be extended. A physical exam was done before the change in formulation of the Zanaflex and was repeated in 4 months.

**Results:** The patient reported that the Zanaflex capsules were more effective than tizanidine and Zanaflex tablets. He reported less somnolence and felt that the drug was effective for longer periods. His modified Ashworth scale while on Zanaflex tablets was 1/4 in the upper extremities and 2/4 in the lower extremities. The patient's modified Ashworth scale changed to 0/4 in both the upper and lower extremities after the change to Zanaflex capsules.

**Conclusions:** This case report demonstrates that Zanaflex capsules are an effective treatment for spasticity secondary to MS. This particular case illustrates a decrease in somnolence with the capsules compared with Zanaflex tablets and an extended half-life when taken with food. This patient reported an improvement in his spasticity with the capsules compared with tizanidine and Zanaflex tablets, which was confirmed by his physical exam.

Amy Morrison, PA-C

University of Texas Southwestern Medical Center, Dallas, TX, USA

### **(W26) Breaking the Silence for Young People When Multiple Sclerosis Enters the Family**

Living a life with multiple sclerosis (MS) brings uncertainty, unpredictability and worry for the future, not only for the person with MS but for the whole family. Often there are physical, financial, social, and economic difficulties, alongside role changes within the family unit. Invariably, young people (11–15 years old) feel isolated because they do not know anyone else who may be in a similar situation with a parent who has MS. This poster identifies/acknowledges the needs of young people affected by MS entering their family. One hundred sixty teenagers responded to and answered a questionnaire consisting of open-minded questions asking about their worries/concerns, any questions they may have, how they cope, where they get their information, and any advice to others in a similar situation. All of these factors have an impact on teenagers who, like their parents, are affected in many ways, and they adapt differently to the situation even when they are brother and sister. The poster shows the various themes that resulted from these questions. One significant theme that emerged was the direct impact that each young person is affected by MS, such as by the mood swings by their parents, making sure the parent does not get stressed, checking if their parent is having a “good” day and he or she is not too tired. These are the hidden signs of MS that professionals tend not to know about, although they are important for daily living in the family unit. The actual physical problems such as reduced mobility and the image of disability do not appear to be such an issue for the young people. Following the results of the questionnaire, a book is being published for the young people who have parents with MS, using their own thoughts and wording.

Kerry Mutch, RGN, MSCN, BSC

The Walton Centre for Neurology and Neurosurgery, Fazakerley, Liverpool, UK

### **(W27) Challenges in Rehabilitation of Multiple Sclerosis (MS) Patients With Non-MS-Related Health Issues: Morfan Syndrome**

**Background:** Management of MS patients in MS clinics rarely addresses non-MS-related problems, deferring them to family physicians. Little information is published about unique needs of MS patients with non-MS-related issues. It is especially important in community-based settings, which have scarce resources outside of the clinic, to be able to carry out comprehensive care for these patients and their unique needs.

**Goal:** Develop a rehabilitation approach that manages patients who are diagnosed with MS while dealing with other acute or chronic illnesses.

**Methods:** This poster is a case review and model of rehabilitation approach. New to our clinic, a 54-year-old woman presented with MS (Expanded Disability Status Scale [EDSS] score 6.5) and Morfan syndrome. The patient had sustained a leg injury that required rehabilitation. A conventional multidisciplinary approach to identify and prioritize the patient's issues was initiated. However, some needs of the patient were outside the scope of expertise of the team. Instead of referring the patient to outside resources to deal with these issues separately, we enhanced our team with additional team members. After rehabilitation, the patient's EDSS score was 5.5, and other goals of rehabilitation were achieved. A detailed rehabilitation plan and model of rehabilitation approach using the enhanced team in a community-based MS clinic are presented.

**Conclusion:** An enhanced multidisciplinary team in a community-based MS clinic can successfully manage MS patients with other serious health concerns.

Galina Vorobeychik, MD, FRCP(C), MSCS; Janene Spring, RN, BScN, MSCN; Jill Nelson, RN, BScN

Fraser Health Multiple Sclerosis Clinic, Burnaby, BC, Canada

### **(W28) Unique Multiple Sclerosis Model Care in Spinal Cord Injury/Disorder Center**

Clients with multiple sclerosis (MS) require comprehensive interdisciplinary care. The spinal cord injury/disorder center (SCI/D) at James A. Haley VA Medical Center accepted MS veterans for the past 7 years in the SCI/D registry. The SCI/D center has been able to provide patient-centered interdisciplinary care (KT, psychologist, occupational therapist, dietitian, nurse, and others) for these veterans. The veterans are very pleased with the continuity of care. This poster presentation provides information about this model of care. The SCI/D is participating in a US Department of Veterans Affairs MS Center of Excellence national longitudinal MS study.

