



Works-in-Progress





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(W01) MS RESPONSE:
INTRODUCING A ONE-STOP ONLINE MS INFORMATION DATABASE

Whether someone is newly diagnosed with 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, 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 as maintaining reliable files posed a tremendous challenge. After setting up a catalogue 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 two-year project is a user friendly, searchable information database highlighting over 500 MS topics and 2,500 links. Cross-references connect users to ASK MS, a MS Society of Canada database with over 2,000 comprehensive educational articles available through a 1-800 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 multi-disciplinary fields.

The database is currently under review by services providers. Our goal is to place the database on the Alberta Division webpage for universal access, at a significant and welcome savings to a non-profit 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:
AN INDIVIDUALIZED FITNESS PROGRAM FOR PERSONS LIVING WITH MS**

The impetus for creating the “Inspired Fitness” program is based in the overall philosophy Inspire Health embraces. Physical therapists have a valuable and necessary role through a continuum of services; from rehabilitation to fitness and prevention. This is particularly apparent in the MS population due to 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, as well as 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, but also emphasize the importance of exercise and fitness for general health benefits.

We created a 12 visit program which includes an initial assessment, an exit interview and phone/email follow-up. The initial assessment will consist of objective measures of flexibility, strength, endurance, balance, and posture. The following 11 sessions will 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. A variety of exercise options such as: Pilates, theraband exercises, stability ball exercises, free weights, and stretching will be utilized depending on the client’s needs and goals. Phone or email consultation for one month following the last visit will keep motivation high and encourage compliance. Prior to 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’ influence on the healthcare community grows, evidence-based physical therapy practice demands we show its efficacy. No current or past studies have looked at its benefits in persons 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 AN APPROPRIATE HOME ASSESSMENT FOR INDIVIDUALS WITH MS

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 MS encounter different physical barriers and have different problems with routine activities and tasks than 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 will outline an analytical process for using an appropriate assessment approach that will meet the needs of a specific client with MS. Based on an analysis of over 60 assessment tools, a conceptual framework was developed that demonstrates the relationship between the key assessment activities (i.e., investigation, interpretation and intervention) and the key factors to be assessed (i.e., 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, handicap and a poor 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 persons with P-MS subjected to neurorehabilitation programs. **OBJECTIVE:** Evaluation of the efficacy of Neurorehabilitation in persons with P-MS. **METHODS:** We reviewed the results from controlled clinical trials which have evaluated the efficacy of neurorehabilitation in P-MS. **RESULTS:** Treatment of spasticity suggests a need for a combination of physical therapy and medication is needed. Interventions for equilibrium and balance with exercise has shown a favorable result. Strength can also be improved with exercise. Conversely, there is no proof of effectiveness for neurorehabilitation treatment for tremor. The efficacy of educational courses on energy conservation by Occupational Therapy (OT) 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 better nutrition and avoid respiratory complications. Respiratory muscle exercises have a beneficial effect on the strength of inspiration. At present, although there is no confirmation of the efficacy of cognitive rehabilitation programs in P-MS. Yoga exercises can improve 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 seems to diminish spasticity. On the contrary hyperbaric oxygen therapy is not useful in MS. **CONCLUSIONS:** Neurorehabilitation in P-MS does not improve the impairment yet has a positive impact on many symptoms, disability, handicap and many aspects of the 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

PPrimary caregivers of individuals with spinal cord injuries (SCI) are often spouses or 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 affects on the caregiver are often negative (Alfano et al., 1994; Kester et al., 1988; North, 1999; Weitzenkamp et al., 1997). Depression, health problems, increased stress, emotional distress, and strain of caregiving have been reported in many studies (Gallagher et al., 1989; Gallo, 1990; Kester et al., 1988; Schulz et al., 1990; Zarit et al., 1986). Coping skills and social support systems can affect the caregiver's stress and quality of life (Lararus and Folkman, 1984). The Caregiver's Wellness Day Event was developed to provide coping strategies and social support to caregivers of individuals with SCI. The aim of this study is to evaluate the Caregiver's Wellness Day Event, view the stressors that are brought on from caregiving, and determine if 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 last three 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 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 female, 80.1% were Caucasian, 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 while 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 more than 14. We will present a detailed description of the psychological characteristics (e.g., coping patterns) of these individuals, relevant IRB-related issues in the development of the database (e.g., informed consent requirement), potential clinical uses of the database (e.g., recruiting for psychotherapy groups and educational programs), and current studies (e.g., the relationship between depression and coping).

