

# MS *in focus*

Issue 7 • 2006

## ● Rehabilitation



multiple sclerosis  
international federation

## Multiple Sclerosis International Federation

MSIF leads the global MS movement by stimulating research into the understanding and treatment of MS and by improving the quality of life of people affected by MS. In undertaking this mission, MSIF will utilise its unique collaboration with national MS societies, health professionals and the international scientific community.

Our objectives are to:

- Support the development of effective national MS societies
- Communicate knowledge, experience and information about MS
- Advocate globally for the international MS community
- Stimulate research into the understanding, treatment and cure of MS

### Designed and produced by

Cambridge Publishers Ltd  
275 Newmarket Road  
Cambridge  
CB5 8JE

01223 477411  
info@cpl.biz  
www.cpl.biz

ISSN1478467X

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## Letter from the Editor



Multiple sclerosis is a complex neurological disease that manifests itself in diverse, often co-existing symptoms that affect a person's mobility and functioning in daily activities, with the consequent negative effect on self-esteem, family and social roles and employment.

For many people with MS, pharmacological therapy alone is not able to address particular symptoms adequately or, in some cases, disease progression. Rehabilitation is a component of the comprehensive management of MS that focuses on function, and adds non-pharmacological strategies for the care of the person. The objectives of rehabilitation in MS are to encourage autonomy and improve the quality of life through goal-oriented programmes that directly involve the person with MS in determining treatment priorities.

The foundation of an effective rehabilitation programme is the team, which includes the person with MS and the family, who work closely with experts from a number of specialised disciplines, including professionals knowledgeable in exercise, technical aids, speech and swallowing, vocational aspects and counselling. Working in collaboration, the rehabilitation team creates a plan, which includes short-term and long-term goals, that meets the individual needs of the person with MS, taking into account his or her priorities, lifestyle and desires.

This issue of *MS in focus* discusses rehabilitation, a topic that is relevant regardless of a person's level of impairment or disease course. Each article presents the underlying principles, aims and evidence from the literature regarding specific areas of MS rehabilitation, contributed by members of teams from around the world.

On behalf of the Editorial Board, we hope that healthcare professionals and people with MS alike find this issue an interesting and useful resource.

I look forward to receiving your comments.

**Michele Messmer Uccelli**, Editor

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The next issue of *MS in focus* will discuss genetics and the hereditary aspects of MS. Send questions and letters to [michele@aism.it](mailto:michele@aism.it) or marked for the attention of Michele Messmer Uccelli at the Italian MS Society, Via Operai 40, Genoa, Italy 16149.

## Editorial Statement

The content of *MS in focus* is based on professional knowledge and experience. The editors and authors endeavour to provide relevant and up-to-date information. Information provided through *MS in focus* is not intended to substitute for advice, prescription or recommendation from a physician or other healthcare professional. For specific, personalised information, consult your healthcare provider. MSIF does not approve, endorse or recommend specific products or services, but provides information to assist people in making their own decisions.

# An introduction to rehabilitation

By George H. Kraft, MD, MS, University of Washington, Seattle, USA

When I contemplate my multiple sclerosis (MS) practice, I am impressed that people with MS never ask for help in preventing their T cells from attacking the myelin of their central nervous system. Rather, they ask for help in improving their ability to function. Often, they ask for help in moving about. Frequently they ask if anything can be done to help them remember things better or feel less tired or depressed. When asked, they often want help with bladder function, even though they may not volunteer it initially.

Thus, people with MS desire rehabilitative care. Of course, they also want medicines to reduce exacerbations and prevent their disease from progressing. But it is improvement in function that is the major plea.

Yet rehabilitation has been slow in coming to MS care. Although now a focus of organisations such as Rehabilitation In Multiple Sclerosis (RIMS) in Europe and the Consortium of Multiple Sclerosis Centers (CMSC) in the United States, this international effort is little over 15 years old. One of the major reasons for the delay in the application of rehabilitative care to MS is that the founder of the field of rehabilitation medicine was reputed to have taught that rehabilitation for people with MS was essentially a waste of time and money; people with MS would progress in their disability, and all the effort would be for naught. Effort should be spent on more “static” disabilities such as spinal cord injury and amputations.

Prior to the establishment of RIMS and the CMSC, there was a handful of pioneering comprehensive MS centres in the United States. The National MS Society (NMSS) was instrumental in this effort, and in 1977 it approached the University of Washington to establish a comprehensive MS centre in Seattle. Other pioneering comprehensive centres at that time also existed in New York, Minneapolis, Denver and Switzerland.

The comprehensive care of people with MS has become more sophisticated over the years. Initially, around the time of the founding of the Washington centre, comprehensive care of MS consisted of improving ambulation (using canes, braces, or wheelchairs) and, possibly, bladder and bowel function. This was the concept of “comprehensive” MS care in the 1970s, a period that I call Phase I.

Phase II occurred in the 1980s and 1990s with the development of a greater appreciation of the many other systems affected by MS. It was during this phase that comprehensive MS care also began to include attention to the management of fatigue, depression, cognitive impairment and vocational matters, among others. The appreciation of deficits in these and other areas was followed by more sensitive means of measuring them and improved approaches to management. Rehabilitation of people with MS had come a long way.

However, I suggest that we are now entering a third phase: Phase III of comprehensive MS care. As we learn more about the inner workings of the

thinking processes of people with MS using qualitative interview techniques, and more about compensatory brain function through functional magnetic resonance imaging (fMRI) studies, we are becoming aware of the intense effort put forth by people with MS to function as well as they do and the role of brain plasticity in allowing this to occur. Previously discrete regions of brain activity become spatially arranged more diffusely – a necessity, as MS lesions destroy old neuronal pathways. This may account for the difficulty in multi-tasking often seen early in the disease process. Consequently, we are now suspicious that isolated system testing – whether in the motor or cognitive sphere – may not give a completely accurate assessment of function in the real world in which some degree of multi-tasking is a prerequisite for success. I believe that we are scratching the surface in our understanding of this at present.

This issue of *MS in focus* discusses rehabilitation of people with MS. The classical fields of physical and occupational therapy are reviewed, as is speech and swallowing therapy and counselling. I am also pleased to see a discussion of vocational issues, as this area of rehabilitation is often overlooked, but can often be one of the earliest casualties due to the difficulty the MS person has with multi-tasking. It has been known for years that employment rates for people with MS are lower than what would be expected. It may be that it is in the vocational sphere that all of the deficits come together, and some measure of vocational performance may be a better single indicator of the severity of MS than is the widely used Expanded Disability Status Scale (EDSS).

Rehabilitation is what people with MS want. This issue provides a concise update.



Chiara Rossi, Italian MS Society

# Physiotherapy: its role in rehabilitation

By Dawn Prasad, Physiotherapist, MS Society of Victoria, Australia



Chiara Rossi, Italian MS Society

Physiotherapy plays an important role in the management of MS. In the early stages following diagnosis, there is a strong emphasis on education and self-management with advice on when it is beneficial to request a physiotherapy assessment. The type of physiotherapy approach and the intensity of the therapy will vary depending on the needs of the person with MS and the findings of the physiotherapy assessment. People with MS do not require constant physiotherapy input; however, there are benefits to bursts of rehabilitation following a relapse or a change in functional capacity. Physiotherapy treatment may occur in a variety of settings such as hospital rehabilitation units as either an in-patient or out-patient, or in the community. In some countries rehabilitation at home is available and may be organised by or through the national MS society.