Carlos Ramirez, MSN, ARNP; Nahid Veit, MSN

US Department of Veterans Affairs, Riverview, FL, USA

### **(W29) Home LINKS: Case-Management Model for Multiple Sclerosis**

Home LINKS (Live Independently Navigating Key Services) is a short-term case-management program designed to promote enhanced quality of life and increased independence and safety for people with multiple sclerosis (MS). It is an integral part of the National Multiple Sclerosis Society, Central New England Chapter's three-tiered direct-delivery model: tier 1, information and referral about MS and community resources, usually accomplished in one conversation; tier 2, expanded information and referral service including researching resources, advocating for services, usually accomplished in several conversations with client and providers; and tier 3, in-home care management assessment, development of care plans, and help to accomplish client-centered goals for continued independent living. Whereas chapter staff manage our tier 3 program in-house and oversee each client, we contract with and train community-based agencies to work with our clients in their homes. The care coordinator visits the client at home. Together they identify areas of need and formulate a care plan. For many clients, especially those feeling overwhelmed or with cognitive difficulties, this hands-on

approach is crucial to obtaining needed support. Care coordinators help clients with completing applications for public benefits or housing; advocating with providers to expedite appointments or obtain referrals; researching local services such as transportation, home-delivered meals, or home care; arranging for accessibility assessments, helping to obtain home modifications and medical equipment; and finding neurologists, legal and mental health services, and social supports. In 2005, we served 2888 clients in tier 1, 99 in tier 2, and 65 in tier 3. Since 2003, the Home LINKS program has served a total of 134 tier 3 families, with steadily increasing referrals. We work closely with the MS clinical centers and other community-based providers to increase awareness of Home LINKS and collaborate on goals for individual clients. Eighty-nine percent of clients stated they would recommend this service to others.

**Dawn Russo, MSW; Judy Cotton, MA; Linda Guiod, RN; Carrie Leggett, LICSW; Christine St. Laurent, RN, MS, MSCN**

\*National MS Society; Waltham, MA, USA

### **(W30) Cognitive Intervention Program for People With Multiple Sclerosis**

Up to 70% of people diagnosed with multiple sclerosis (MS) will experience some form of cognitive impairment as a result of the disease. However, few people receive direct treatment to help manage this symptom. People with MS report the intrusiveness of cognitive symptoms and their negative impact on their ability to perform everyday activities in a society that is progressively becoming more demanding. Therefore, the need for cognitive interventions has become an urgent rehabilitation priority. This work in progress presents the development of a group cognitive intervention program for people with MS. The intended outcomes of the intervention include 1) increasing participants' knowledge and awareness regarding the impact of cognitive impairments, 2) building skills and strategies to enable self-management of cognitive difficulties, and 3) increasing self-efficacy and sense of control regarding cognitive symptoms. Through the use of cognitive behavioral therapy principles, the intervention program aims to promote behavioral changes through both personal and individualized goal setting and group support and interaction. Participants will learn about the different types of cognitive impairment common in MS and how cognitive impairments interact with other MS symptoms. Various cognitive management strategies will be demonstrated during the intervention, including internal strategies, environmental modifications, and external strategies in the form of aids. In addition, participants will be supported to develop a more positive outlook regarding their cognitive difficulties. The poster displays the theoretical background guiding the intervention, the goals and objectives of the program, key outcomes, and a description of the intervention sessions. By increasing MS patients' sense of control over their cognitive symptoms, they can potentially increase their levels of functioning and overall satisfaction in their daily lives. Rehabilitation professionals who work with MS patients will be able to administer the intervention program in various clinical and community settings.

**Eynat Shevil, MS, OTR**

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### **(W31) Injection-Site Pain in Relapsing-Remitting Multiple Sclerosis Patients Receiving Subcutaneous Disease-Modifying Therapies**

**Objective:** Compare injection-site pain (ISP) in patients with relapsing-remitting multiple sclerosis (RRMS) administering subcutaneous (SC) disease-modifying therapies (DMTs).

**Background:** DMTs are the standard treatment for patients with RRMS. Patients receiving SC injections can experience ISP, which is often dose, gauge, or solution-component dependent. ISP may result in compliance issues and therapy switches and add additional burden to nursing time. Although the needle gauge for interferon beta (IFNB)-1a (Rebif) was recently reduced to minimize ISP, no comparisons with other DMTs are available to date. Approximately 85% of patients surveyed by the manufacturer considered the new gauge to be an improvement over the original injection device. ISP and site reactions have been reported in 66.4% and 45% of glatiramer acetate (Copaxone) patients, respectively. No comparisons have been made between glatiramer acetate and the other DMTs.