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(W08) POSTMORTEM TISSUE IS IMPORTANT COMPONENT OF MS RESEARCH: THE CRITICAL ROLE OF MS TISSUE BANKS

GOAL: Due to 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. While this tissue is not generally obtainable from living people, it can be obtained postmortem.

METHODS: The Rocky Mountain Multiple Sclerosis Center (RMMSC), 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 (HBSFRC) 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 2,435 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 since modern research methods may benefit from the most up-to-date banking techniques.

Study supported by: National Multiple Sclerosis Society.

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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 predefined 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) A FALLS PREVENTION EDUCATION PROGRAM FOR OLDER ADULTS WITH MS

Background: A number of falls 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 MS.

Methods: Through telephone interviews with 354 individuals with MS aged 55+, data were collected on falls risk factors, as well as interest in and preferences for falls prevention education. These data, together with the expertise and input of an international Work Group, were used to design a group-based falls 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 psycho-educational 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 falls prevention educational 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 falls 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 will describe 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 will be 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 multi-disciplinary clinical expertise has been used to develop and test a falls prevention education program specifically for this population.

Study supported by: Retirement Research Foundation.

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(W12) RENEWAL: RESOURCES, NETWORKING, WELL-BEING AND LEARNING
FOR CAREGIVERS OF VETERANS WITH MS

BACKGROUND: MS Centers and advocacy groups have directed efforts to educating and empowering individuals affected by the disease. Less effort has been directed to meeting the needs of caregiver(s), most of whom are female. In order to assist veterans with MS and optimize their health care, the Veterans Health Administration (VHA) must also address the needs of their caregivers.

OBJECTIVE: To establish a pilot, customized program for caregivers of veterans. To then modify and disseminate that program to other MS Centers.

SETTING: The VA 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 underway and includes a six week, twohour per week pilot educational program. 400 caregivers of veterans who are 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 six 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 six week pilot program. This poster will present feedback from caregivers both about the course and on 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.

Study supported by: Multiple Sclerosis Foundation. VA MS Center of Excellence - West

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(W13) THE INTERNATIONAL ORGANIZATION OF MULTIPLE SCLEROSIS MENTORSHIP PROGRAM IN MS 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.

The IOMSN supports the professional development and training of nurses in the comprehensive care of people affected by MS. This program provides the nurse apprentice with 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.
- 3) Describe future learning needs for other educational opportunities.

COMPONENTS OF MENTORSHIP:

- 1) Collaborative nursing care of MS patients/families, care partners.
- 2) Involvement with the interdisciplinary healthcare team.
- 3) Identification of opportunities for participation in activities such as self-study, lectures, professional meetings, seminars, or workshops.

ELIGIBILITY: An RN license or approved equivalent in other countries, and at least 12 months of clinical experience in nursing was required.

LENGTH OF MENTORSHIP: The length of the mentorship was two days.

ACKNOWLEDGEMENT OF COMPLETION: Upon completion of the mentorship, documentation was provided to the apprentice acknowledging his/her participation in and completion of the program.

EVALUATION: The apprentice evaluated the program via a written evaluation. In addition, the IOMSN will conduct follow-up surveys during the next two years with the apprentice to determine long-term outcomes of the program.

This poster will present 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 relevant information to this program.

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**(W14) TRAINING MS NURSES FOR ADVANCED PRACTICE MODELS OF CARE
INTERNATIONAL ORGANIZATION OF MS 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 a number of roles within an MS center, clinic, or private practice. These include 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 impact 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 will provide training and ongoing advice and support for APNs either in the clinical setting or within the area of MS nursing research.