Physiotherapy is beneficial in the treatment of many symptoms of MS and during rehabilitation the physiotherapist will work with the person with MS to achieve functional goals. Some symptoms helped by physiotherapy, often in conjunction with other disciplines, are listed here:

**Weakness** is a major symptom of MS and leads to a reduced ability in walking, standing and transfers – as well as problems with daily living activities that involve the upper limbs. Physiotherapy techniques to improve strength may involve the physiotherapist handling the person with MS to provide manual resistance for movements; examples include exercises using the weight of the body against gravity, or exercises using weights or elastic bands to provide progressive resistance. During the rehabilitation phase, strengthening exercises are often focused on regaining control of particularly weak muscles and correcting muscle imbalance to restore postural stability.

Weakness is thought to be a factor in **fatigue** because weak muscles work less efficiently and tire more quickly – therefore strength training helps to reduce fatigue. Weakness also influences

balance and co-ordination and recent research into the benefits of strength training have shown improvements with functional tasks.

**Reduced motor control** (or paralysis) of a leg or an arm may result from damage to the nerve pathway supplying the muscles that control the limb. Recovery of control will be dependent on where the damage occurs and the severity of the damage. Physiotherapy may help restore lost movement when there is still the possibility of nerve impulses activating weak muscles. If restoration of movement is not possible then the physiotherapist may prescribe an external orthopaedic appliance that helps the movement of the limbs (an orthosis) such as a foot splint to improve walking.

**Reduced balance** occurs when there is a problem with the vestibular system of the brain, or sensory losses, or weakness. Physiotherapists are skilled at assessing the contributing factors to the balance problem and prescribing remedial techniques. Education and promotion of some compensatory strategies are often part of the solution; for example, vision is very important for providing additional information to the brain – therefore, putting on a light when getting up to go to the toilet at night, is very useful in reducing the risk of falling. People with MS who have impaired balance should be assessed by a physiotherapist; without physiotherapy input people often adopt compensatory strategies to reduce the risk of falls. Over time these strategies can lead to

### Physiotherapy for people with MS

- Comprehensive assessment of level of impairment due to MS
- Formation of functional and achievable goals
- Treatment
- Evaluation of response to treatment
- Education and promotion of healthy lifestyle
- Plan for follow-up rehabilitation



*Physiotherapy is beneficial in the treatment of many symptoms of MS.*

greater secondary problems, such as joint strain, increased fatigue, and muscle imbalance.

**Spasticity** is a symptom experienced by many people with MS caused by changes in the nerve impulses to the muscles resulting in spasms and stiffness. Physiotherapists are involved in teaching people with MS and their carers stretching and positioning techniques which help to relieve spasms and prevent shortening in muscles that are prone to spasms. Often, medication such as baclofen or tizanidine is required to help control the spasticity and physiotherapists are important in monitoring the effectiveness of the prescribed medication over time.

**Pain** in MS may be related to the areas of the central nervous system that are affected, and is commonly termed neurogenic or neuropathic pain; this is treated by the use of medication such as gabapentin. Other types of pain in MS may be related to muscle spasms and joint strains and can be treated by physiotherapy with success. For people with limited mobility, it is important for physiotherapists to assess the level of seating and postural support required, and to provide advice on adequate pressure relief.

**Tremor** can be a difficult symptom that limits functional ability. A variety of treatments may be tried, including repetitive patterning movements which aim to improve co-ordination, adding weights to wrists to reduce the amplitude of the tremor, and education about positioning to increase stability of the arm or leg.

### **Liaison with other disciplines**

Ideally physiotherapists work closely with other health professionals on the rehabilitation team. Often there is overlap, with functional goals directed by one discipline helping the goals of another discipline become achievable. A good example of close collaboration is when physiotherapists and occupational therapists perform joint wheelchair and seating assessments; the combined expertise of both disciplines ensures that postural needs, pressure care needs and functional capacity are all met within the same assessment process.

Physiotherapists are responsible for promoting a healthy and active lifestyle to people with MS to help reduce the impact of any relapses and to promote recovery. In the past, people with MS were not encouraged to exercise, particularly those with fatigue; however, more recent research into exercise has highlighted its positive effects and found that fatigue is actually reduced by a more active lifestyle. For people who are no longer able to exercise by themselves, physiotherapists have an important role in teaching carers how to perform regular stretches and positioning techniques.

At the completion of an in-patient rehabilitation period, it is important for physiotherapists to provide a suitable home programme or advice on suitable exercise and activities to promote continued well-being.

The physiotherapist plays a primary role in a comprehensive rehabilitation programme. Physiotherapy is appropriate at different stages of the disease for people with various levels of impairment and can be effective for treating many problems due to or associated with MS.



# Speech and Swallowing

Jeri A. Logemann, PhD, Ralph and Jean Sundin Professor, Department of Communication Sciences and Disorders, Northwestern University, Evanston, Illinois, USA