**Methods:** Patients starting SC IFNB-1b (Betaseron), IFNB-1a, and glatiramer acetate were recruited over a 3-month period. Patients self-assessed ISP using a 0- to 10-cm pain visual analog scale (VAS) (0 cm = no pain, 10 cm = worst pain). ISP was recorded before and after each injection, then 10 minutes, 60 minutes, and 24 hours postinjection for the first month and weekly up to 3 months. Patients received follow-up phone calls from the clinical nurse specialist at 48 hours and 1 week after first injection and were assessed at the clinic at 1 and 3 months.

**Results:** Eighteen patients were recruited: 8 IFNB-1a, 2 IFNB-1b, and 8 glatiramer acetate. A comparison of ISP for the three treatment groups is presented.

**Conclusion:** The results will assist MS nurses and physicians to provide adequate education and support to patients with ISP. This may also assist in setting realistic expectations, reducing ISP problems and therapy switches.

**Janene Spring, RN, BSCN, MSCN; Jill Nelson, RN, BSCN; Nicole Beauregard, MSC; Galina Vorobeychik, MD, FRCP(C)**

Fraser Health MS Clinic, Burnaby, BC, Canada

### **(W32) Abuse and Neglect of Individuals With Multiple Sclerosis: Identification and Intervention**

Individuals who have physical and cognitive disabilities report higher incidences of abuse or neglect than the general population. People with multiple sclerosis (MS) have not previously been considered a high-risk group. The nature of the disease itself, however, affecting both physical and cognitive abilities, places the person with MS at higher risk for abuse. There is a growing body of literature indicating that people with MS are at increased risk for physical or sexual abuse, neglect, and financial exploitation. Additionally, women, who in general report a higher incidence of abuse, are also affected by MS two to three times more than men. Clinicians are mandated to report abuse; however, few receive more than cursory discussion of signs/symptoms of abuse or neglect during their professional training. Cases in which the person may be the victim of abuse or neglect may be subtle,

requiring careful documentation and collaboration with other clinicians and community agencies. When abuse/neglect are encountered in the clinical setting, even the most experienced provider may not know how to respond quickly and appropriately to protect the patient from further harm. Abuse of individuals with MS occurs not just in institutional settings such as skilled nursing facilities or assisted living facilities but in the home, perpetrated by caregivers and/or family members, people with whom the clinician may be very familiar. Early intervention is critical in preventing long-term physical and psychological damage to the person with MS. This poster explores the scope of the problem, reviews signs and symptoms that may indicate abuse is taking place, and offers suggestions and resources that can be integrated into clinical practice. With increased awareness and collaboration, health care providers can dramatically improve the safety and quality of life of their patients with MS.

**Tara Stablein, LICSW, MSCS**

VA Puget Sound Healthcare System, MS Center of Excellence West, Seattle, WA, USA

### **(W33) Enabling Multiple Sclerosis Support Program Development**

The multiple sclerosis (MS) experience not only affects those living with the illness but also those closest to the individual. At the MS Society of Canada, Alberta Division, the need for support programs that enhance quality of life in rural communities led to the development of "train the trainer" manuals. Both programs described below focus on opportunities to network, either on an individual basis or within a group setting. The key to establishing successful MS programming is collaboration in the development, implementation, and maintenance of specialized resources. The objective of these interrelated resources is to provide program developers with user-friendly tools to establish customized support programs in any community.

*MS Peer Support Training Guide:* No one understands the challenges of living with MS like others living with MS. The Peer Support Guide draws heavily from shared experiences of those living with MS, providing developers with a wide range of useful tools such as development outlines, training outlines, volunteer training manual, documentation templates, volunteer guide, and resources.

*MS Support Group Facilitator Training Guide:* In Alberta, support groups are a vital component of the MS community. Using trained facilitators has proven to be a successful strategy for establishing group cohesion and encouraging longevity. Support-group management resources are comprised of three parts: administrator's guide, contact facilitator guide, and self-help group leader's guide.

Rural community isolation, identified as a struggle for people living with MS, has been greatly reduced with the help of standard training materials for staff and volunteers seeking to provide MS support services.