CLINICAL OBJECTIVES

- Define essential components of the APN clinical educator role
- Identify domains of MS APN Practice
- Identify key components of multiple sclerosis physical assessment
- Discuss strategies for MS symptom management
- Describe the role of the APN in initiation and maintenance of individuals on DMT's
- Critically analyze the role of the MS APN as part of the multidisciplinary healthcare team

RESEARCH OBJECTIVE

- Discuss the essential components of MS Nursing research
- Engage in an MS nursing research activity of choice
- Establish a network of collaboration with other nurse researchers

METHODOLOGY

This poster will present the full scope of this initiative to include the scope of didactic and “hands on” learning, the selection process for learners and advisors, and the evaluation process.

OUTCOMES

We will present short-term and long-term outcomes for this project along with implications for practice.

IMPLICATIONS FOR PRACTICE

IOMSN will summarize implications for nursing practice in North America and globally.

Study supported by: This project was funded by an unrestricted grant from Teva Neuroscience.

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(W15) STANDARDS OF CARE: WHAT CLINICIANS NEED TO KNOW TO CARE FOR END STAGE MS PATIENTS IN A LONG TERM CARE FACILITY

People with 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 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. The National MS Society 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 was published under the guidance of a National MS Society task force (“Nursing Home Care of Individuals With MS: Guidelines & Recommendations for Quality Care”). 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:
A COMPARISON OF FREQUENCY, IMPORTANCE, AND SELF-EFFICACY

Rehabilitation care in multiple sclerosis (MS) is typically dedicated to enhancing participation in a variety of settings, including the home, community, workplace, and educational environments. The purpose of this study is 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 and 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 with rankings for frequency and self-efficacy (i.e., “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, the items “managing the 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 on 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 impact on the ability of the patient to manage these visits. To cope with this problem, patients tend to limit fluids prior to clinic visits making procedures such as phlebotomy and intravenous initiation difficult and uncomfortable. In this case study, the effect of DDAVP was evaluated on one patient with multiple sclerosis 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 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 pre-infusion. Oral 0.2mg DDAVP, followed by oral and IV hydration, was administered one hour prior to phlebotomy and (drug/placebo) infusion. **RESULTS:** Phlebotomy and IV insertion were much easier and the patient experienced no hypotension. As well, the patient had better bladder control during the study visit. **CONCLUSIONS:** Pre-treatment with oral DDAVP permitted hydration while preventing urinary urgency and incontinence. This improved the experience and safety of trial procedures. DDAVP should be considered as an effective strategy to use in patients who self-dehydrate to control bladder dysfunction in the clinical trial setting as well as for treatment of nocturia or urinary frequency that interrupts social outings.

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**(W18) THE IMPORTANCE OF THE FAMILY IN THE NEUROPSYCHOLOGICAL
REHABILITATION PROGRAM TO TREAT PATIENTS WITH MULTIPLE SCLEROSIS**

INTRODUCTION: Multiple Sclerosis is a disease that affects not only the patient's life, but also the life of everyone that lives with them, such as family members. Therefore, it's very important to involve family members in treatment, as we have done in the Neuropsychological Rehabilitation Program (NRP) at Brazilian MS Society (ABEM). The program includes neuropsychologists, occupational therapists and a speech therapist.

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

METHODS:

- Psychoeducation of the patients and their families about MS, neuropsychological rehabilitation, the functioning of the NRP, and cognitive function.
- Family interviews to get more informations about the patient, the familiar dynamics, and daily routines.
- Home visits to analyze the environment, to suggest adaptations and strategies to improve the patients' 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 support and help patients with their homework (practicing compensatory strategies and making environment modifications), improved neuropsychologic function seems 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 the patients' and relatives' quality of life.

Study supported by: Brazilian MS Society (ABEM). I work as Neuropsychologist at Brazilian MS Society (ABEM). The co-authors and I developed the study with the patients and their families that have been treated at this institution.

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(W19) CASE REPORT- IMPROVED WALKING ENDURANCE IN A 57-YEAR-OLD MAN WITH MS FOLLOWING INTERMITTENT EXERCISE.