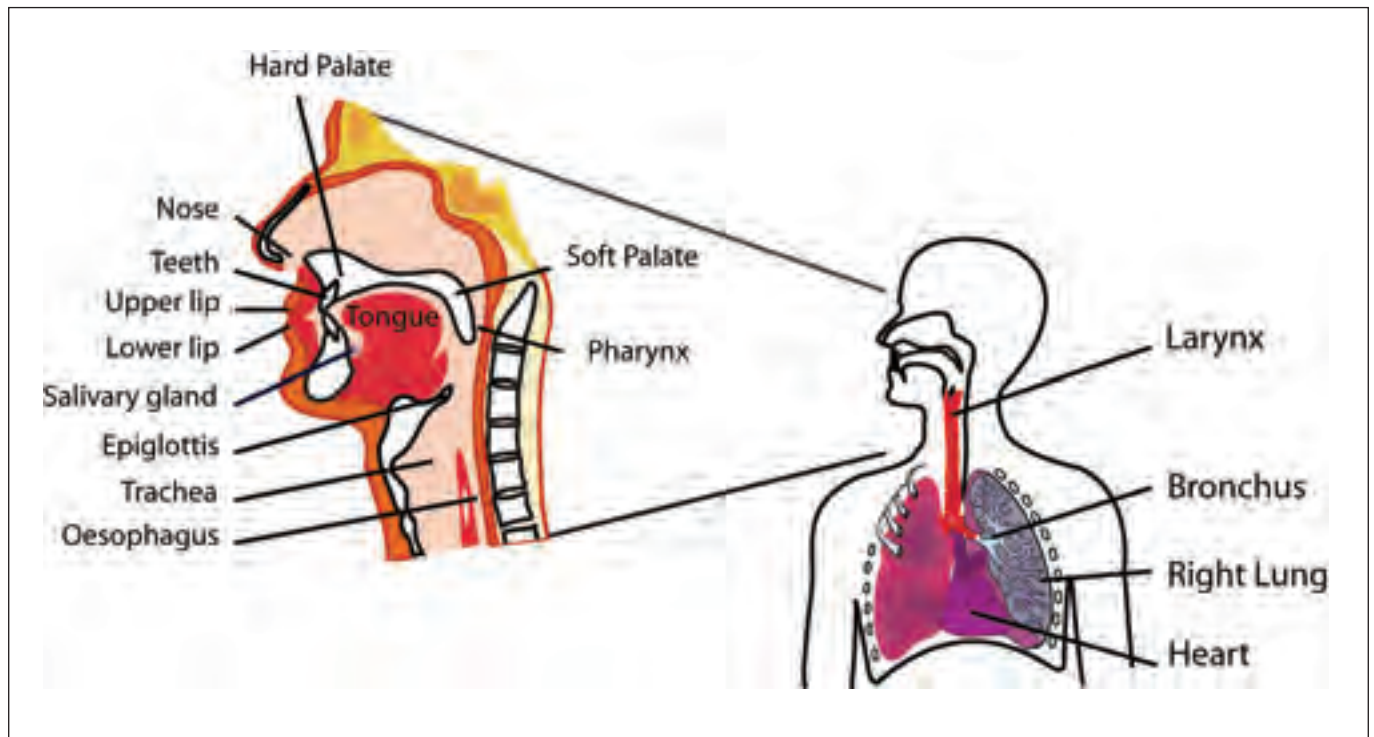
Multiple sclerosis can cause speech and/or swallowing changes at various points in the disease process, depending on the exact locus of damage in the central nervous system. The general approach to rehabilitation of speech and swallowing disorders in people with MS is to conduct a careful evaluation of each function and then to design an appropriate treatment protocol.

Speech evaluation generally involves an articulation test in which a speech-language pathologist asks the individual to produce words and sentences using all of the sounds of the person's native language to assess whether or not they are produced correctly. The pathologist defines the range of lip, tongue, soft palate, throat (pharyngeal) and voice box (laryngeal) function, and evaluates voice quality, reflecting laryngeal function and palatal movement and fluency of speech. He or she examines the rate and rhythm of speech, since this is controlled by some parts of the central nervous system. Results of this evaluation identify the muscles that are not functioning correctly and the exact nature of the abnormality.

Assessment of swallowing dysfunction usually begins by interviewing the person regarding their awareness of any disorders while eating

or drinking. A clinical assessment of the oropharyngeal area is important, and the range of motion of the lips, tongue, palate, and control of the larynx are assessed. In addition, the speech pathologist notes any particular eating habits, such as putting the chin down or pushing hard while swallowing. It is important to ask the person whether certain foods create more difficulties than other foods and whether swallowing is more difficult at various times of the day. At the end of this clinical assessment of oral and pharyngeal function, a special instrumental examination may be recommended. If the speech-language pathologist decides that there is risk of a pharyngeal stage problem that is not visible on clinical assessment because the pharynx (throat) is invisible beyond the back of the mouth, he or she may recommend an x-ray study (modified barium swallow) or an endoscopic examination.

Modified barium swallow, a moving x-ray, is able to assess the function of muscles in the mouth, pharynx, and larynx during the swallow and determine both the safety and efficiency of the individual's swallowing. Safety is critical to ensure that aspiration, or food entering the airway, does not occur. Efficiency of eating is also important, as people with MS must take in adequate fluids and calories in order to



*Parts of the body involved in speech and swallowing.*

maintain weight and health. The modified barium swallow is a simple procedure in which moving x-rays are taken while the individual completes two swallows of measured amounts of liquid: 1, 3, 5, 10 ml of thin liquids, cup drinking of thin liquids, 3 ml of pudding, and two small pieces of a cookie or biscuit coated with barium pudding which the person chews and then swallows. Fourteen swallows are usually visualised to assess swallow safety and efficiency. It is a simple test which takes less than five minutes of x-ray exposure. From this test, the clinician can identify the swallow disorders that are causing any difficulty. When the cause of a disorder has been identified, the clinician can introduce treatment strategies during the x-ray study to document the effectiveness of the treatments.

### **Treatments for swallowing difficulties**

Treatments for swallowing difficulties (dysphagia) may include: 1) changes in head or body position to re-direct the flow of food, 2) heightening sensation prior to the swallow to elicit a faster swallow, 3) applying voluntary

controls during the swallow to improve selected muscle functions, or 4) changing diet textures to reduce the risk of food going into the airway or to improve the efficiency of the swallow. Changing the food consistency is generally the last choice, since people often find it unpleasant to eliminate certain foods from the diet or to thicken liquids. At the end of the x-ray study, the speech-language pathologist writes a report that defines the swallow disorders present, the most effective treatments, and outlines a treatment/management programme.

### **Common swallowing disorders resulting from MS**

The most common swallow disorder occurring in people with MS is a delay in triggering the pharyngeal stage of the swallow. This disorder results in food or liquid dropping into the pharynx before the pharyngeal motor actions have begun, including protection of the airway. The person can aspirate and may not cough. Even patients with MS who deny any dysphagia may exhibit a delay in the swallow.

Other swallowing problems include reduced laryngeal elevation, which leads to reduction in opening of the valve into the oesophagus, and reduction in movement of the lowest part of the tongue, the base of the tongue, which causes food to be left behind in the pharynx.

Interventions for these disorders focus on therapy to improve the triggering of the pharyngeal swallow by heightening sensation prior to the swallow, exercise programmes to improve laryngeal lifting, and exercises to improve tongue base action. Unfortunately, studies of the effectiveness of all swallow-related therapies in people with MS have not been done in large numbers of subjects. The effectiveness of treatment for an individual can be done during the radiographic study by introducing selected treatments and examining their immediate effects.

### **Applicability/relevance of various interventions**

Few studies have examined the effectiveness of treatment for speech and swallowing problems in people with MS. Since there is no evidence that exercises can be harmful, it is not uncommon for aggressive therapy programmes involving exercises to be recommended.

### **Working with other disciplines**

Speech-language pathologists often cooperate with a number of other disciplines in the management of speech and swallowing difficulties. Often, changes in head or body position can facilitate swallowing or improve breath support for speech production. Physical positioning may require intervention by a physical therapist or occupational therapist in conjunction with the speech-language pathologist. The old idea that swallowing required a specific posture with feet on the floor and the trunk upright has been found to be untrue. In fact, there are people who actually swallow best lying down. Speech-language pathologists also interact with

nurses, nursing aides, and dietitians in promoting an optimal diet and caloric intake. Collaboration with the individual, the family, nurses, physicians, and others on the care team is critical to help the care team better understand the nature of the individual's speech and swallowing disorders and to determine the best ways to help promote adequate oral intake as well as to maximise oral communication. If alternative communication systems are needed due to speech becoming difficult to understand, a speech-language pathologist may recommend the appropriate instrument and provide training in its use.