**Aileen Steele, BA Psych**

MS Society of Canada, Alberta Division, Edmonton, AB, Canada

### **(W34) Center Dedicated to Enhancing Quality of Life of People Living With Multiple Sclerosis**

Multiple sclerosis (MS) is a disease with implications that reach beyond the scope of myelinated neurons. Although the medical needs of MS patients can be addressed by the neurologist's office, it is difficult to address all of the social, legal, psychological, and financial issues of MS during a medical visit. Louisville Comprehensive Care MS Center was created to provide educational, legal, social, and nutritional assistance for patients and caregivers affected by this disease. The Louisville model offers free services to MS patients with the intent to equip them with the necessary resources and tools needed to address the multitude of complex issues encountered during the course of their life. A staff social worker is available for consultation and leads a caregiver support group. A mental health counselor is available for individual and/or family counseling sessions. A registered dietitian is also available to discuss dietary concerns. The center has a library with electronic and print media accessible to all patients. Educational programs tailored to the MS patient are offered at least once a month throughout the year. Medically accredited educational programs are also available for MS patient providers. Opportunities exist for organized exercise therapy, art therapy, and legal counseling. Financial counseling is also available through the center for those requiring assistance. The center offers links to ongoing MS clinical trials. The center offers these resources through educational grants and institutional and individual donations. The center provides a model for addressing many of the needs of the MS patient. It is committed to receiving input from the MS community. The educational, emotional, occupational, physical, and psychological requirements of MS patients drive the programs offered through the center. Contributions from the local community allow the center to be comprehensive in its approach to those who suffer from MS.

**Robert Tillet, Jr, MD, MSCS; Roy J. Meckler, MD; Yvette F. Rojas, Executive Director; Heather Osborne, Program Director**

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### **(W35) Using Art as Catharsis With Multiple Sclerosis Clients: One Group's Experience**

An extensive body of research suggests that chronic and disabling diseases such as multiple sclerosis (MS) can have deleterious effects on the person, not just because of the physical symptoms and the discomforts that MS can cause but through its broader effects on self, life roles, occupational performance, and quality of life. As a result of these changes and losses, depressive reactions that are common among people with MS can further degrade the quality of life. Engaging in art as a modality, specifically painting, can have cathartic effects in assisting individuals dealing with depression and loss to explore and develop a new leisure activity, divert thoughts away from problems and troubles, promote an experience of spontaneity and creativity, enable the expression of grief and anger in a positive way, and promote confidence in self through the display of one's creative effort. Participating in a group art experience also creates opportunities for social engagement and discussion about personal stories and meanings represented in the painting projects. Displaying the artwork as a group collection at various public venues

gives further opportunity for personal articulation of the MS experience to a broader audience. This poster looks at the art experience in the MS Wellness Program, guided by Brett Weber, PhD, an impressionist artist who has MS. Case studies illustrate the use of painting as a catharsis, a sampling of the personal experiences related to MS developed through this activity, and the impact on well-being and sense of meaning for the program participants.

**Jerry Werner, COTA/L, MSCS; Brett Weber, PhD**

Good Shepherd Rehabilitation Hospital, Allentown, PA, USA

### **(W36) MS ACTIVEnow: Expanding Role of Exercise in Lives of People With Multiple Sclerosis**

Until recently, physical activity and exercise were contraindicated for people with multiple sclerosis (MS) because of thermosensitivity, fatigue, and vision-related issues. The importance of regular physical activity in the lives of people with MS is now increasingly recognized as an important adjunct to traditional medical and other therapeutic interventions. As such, physical activity programming extends the concept of combinational therapeutic interventions. We explored the meaning of regular physical activity in 37 people with moderate to severe Expanded Disability Status Scale MS in a qualitative study comprising a series of personal interviews. Engaging in exercise was a means of "refusing to surrender" to the effects of chronic disease and associated with a "reclamation of personal resources" including sense of identity, self-esteem, sense of personal control, dignity, and psychological and physical functioning. No negative effects of exercise were reported, although barriers cited included lack of facilities, lack of programs within the community, and lack of expertise associated with exercise and MS in fitness professionals. Therefore, we have developed the MS ACTIVEnow program at the MS Society of Canada, Alberta Division, Edmonton Chapter to increase community capacity for active living for people with MS. A full-time MS ACTIVEnow coordinator and MS Society-funded, university-based MS ACTIVEnow fellow are responsible for developing and delivering programs, developing training (multimedia) materials, and conducting community education sessions for professionals to create community capacity for active living by people with MS. The MS ACTIVEnow program also includes medical professionals as part of a referral network with regard to access to appropriate sites.

**Garry Wheeler, CPsych**

MS Society of Canada, Edmonton Chapter, Alberta Division, Edmonton, AB, Canada

### **(W37) How Health Literacy Affects Patients With Multiple Sclerosis**

Many people do not understand health information. More important, those who do not understand the information are often reluctant to say so. Literacy skill level impacts health. Low literacy makes people who are already ill more vulnerable. Health literacy links literacy level with the ability to act on health information and take control of one's health. Clear communication of your health message can make all the difference in effective patient care. Patients with multiple sclerosis (MS) receive an abundance of information on the disease, prognosis, symptom management, and complex treatment options that is vital to their self-management, health maintenance, and quality of life. An estimated 50% of people with MS experience cognitive deficits of memory loss and diminished capacity for learning, processing, and recalling information. Nurses in clinical practice can improve health teaching to their patients by identifying and removing barriers to learning and building collaborative nurse-patient partnerships.

**Ann Chioveti, RN, BN, MHS**

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