Fatigue is one of the most common MS symptoms. Although exercise has been shown to be beneficial for persons 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 allow 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 persons with MS could make exercise gains with a minimum of fatigue. The purpose of this case report is to describe a successful intermittent exercise program for a 57 YO male with moderate disability (EDSS 5.0) due to MS. At baseline the patient showed limited endurance in walking tasks. His 6-minute walk test was 734 feet. He was unable to walk longer than 2 city blocks (approximately 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 two 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) THE 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 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 very challenging. The iMed patient management system (<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, neurologic status, relapses, treatments, neurologic rating scores on various scales, and results from MRI, cerebrospinal fluid, and evoked-potentials 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) 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 different 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.

Study supported by: Serono, Inc.

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(W21) MULTIPLE SCLEROSIS (MS) SUPPORT STAFF GUIDE

BACKGROUND: Information for non-clinical 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 healthcare professionals.

OBJECTIVE: To provide knowledge and resources to support staff members servicing patients with MS.

MATERIALS AND METHODS: Structured questionnaires were sent out to 103 CMSC sites with “full membership” status including 58 VA MS Centers and 654 patients at the Indiana Center for Multiple Sclerosis. 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 Multiple Sclerosis was designed to gather information about their knowledge of multiple sclerosis and explore how MS Center non-clinical staff members can better help communication between physicians, caregivers and patients.

DISCUSSION: This project is 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 healthcare professionals. The study will hopefully provide the support staff with improved knowledge to assist more efficiently, to better understand the disease process and to increase compliance with the ongoing medications.

Study supported by: This study is supported by a grant from Teva Neuroscience.

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(W22) ADDRESSING SEXUAL HEALTH NEEDS THROUGH A VARIETY OF 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 though 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 discussed followed by a question and answer session. Love Boat Luncheon- sexual and bladder health discussed during riverboat cruise. Sex in the City Program-a 2 night program series that featured physicians, nurses, and sexual health counselors. Issues related to emotional/sexual abuse- an expert within this field is available on site for clients and clinic staff at the two NMSS 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 persons with MS must include information to manage sexual symptoms well as 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 MS have focused on identifying factors that differentiate the employed from the unemployed for predicting which individuals are at risk for leaving the workforce, which included disease and demographic characteristics, pre-morbid 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 sub-categories, is currently being administered in 15 European countries to approximately 1,000 people with MS. Subjects are stratified by employment status and according to whether or not 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 utilized 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 utilized as a lobbying tool, at the European Union level, to help guarantee appropriate interpretation and application of the EU directives on employment of disabled people in member-states.

Study supported by: European Multiple Sclerosis Platform (EMSP).

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**(W24) COMPARE - COMPARING MUSIQOL AND MSQOL-54 IN MS 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 QoL (MusiQoL) questionnaire is a self-administered, MS specific multidimensional QoL instrument uniquely constructed from the MS patients' perspective. The questionnaire was co-developed 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, multi-center study are to: assess the utility of MusiQoL instrument in clinical practice in comparison to a disease specific QoL instrument (MSQOL-54) in subjects with relapsing forms of MS (RMS) on Rebif® therapy; and to 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 (EDSS-expanded disability status scale) and psychological health outcomes (MMSE -Folstein minimal status examination; FAB-frontal assessment battery; HADS-hospital anxiety and depression rating scale) will be collected bi-annually 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.

Study supported by: Serono Canada Inc. Sun Cheung is an employee of Serono Canada Inc. (Associate Director, Neurology) Fraser Moore, Liesly Lee, Mary Lou Myles, and Richard Leckey have received consultancy fees for their role in the development of this study

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(W25) ZANAFLEX CAPSULES FOR THE TREATMENT OF SPASTICITY IN MS: A CASE REPORT

OBJECTIVE: To determine if 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 clinic for a routine follow up visit. This patient's spasticity was being managed with daily stretching and exercise, baclofen 20mg tid, and Zanaflex tablets 12mg 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 12mg 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 prior to the change in formulation of the Zanaflex and was repeated in four 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 of time. 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 as compared to Zanaflex tablets and an extended half-life when taken with food. This patient reported an improvement in his spasticity with the capsules compared to tizanidine and Zanaflex tablets, which was confirmed by his physical exam.