Speech and swallowing therapy can be critical in achieving maximum function for the person with MS, especially as the disease progresses. Regular reassessments may be needed as the disease exacerbates or remits.



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# Occupational therapy helps to manage daily life

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A compensatory rehabilitative approach can appropriately complement treatment with symptomatic and disease-modifying therapies for people with MS. This process involves the modification of techniques and the development of new strategies to compensate for functional limitations. Occupational therapy is an important part of this approach, and focuses on skills that are important for the “occupations” of daily life and on reducing participation restrictions and activity limitations.

## Evidence from the literature

The role of occupational therapy in multi-disciplinary rehabilitation is well acknowledged. However, the multi-disciplinary character of MS treatment means it is difficult to demonstrate the net effect of occupational therapy, as people receiving multi-disciplinary rehabilitation will be seen to benefit from interventions from a variety of fields. While currently there is no reliable scientific evidence available that occupational therapy helps people with MS in managing their disease, it is likely that most professionals and individuals with MS, based on experience, do see benefit from occupational therapy interventions. Small studies have found that fatigue can be relieved using energy conservation techniques.



Italian MS Society

*Communication is one life domain addressed by occupational therapy.*

## Primary objectives and aims

The primary objective of occupational therapy is to enable individuals to participate in self-care, work and leisure activities that they want or need to perform, thereby optimising personal fulfilment, well-being and quality of life. The occupational therapist evaluates whether people with MS are limited in the life domains that are important to them (Figure 1) and determines strategies for overcoming these difficulties. Possible strategies include restoration, compensation, adaptation and prevention (Table 1).

## Interventions

Evaluation is the first step in the occupational therapy programme. The therapist assesses the performance skills in daily life activities, assesses general physical and cognitive abilities, discusses personal goals and may assess the home and work environments to evaluate the potential need for modifications. A customised occupational therapy rehabilitation

programme improves the individual's ability to perform daily activities within his or her own unique situation, thus, often requiring a combination of different techniques.

### Applicability at different stages of the disease

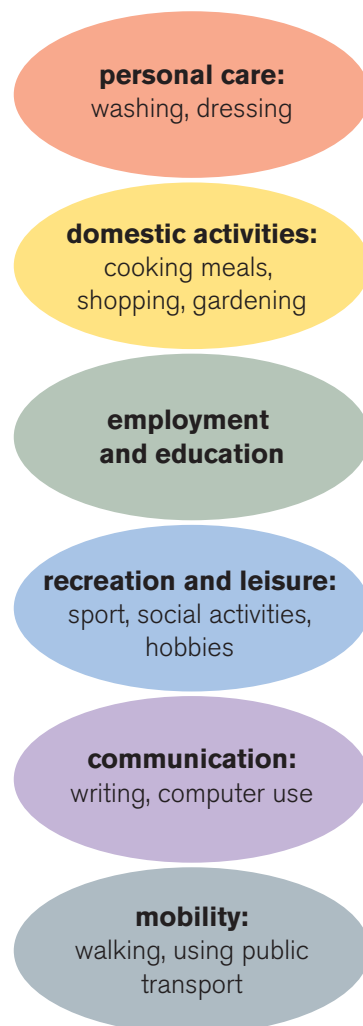
For people in the early stage of MS who experience changes in their ability to function effectively at some tasks, the occupational therapist focuses on teaching new strategies for dealing with fatigue, information about home environment adjustments, modifications to the car or workplace as well as job performance. Energy management courses may also be most appropriate at an early stage of the disease.

If functional loss increases, the occupational therapist assists the person with MS in maintaining and improving skills in different areas of the life domains. Depending on the functional abilities and needs of the individual, more attention may be focused on compensation techniques in combination with advice on obtaining an assistive device, as well as the opportunity to try out different devices and other options to meet short and long-term needs.

### Occupational therapy in the home

Meeting the individual and the family in their environment can provide the occupational therapist

**Figure 1: Life domains**



with valuable information that may not be readily available when assessing the person within a healthcare setting. The assessment includes an evaluation of the individual's current functional status in relation to the performance of activities of daily living.

An assessment of the home situation includes the evaluation of the need for assistive equipment and training. Finally, the occupational therapist's visit to the home can serve to determine whether additional paid assistance may be useful.

### Working with other disciplines

Collaboration with professionals promotes independence in all life domains. Occupational therapists work with social services for organising home visits, with physiotherapists regarding functional exercises, with speech and swallowing therapists on issues related to communication, with

nurses in performing evaluations and improving performance in activities of daily living and with neuropsychologists and speech therapists on cognitive training.

### Conclusion

Occupational therapy focuses on learning strategies for managing daily life, based on the person's physical, social and psychological needs.

**Table 1: Strategies used by occupational therapists**

<b>Restoration</b>	Maintain and restore maximum impaired functions
<b>Compensation</b>	Providing alternative methods and techniques to maintain independence
<b>Adaptation</b>	Advice and instruction on adaptive equipment and home adaptations
<b>Prevention</b>	Prevent limitations in functional abilities or worsening of symptoms

(From Lanckhorst GJ, Rehabilitation of patients with multiple sclerosis. In: *A Problem-Oriented Approach to Multiple Sclerosis*, Acco, 1997.)

# Help to stay at work: vocational rehabilitation

By Phillip D. Rumrill Jr., Kent State University, Center for Disability Studies, Kent, Ohio, USA

People with MS constitute a valuable labour resource for the societies in which they live. They are often well-educated and skilled workers with extensive employment histories, which is not surprising given that MS typically manifests itself in early-to-middle adulthood (after people have begun and, in many cases, established their careers). Too often, however, these highly trained, productive, and experienced workers leave the work force shortly after MS diagnosis, usually of their own choosing and usually before the illness has rendered them unable to work.

Experts do not know exactly why so many people with MS leave the work force prematurely, but some of the most commonly reported barriers to continued employment among people with MS include the unavailability of transportation to and from work, difficulties in obtaining on-the-job accommodations, lack of awareness of assistive technology, limited awareness of employment issues on the part of treating physicians, disincentives to work in government assistance programmes, the unpredictable and sometimes progressive nature of MS, and employer discrimination.

Studies of people with MS show that men, people with higher levels of education, people who do not

experience cognitive impairments, workers whose jobs require little physical exertion or exposure to heat, management or professional-level workers, and those whose employers have formal disability-related personnel policies are the most likely to retain employment over time.

Vocational rehabilitation provides a mechanism for people with MS to make adjustments in their careers and to continue working as long as they wish to. The purpose of vocational rehabilitation is to provide services, supports, and training that enable people with disabilities to obtain, maintain, and advance in jobs that are compatible with their interests, abilities, and experience. Early intervention is emphasised. For people with MS, that often means job retention services because the majority of people with MS are working at the time of diagnosis. Career re-entry services such as job placement assistance and career counselling are offered to people with MS who have left the work force but wish to return to it. In both job retention and career re-entry services, featured interventions include a comprehensive evaluation of vocational interests and aptitudes, identification and implementation of workplace accommodations, training in the use of assistive technology, self-advocacy training, and consultation with employers on a wide range of disability-related matters.



Vocational rehabilitation is an interdisciplinary enterprise that blends the expertise of professionals in the fields of medicine, allied health, psychology, counselling, social work, engineering, technology, human resource development, and law. The person with MS plays a prominent role, as all decisions regarding services are made in deference to the person's stated goals and preferences. Abiding precepts in vocational rehabilitation are (a) that there is an inherent dignity in working, (b) that people are better off working than not working, and (c) that disability in and of itself should not prevent someone from working if he or she wishes to do so. All available evidence indicates that the onset of MS or any other chronic illness rarely affects vocational interests, that is, the field in which one prefers to work.

MS may affect the person's abilities in certain areas, in which case a premium is placed on modifying the job that the person is accustomed to or finding another job that is closely related to his or her customary occupation. Often, this modification or transfer is accomplished through the implementation of workplace accommodations, with employer co-operation.

For people with MS, the workplace accommodations that have proven effective in helping them stay in the work force include schedule modifications (the most common form of

workplace accommodation implemented on behalf of people with MS), memory aids to combat cognitive impairments, motorised scooters to combat fatigue and mobility problems, climate control in the work station, low vision aids (e.g. magnification machines, voice output software), accessible parking, building renovations to allow for wheelchair access, cooling vests, ergonomic keyboards, voice-activated computer programs, and telecommuting or home-based employment. In some countries, the employer is required to pay for needed employee accommodations. In others, government agencies and sometimes the worker herself or himself assume the costs of accommodations.

Regardless of the country in which one lives, knowing the legal protections available to workers with disabilities, the community services available, and the financial and other resources that can facilitate continued employment is a critical factor in the long-term vocational success of a person with MS. Even more importantly, maintaining an active and effective symptom management regimen, identifying changes in one's health status and job performance, generating solutions to disability-related problems at work, and advocating for oneself with employers to implement those solutions are the most powerful antidotes to the negative impact that MS can and too often does have on a person's career.

# The role of counselling in rehabilitation

By C.N. Tromp, Psychologist and R. Petter, Social Worker, MS Clinic, Groningen University Hospital, Groningen, The Netherlands



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Counselling people with MS is more than just listening and giving advice. It is a form of helping an individual to deal with personal problems relating to the disease that is often absent from conversations with family, friends and some healthcare professionals. It is about providing support and helping people change, and not primarily about promoting practical solutions.

A counsellor is not committed to a certain medical treatment policy, and therefore, aspects of dealing with the disease can be discussed without direct consequences for treatment. Counsellors can also be helpful in shaping the style of living with MS according to the person's wishes and needs. An optimal treatment programme for a healthcare provider can be difficult and unsatisfactory for the individual treated. A person with MS can often exert more influence on his or her life and disease management than he or she may think. Helping people with MS realise their autonomy in decision-making is part of the counselling process.

*Counselling for people with MS focuses mainly on coping with the uncertainties and unpredictability of the illness.*



### **Aims of counselling**

Counselling for people with MS focuses mainly on coping with the uncertainties and unpredictability of the illness. Each person with MS, regardless of the type and course of the illness, must adapt continuously to changing symptoms and find ways to live with relapses and remission. Learning to assess the effects of these changes (both physical and cognitive) on daily life, setting priorities for where energy should be concentrated and recognising the need for new priorities for activities and tasks, making therapeutic decisions, redistributing responsibilities within the family, and making vocational choices, are some of the important topics that can be discussed during counselling with a professional counsellor who has an understanding of MS.

After diagnosis, the need for information, advice and reassurance, especially about the prognosis and therapy options, is foremost. Information about the illness, both from the medical side and regarding public resources, especially that taken from the Internet, can be evaluated and interpreted, with particular reference to the person's own opinion about it, with the assistance of the counsellor. When a person with MS is not followed and supported during this early period, dealing with the disease can be a lonely, isolating experience. A counsellor can be an important resource during this time and at various times throughout life with MS.

### **Discussing difficult topics**

No one can read the minds of others, so the need to be specific and clear when communicating about personal and perhaps difficult subjects such as the amount of help and support that is required, can put a strain on relationships, especially when support needs may fluctuate from one day to another. This constant effort to be both candid and tactful can be very challenging and discouraging both for the person with MS and those around him or her. The situation often creates a need for the person with MS to be outspoken and assertive in expressing

needs and desires with family members.

Assertiveness that is appropriate for the situation and contexts may require practice. The counsellor can play a role in helping the person rehearse and prepare discussions on difficult topics with family members and can provide encouragement and feedback.

### **Topics of counselling**

Up to 50 per cent of patients with MS in the relapsing/remitting condition develop serious, and sometimes permanent psychological symptoms. Prevention or management of these symptoms is another aim of counselling efforts. Psychological problems include depression, stress reactions and chronic fatigue. Cognitive problems can be a major concern, requiring an understanding of not only the individual, but also of those around the person with MS. Shifts in the competence and roles of parents or children within a family structure are sometimes difficult to accept. For parents, dealing with the requirements of younger family members, who often come home from school or work and expect attention and care, exactly at a moment when their parent is most exhausted, can be frustrating. Working out practical solutions can be part of the counselling process.

Counsellors knowledgeable in MS can also have a role in working with children whose parent has MS. Meeting with the entire family, with the child or children individually, as well as participating in the development of programmes and activities organised for children of people with MS, are all ways in which a counsellor can help families to deal with the challenges of MS.

Counselling can be of value both for the person with MS as well as for those who are close to the individual who deal with MS in their personal lives – either directly or indirectly. Indications for counselling include a broad range of subjects, which require close and timely co-operation with other professionals, including the nurse, neurologist and social worker, in order to be a valuable supplement to regular care.

# Your questions answered

Readers of *MS in focus* ask questions to the Editor, Michele Messmer Uccelli.

www.photos.com



**Q.** My neurologist suggested that I be evaluated for an exercise programme that I can do at home. Wouldn't a more intensive, in-patient rehabilitation programme be more effective?

**A.** Studies have found some benefits for both in-patient and out-patient rehabilitation approaches. The most important aspect to keep in mind is that the frequency, intensity, and setting of a rehabilitation programme must be based on individual needs. A comprehensive evaluation prior to beginning any rehabilitation programme will help to determine what is most appropriate for you.

**Q.** If people with MS experience extreme fatigue why would exercise be helpful? Wouldn't it just worsen the fatigue?

**A.** Exercise can improve strength, stamina and cardiovascular fitness, as well as maintain a healthy weight. If practised following some basic rules, these benefits can be achieved while avoiding the negative effects of MS fatigue. It is always important and helpful to consult a physiotherapist to learn what types of exercise are appropriate for one's capability and level of functioning. Avoiding exercising in excessively warm places, taking breaks and drinking fluids before, during and after exercise can all be helpful strategies in managing fatigue while exercising.