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**(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 (11-15yr) feel isolated, as they do not know anyone else that may be in a similar situation with a parent whom has MS.

This poster identifies/acknowledges the needs of young people affected by MS entering their family.

160 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 from and any advice to others in a similar situation. All of these factors have an impact on the 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 is the direct impact that each young person is affected by MS such as the mood swings by their parents, making sure the parent does not get stressed; checking if their parent is having a “good” day and they are not too tired. These are the “hidden” signs of MS that professionals tend not to know about although very important for daily living in the family unit. The actual physical problems such as reduce 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.

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(W27) CHALLENGES IN REHABILITATION OF MS PATIENTS WITH NON-MS RELATED HEALTH ISSUES: MS AND MORFAN SYNDROME

BACKGROUND: Management of MS patients in MS Clinics rarely addresses non-MS related problems, deferring them to family physicians. There is little information published on 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 MS Clinic, to be able to carry out comprehensive care for these patients and their unique needs.

GOAL: To develop a rehabilitation approach that manage patients who are diagnosed with multiple sclerosis and at the same time are dealing with other acute or chronic illnesses.

METHOD Case review and model of rehabilitation approach.

New to our clinic, a 54 year old female presented with multiple sclerosis (EDSS 6.5) and Morfan Syndrome. The patient had sustained a leg injury that required rehabilitation. A conventional multidisciplinary approach to identify and prioritize 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. Detailed rehabilitation plan and model of rehabilitation approach, using the "enhanced team" in a community-based MS Clinic will be presented.

CONCLUSION: An enhanced multidisciplinary team in a community based MS Clinic can successfully manage MS patients with other serious health concerns.

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(W28) A UNIQUE MS MODEL CARE IN THE SCI/D CENTER

Clients with Multiple Sclerosis require a comprehensive interdisciplinary care. Spinal Cord Injury/Disorder at James A. VA Hospital accepted MS veteran for the past seven years in the SCI/D registry. The SCI center has been able to provide the “patient center interdisciplinary care(KT, Psychologist, OT, Dietician nursing and others” for these veterans. The veteran are very pleased with the continuity of care. This poster presentation will provide information about this model of care. The SCI/D is participating in MS Center of Excellence VA national longitudinal MS study

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(W29) HOME LINKS (LIVE INDEPENDENTLY NAVIGATING KEY SERVICES): CASE MANAGEMENT MODEL FOR MS

Home LINKS is a short-term case management program designed to promote enhanced quality of life and increased independence and safety for people with MS. It is an integral part of the NMSS, Central New England Chapter's 3-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
- Tier 3. In-home care management assessment, development of care plans, and help to accomplish client-centered goals for continued independent living

While Chapter staff manages our Tier 3 program in-house, and oversees 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
- 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. 89% of clients stated they would recommend this service to others.

Study supported by: This service is co-funded by the Central New England Chapter of the National Multiple Sclerosis Society and the Commonwealth of Massachusetts Department of Public Health.. Linda Guidod, Judy Cotton, and Dawn Russo are employed by the Chapter Programs Department of the Central New England Chapter of the National Multiple Sclerosis Society. Carrie Leggett is a member of the Home LINKS Advisory Committee and a private care coordinator who works with clients from the Chapter. Christine St. Laurent is a member of the Home LINKS Advisory Committee and the Chapter Programs Committee at the Central New England Chapter of the National Multiple Sclerosis Society.

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(W30) A COGNITIVE INTERVENTION PROGRAM FOR PERSONS
WITH MULTIPLE SCLEROSIS

Up to 70% of persons 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. Persons 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 persons 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 both through personal and individualized goal setting and through group support and interaction. Participants will learn about the different types of cognitive impairments common in MS and how cognitive impairments interact with other MS symptoms. A variety of 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 will display the theoretical background guiding the intervention, the goals and objectives of the program, key outcomes, and a description of the intervention sessions. By increasing persons with MS 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 a variety of clinical and community settings.

Study supported by: This study is currently not sponsored.