**Q.** I can walk without help for short distances, although I gradually become unsteady if I need to walk for an extended period of time. In that case I hold on to whoever is with me for support. My neurologist wants to refer me to an occupational therapist for an evaluation of my walking. I'm afraid that the therapist will tell me I need a stick or even worse. I can't help feeling that it would be better if I kept on for as long as possible without an aid. It's like once you start with a stick a wheelchair is just around the corner. Plus, a stick is for the elderly and I'm only 35. Should I hold out longer or give in?

**A.** Many people with MS may feel like you do, that accepting a technical aid is a form of "giving in" to the disease. It doesn't help that our society values health and fitness and that technical aids such as sticks, braces and wheelchairs are often seen as "symbols" of disability. Technical aids, are tools for maintaining independence that can permit a person with MS to overcome daily difficulties and to better manage MS symptoms, such as fatigue. In short, technical aids can help you to participate more easily in all of the activities that you enjoy and that make up your life.

# Recommendations on Rehabilitation Services for Persons with MS in Europe

On December 18, 2003, the European Parliament approved a resolution on the rights of people with multiple sclerosis, an important achievement for the 400,000 people affected by MS living in European countries. Among the strategic points of the resolution is the call for a European Code of Good Practice, to be adopted in the different Member States.

The *Recommendations on Rehabilitation Services for Persons with MS in Europe*, an initiative of the European Multiple Sclerosis Platform (EMSP), with the endorsement of Rehabilitation in Multiple Sclerosis (RIMS), is an important step toward achieving this goal of Europe-wide good practice.

The *Recommendations* are the final result of an intense process that was begun in 2003 by the EMSP with the involvement of their membership, 29 European MS societies, and the support and contributions of individual RIMS members.

The first step to establishing *Recommendations on Rehabilitation Services* was to assess the current availability of rehabilitation services across Europe. National MS societies in 15 member countries of the EU, ten countries that entered the EU in May 2004, and eight extra-EU countries participated in the survey.

The survey included questions on several aspects of health organisation specifically related to rehabilitation, including healthcare system structures, specific legislation for people with disabilities, the availability of

information on MS within healthcare structures and different rehabilitation services. In autumn 2003, a panel of 18 professionals and experts from both Western and Eastern European countries, including individual RIMS members, drafted a document. This draft was then discussed at an international seminar attended by professionals and officers representing rehabilitation centres and MS societies from 23 European countries, before a final version was produced.

The EMSP assumes the important responsibility for the dissemination of the *Recommendations* to all its Member Societies, who, in turn, will make the document available to people with MS and professionals. Most importantly, the *Recommendations* are specifically addressed to policy makers who have the opportunity and the responsibility for responding to the needs and requests of all citizens living with MS.

It is the intention of the EMSP that this document be utilised as a lobbying tool at national and European levels. The *Recommendations* establish standards for rehabilitation services that people with MS have the right to access, regardless of nationality.

The *Recommendations* were presented by the EMSP during the MS Information Hour in the European Parliament on October 20, 2004.

For a copy of the recommendations, please contact Christoph Thalheim at [ms-in-europe@pandora.be](mailto:ms-in-europe@pandora.be)

# MS in focus introduces Anders Romberg

Helle Lyngborg interviewed Anders Romberg, physiotherapist-researcher from Finland, about his work, his research and the important centre with which he is associated.

Anders Romberg is a physiotherapist at the Masku Neurological Rehabilitation Centre (MNRC), which is a facility of the Finnish Multiple Sclerosis Society, located near the city of Turku. Anders has twenty years of experience in neurological rehabilitation.

## Can you describe the MNRC?

The MNRC was founded in 1988 and has grown from 52 to 87 beds and from 32 to 120 staff members. Today 1,400 patients, of whom approximately 1,000 with MS, are treated yearly in the centre. The average length of stay is 21 days. The services offered by MNRC include in-patient rehabilitation only, with a special emphasis on adaptation training for newly diagnosed patients and rehabilitation for individuals with significant impairments. The MNRC also serves as a resource centre for people with rare neurological diseases.

The work in the MNRC is based on an interdisciplinary team approach. The staff (divided into pink, blue and green teams) includes three neurologists, six psychologists/neuropsychologists, three social workers, two speech therapists and a number of occupational therapists, physiotherapists and nurses all more or less specialising in neurological rehabilitation.

The vast majority of services provided at the MNRC are reimbursed by the Social Insurance Institution of Finland. The centre has had the ISO-9001 standard (SFS) certification since August

2002. In practice, this means that the quality of the work is continually evaluated, that the centre has a staff person who is responsible for quality control, and that external audits are periodically made in order to assess the level of quality of the services provided. For the individual patient this offers a guarantee of the provision of optimal rehabilitation services.

## What are your role and responsibilities?

As a physiotherapist, I plan, perform and evaluate physiotherapy programmes for individual patients. As a team member I also participate in admission, follow-up and discharge meetings together with other rehabilitation professionals.

I am also involved in research and have published a number of scientific articles as well as a book (in Finnish) entitled *MS and Exercise – Joy, Quality of Life & Functional Ability* (2005). My recent research interests include effects of long-term exercise on MS, and the effects of heat stress on fatigue and functional ability. Dr Juhani Ruutiainen, Director of the MNRC, and Päivi Hämäläinen, Director of Neuropsychology, are my primary research collaborators.

## In your experience, has there been an evolution in MS rehabilitation over the years?

Indeed. High-quality studies have shown that rehabilitation can truly benefit people with MS and that the effects can be long-lasting. It is difficult to

estimate how much the scientific evidence actually influences clinical practice, but what is certain is that rehabilitation professionals have become more critical in the way they work. There is greater consistency in evaluation tools and the way rehabilitation outcomes are measured in MS centres.

We have seen an evolution in the treatment of bladder problems with improved catheterisation techniques. A better understanding of electrical stimulation and pelvic floor exercises, among other aspects of rehabilitation, has meant that symptom improvement is possible for many people with MS, thus, improving their quality of life.

There has been progress in understanding the neurophysiological basis for neurological rehabilitation in MS. Brain plasticity, the capability of brain structures to adapt to new situations and to build new networks, provides an exciting base on which to build, providing evidence that research in rehabilitation plays an important role.

**What aspects does rehabilitation research have in common with other types of research, for example, with clinical trials, and how does it differ?**

In rehabilitation research in MS, different types of study approaches and designs are needed to capture the complex interventions, outcomes and human interactions that characterise most aspects of rehabilitation. Descriptive or cross-sectional studies are useful to uncover frequent features in MS symptomatology that might be relevant for, or taken into account when considering new treatments. Qualitative studies are helpful in understanding the individual experiences of rehabilitation (because so much of rehabilitation is based on individual face-to-face or hands-on contact).

Conducting a randomised clinical trial in rehabilitation is complicated. Randomising the participants to different arms of a trial without them knowing which treatment they are getting, and



Seija Suominen

**Anders Romberg, physiotherapist.**

including a placebo treatment, are difficult aspects to overcome. There are also ethical considerations when randomly assigning patients to a less-than-optimal treatment (or no treatment) condition when we already know (presumably based on clinical experience) that a particular treatment is the best option.

**What impact does/can rehabilitation research have on people with MS?**

In short, rehabilitation research improves care and treatment for people with MS. For example, based on our study results, physiotherapists at the MNRC have more precise knowledge about what should be taken into account when planning home exercise programmes for people with MS. The results have also provided support for improving adherence to home exercise protocols.

Research also has the potential for demonstrating the value of rehabilitation in MS. Financial resources are always limited and research is among the best tools for showing that rehabilitation is justified in such a complex and unpredictable disease as MS.

# The Italian MS Society meets peoples' rehabilitation needs

By Chiara Provasi, National Headquarters, Italian Multiple Sclerosis Society, Genoa, Italy

## Background

When the Italian MS Society's in-home rehabilitation service was established in 1976 in Genoa, there were no services provided by the National Healthcare System (NHS) that met the needs of severely impaired people with MS who had difficulty leaving their homes and who were thus not receiving services from which they could benefit. In addition, the NHS gave priority for rehabilitation to people in acute situations rather than those with a chronic illness. Also, the public facilities offering rehabilitation through the NHS had, and continue to have, limited hours that preclude many employed people with MS from accessing services.

The MS Society assumed all costs for the service until 1982, when the NHS officially recognised the importance of in-home rehabilitation for many people with MS, in order to avoid lengthy hospital stays and to reduce costs related to frequently transporting severely disabled individuals to a rehabilitation facility.

## Aims:

- To offer rehabilitation services to people who otherwise would not access these services due to the seriousness of their condition, architectural barriers of the home or transportation difficulties.
- To provide a more flexible possibility for receiving rehabilitation services for people with MS who are employed.

## Marketing the service

The MS Society has information stands in the

major MS diagnostic and treatment centres where information about the in-home rehabilitation service is provided.

Public health-related service providers often let people with MS know of the rehabilitation service and direct them to phone for further information. This serves to avoid a lengthy waiting period for receiving rehabilitation through an NHS facility.

Regular information about the rehabilitation service appears in the MS Society's magazine.

Word-of-mouth has proven to be an efficient marketing tool for the service as well.

## Organisation of the service

A social worker receives an inquiry from an interested individual, explains all services available, attempts to understand the needs and interests of the person and determines if access to the rehabilitation service is appropriate.

The team, consisting of a rehabilitation physician, nurse, occupational therapist, physical therapist, social worker and psychologist, meets with the individual at the out-patient rehabilitation centre for a comprehensive evaluation. The initial evaluation may also be performed in the person's home by the entire team if it is impossible for the individual to reach the rehabilitation centre.

The team determines whether the person is appropriate for rehabilitation, if rehabilitation can be provided within the home (i.e. is the home the most appropriate environment) and develops the rehabilitation plan.



Italian MS Society

### *Italian MS Society rehabilitation team in Genoa.*

Services available through the in-home rehabilitation service include the following:

- Physical therapy
- Psychological support
- Speech and swallowing therapy
- Advice on technical aids and home modifications
- Evaluation and training for the individual and family by the nurse

### **Results**

The region of Italy covered by the in-home rehabilitation service has an estimated 1,500 people with MS. The service currently follows 651 individuals in their homes. Rehabilitation, support and consultancy are carried out by 13 rehabilitation physicians, 75 physiotherapists, two occupational therapists, six psychologists, one nurse, one social worker and one administrator.

### **Expenses**

- Hourly fee for rehabilitation staff
- Reimbursement for home visits that require excessive travel time
- Continuing education for staff
- Administrative costs

### **Disadvantages of the service**

- May be difficult for rehabilitation professionals to reach some areas of the region served
- Can be a barrier to socialisation
- Provides a “non-neutral” environment that

potentially can place the rehabilitation professional at a disadvantage

- Creates difficulties for use of special equipment

### **Advantages of the service**

- Creates better opportunities for involving family members in the rehabilitation plan
- Training is performed in the person's real-life situation and not in an artificial healthcare setting
- Allows significantly disabled individuals to receive rehabilitation
- Allows employed people with MS more flexible access according to their individual needs, without the necessity of taking time off of work
- Eliminates worsening of fatigue experienced by many people with MS due to travelling, heat, waiting, and other negative aspects associated with attending an out-patient clinic
- Provides the ideal setting for testing of and training in the use of assistive devices

In-home rehabilitation, provided by professionals who receive specialised continuing education, can be an important service for many people with MS. While there are some disadvantages, the service has proven that hospitalisation for rehabilitation is not necessary in all cases, and so also serves to contain costs.

*For more information contact Dr Maria Laura Lopes De Carvalho, Italian MS Society Rehabilitation Centre at [segreteriaism@iol.it](mailto:segreteriaism@iol.it).*

# Results of the online survey on rehabilitation

Responses to an online survey on the MSIF website ([www.msif.org](http://www.msif.org)) have revealed what some of our readers think about rehabilitation.

**One hundred and twenty seven people with MS responded to the survey, all of them have participated or are currently participating in a rehabilitation programme (i.e. a programme that is based on evaluation and recommendations by a rehabilitation professional).**

Respondents reported that they accessed rehabilitation via both out-patient centres and clinics or through in-home rehabilitation programmes. Even though the programme could include a number of different interventions, the most commonly reported areas were physiotherapy and occupational therapy. Respondents accessed social or rehabilitative nursing, cognitive re-training and vocational rehabilitation less frequently, perhaps indicating that the main focus of rehabilitation programmes continues to be primarily the physical aspects of MS.

**The box provides details on the interventions most frequently accessed by respondents.**

Symptom management was the topic discussed most frequently during rehabilitation, while issues such as housing, driving, relationships and financial planning received less attention.

Although many experts would agree that taking part in a rehabilitation programme is an important part of the overall management of MS, consistent follow-up may be helpful in adjusting the programme according to the person's changing needs. This seems to be an important

area for improvement, since the majority of respondents reported that they did not receive any follow-up or on-going physical training. A majority of respondents felt that their rehabilitation programme was too brief and therefore not beneficial. Many reported that improperly managed fatigue during exercise, professionals lacking knowledge in MS and lack of benefit led to their dissatisfaction with rehabilitation overall.

The results show that although many people with MS do receive rehabilitation, it appears that it does not always meet their expectations. Studies that provide evidence for the most beneficial types, frequency and settings for rehabilitation could contribute to improving satisfaction. Research in this field may also lead to the development of specific guidelines on rehabilitation in MS.

## Types of interventions

Physiotherapy	73 %
Occupational therapy	34 %
Psychology	17 %
Rehabilitation of bladder, bowel and sexual disorders	10 %
Rehabilitation in speech, language and swallowing disorders	6 %
Vocational rehabilitation	6 %
Rehabilitation nursing	6 %
Cognitive re-training	4 %
Social nursing	3 %

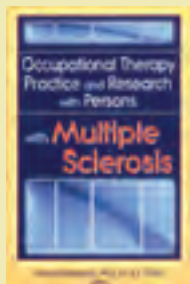


# Reviews

## Book review: Occupational Therapy Practice and Research with Persons with Multiple Sclerosis

Edited by Marcia Finlayson, PhD, OT

Review by Jens Olesen, PT, clinical supervisor, Master of Education, Denmark



The aim of this important book is to present current knowledge about different rehabilitation approaches within the MS area from an occupational research perspective. I was impressed by the book and the editor's openness to offer us a more trans-

disciplinary approach to MS research, as well as practice, in the world of MS rehabilitation. The book is essential reading for physicians, occupational therapists, physical therapists, nurses, psychologists, and other disciplines engaged in rehabilitation. It presents valuable tools and perspectives for everyone working in MS rehabilitation.