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(W31) INJECTION SITE PAIN IN RRMS PATIENTS RECEIVING SUB CUTANEOUS DISEASE MODIFYING THERAPIES

OBJECTIVE: To compare injection site pain (ISP) in patients with relapsing remitting multiple sclerosis (RRMS) administering sub cutaneous disease modifying therapies (DMTs).

BACKGROUND: DMTs are the standard treatment for patients with RRMS. Patients receiving sub cutaneous injections can experience ISP which is often dose, gauge or solution component dependent. ISP may result in compliance issues, therapy switches and add additional burden to nursing time .

Although the needle gauge for IFNB-1a (Rebif) was recently reduced to minimise injection site pain, 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.⁸

ISP and site reactions have been reported in 66.4% and 45% of glatiramer acetate (Copaxone) patients respectively.^{6,7} No comparisons have been done between glatiramer acetate and the other DMTs.

METHOD: Patients starting sub cutaneous IFNB-1b (Betaseron), IFNB-1a (Rebif) and glatiramer acetate (Copaxone) were recruited over a 3 month period.

Patients self assessed ISP using a 0-10cm pain visual analogue scale (VAS)(0cm = no pain, 10cm = worst pain). ISP was recorded before & after each injection, then 10mins, 60mins and 24 hours post injection 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 post first injection and were assessed at the clinic at 1 and 3 mths.

RESULTS: 18 patients were recruited; 8 IFNB-1a (Rebif), 2 IFNB-1b (Betaseron) and 8 glatiramer acetate (Copaxone). A comparison of the ISP for the 3 treatment groups will be presented.

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

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**(W32) ABUSE AND NEGLECT OF INDIVIDUALS WITH MS:
IDENTIFICATION & INTERVENTION**

Individuals who have physical and cognitive disabilities report higher incidences of abuse or neglect when compared to the general population. Persons 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 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 to preventing long term physical and psychological damage to the person with MS. This poster will explore the scope of the problem, review signs and symptoms that may indicate abuse is taking place, and offer 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.

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(W33) ENABLING MS SUPPORT PROGRAM DEVELOPMENT

The 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.

1) 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 a wide range of useful tools such as: development outlines, training outlines, volunteer training manual, documentation templates, volunteer guide, and resources.

2) MS Support Group Facilitator Training Guide

In Alberta support groups are a vital component of the MS community. Utilizing 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: The Administrators Guide, Contact Facilitator Guide and Self- Help Group Leaders Guide.

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

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(W34) A CENTER DEDICATED TO ENHANCING THE QUALITY OF LIFE
OF PEOPLE LIVING WITH MULTIPLE SCLEROSIS

Multiple Sclerosis (MS) is a disease with implications which reach beyond the scope of myelinated neurons. While 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 ("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 as well as 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 Multiple Sclerosis.

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(W35) USING ART AS CATHARSIS WITH MS CLIENTS...ONE GROUP'S EXPERIENCE

An extensive body of research suggests that chronic and disabling diseases such as Multiple Sclerosis 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 which are common among persons 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 will look at the art experience in the MS Wellness Program, guided by Brett Weber, Ph D, an impressionist artist who has MS. Case studies will be used to 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.

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(W36) MS ACTIVENOW:
EXPANDING THE ROLE OF EXERCISE IN THE LIVES OF PERSONS WITH MS

Until recently physical activity and exercise were contraindicated for persons with MS due to thermosensitivity, fatigue and vision-related issues. The importance of regular physical activity in the lives of persons 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 persons moderate to severe EDSS MS in a qualitative study comprising of 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, psychological and physical functioning. No negative affects of exercise were reported although barriers cited included lack of facilities, and 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 Alberta Division and Edmonton Chapter to increase community capacity for active living for persons 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 (multi-media) materials, and conducting community education sessions for professionals in order to create community capacity for active living in persons with MS. As well, the MS ACTIVEnow program will utilize medical professionals as part of a referral network with regard to access to appropriate sites.

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(W37) HOW HEALTH LITERACY AFFECTS PATIENTS WITH MS

When it comes to health information, many people just do not understand it. More importantly, 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 upon 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, 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.

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