Seven articles discuss different systematic research methods and ways of collecting and interpreting data in MS rehabilitation to supplement more biomedical-oriented approaches. In this respect the book also serves to bridge different research paradigms. The topics covered include: health-related service needs of older adults with MS; the differences in the symptoms and functional limitations experienced by people with MS who are referred to occupational therapy compared to those who are not; the range of fatigue assessment tools available for clinical and research applications; the effect of wheelchair use on quality of life, and the implications of tremor on everyday activities; the development and use of lifestyle management programmes and coping processes used by women who are aging with MS. I highly recommend this book not only because it is easy to read, but also because of the research that is presented.

*Publisher: Haworth Press, 2004*  
*ISBN 0789023806, Price US\$27.97*

## Website review: Abledata.com

Review by Ian Douglas, International Programme Manager, MSIF, London, UK



Abledata.com is an US-based website that provides information on assistive technology and rehabilitation equipment available from domestic and international sources.

The website is easy to use, and simply set out with no irritating "pop ups" or other complications which can slow the downloading of web pages. It has four main sections. The first, "Products", lists web links for suppliers of products in categories ranging from "Architectural Elements" to the "Workplace". As a measure of the comprehensive nature of the site's database, the section on "Wheeled Mobility" has eight sub-sections with, for example, 354 links under "Powered Wheelchairs" and a further 483 links in the "Manual Wheelchairs".

In addition to the main section on products, Abledata.com has a detailed "Information Centre" which provides all the "Internet resources known to us on a selected disability issue – all on one page". This section looks further than just products or aids, and gives links to (US-based) support and campaigning organisations, as well as a number operating at the State level. It also lists online publications and related conferences and other events.

Finally, one of the other four main sections, "Consumer Forum", appears less well serviced than the other sections, though this does not really detract from the usefulness of the other comprehensive listings.

The site has a useful internal search engine (it would be unwieldy if it did not) and the option to register and sign up for email updates. In summary, a useful if unexciting site, primarily for those based in the US, with more limited use for those in other countries for obvious reasons.

## Video/DVD review: Serenity In Action – Tai Chi

Review by Razia Mohamedali, Kenya



This is a very interesting video of about 30 minutes.

The exercises are relatively simple and easy to follow, with the exception of Section Three, where the movements are a bit difficult to follow, especially if the person doing them has the common MS problem of incoordination.

People with MS should not despair if unable to do them the first time as things will improve with regular practice. They are also not strenuous and therefore very “MS friendly”. Some of the exercises are specifically aimed at improving balance, which is quite a problem for people with MS and should be of help.

The movements are demonstrated by the participants and are also shown from the wheelchair position.

Unfortunately, specific instructions to help you carry out the exercises (such as how to breathe properly) appear at the end of the video rather than before the exercises begin. My advice to those planning to buy this video is: be sure to watch the entire video before beginning to perform the exercises in order to benefit fully from them.

This video was produced by Qi Therapy Production and is priced at US\$24.95 (retail).

*It can also be ordered from P.J. Klein, P.T. EdD at the following address:*

*Qi Concepts*

*c/o Bill Adams Martial Arts and Fitness Centers*

*3211 Transit Rd, Elma, NY 14059, USA.*

*kleinqj@adelphia.net*

*Telephone: +1 (716) 668-5004*

# Relevant

## Physiotherapy

Patti et al (2002). The impact of outpatient rehabilitation on quality of life in multiple sclerosis. *Journal of Neurology*, 249: 1027–1033

Kileff and Ashburn (2005). A pilot study of the effect of aerobic exercise on people with moderate disability multiple sclerosis. *Clinical Rehabilitation*, 19: 165-169

White L J (2004). Resistance training improves strength and functional capacity in persons with multiple sclerosis. *Multiple Sclerosis*, 10: 668 - /674

## Occupational Therapy

Mathiowetz V, Matuska K M, Murphy M E (2001). Efficacy of an energy conservation course for persons with multiple sclerosis. *Archives of Physical and Medical Rehabilitation*, 82: 449-456

O'Hara L, Cadbury H, De S L, Ide L (2002). Evaluation of the effectiveness of professionally guided self-care for people with multiple sclerosis living in the community: a randomized controlled trial. *Clinical Rehabilitation*, 16: 119-128

Steultjens E M, Dekker J, Bouter L M, Cardol M, Van de Nes J C, Van den Ende C H M (2003). Occupational therapy for multiple sclerosis (Cochrane Review). In: *The Cochrane Library*, Oxford: Update Software, Issue 3, 12p

Tipping L (1994). Multiple Sclerosis. In: Turner A, Foster M, Johnson S E (eds) *Occupational therapy and physical dysfunction*, New York: Churchill Livingstone, pp. 497-512

# references

Duportail M (1997). Technical Appliances, assistive and adaptive equipment. In: Ketelaer P, Prosiegel M, Battaglia M, Messmer Ucelli M (eds). *A Problem-Oriented Approach to Multiple Sclerosis*, Leuven/Amersfoort: Acco, pp 329-331

Lanckhorst G J (1997). Rehabilitation of patients with multiple sclerosis. In: Ketelaer P, Prosiegel M, Battaglia M, Messmer Ucelli M (eds). *A Problem-Oriented Approach to Multiple Sclerosis*, Leuven/Amersfoort: Acco, pp 15-17

## Speech and swallowing

Abraham, S A, & Yun, P T (2002).

Laryngopharyngeal dysmotility in multiple sclerosis. *Dysphagia*, 16: 69-74

Calcagno P, Ruoppolo G, Grasso M D, De Vincentiis M, Paolucci S (2002). Dysphagia in multiple sclerosis. *Acta neurologica Scandinavica*, 105: 40-43

Fabiszak A (1987). Swallowing patterns in neurologically normal subjects and two subgroups of multiple sclerosis patients. Unpublished dissertation. Northwestern University

Logemann J A (1993). *A manual for videofluoroscopic evaluation of swallowing* (2nd ed), Austin, TX: Pro-Ed

Logemann J A (1998). *Evaluation and treatment of swallowing disorders* (2nd ed), Austin, TX: Pro-Ed

Wiesner W, Wetzel S G, Kappos L, Hoshi M M, Witte U, Radue E W, Steinbrich W (2002). Swallowing abnormalities in multiple sclerosis: Correlation between videofluoroscopy and subjective symptoms. *European Radiology*, 12: 789-792

## Vocational rehabilitation

Rumrill P, Roessler R, Fitzgerald S (2004). Vocational rehabilitation-related predictors of quality of life among people with multiple sclerosis. *Journal of Vocational Rehabilitation*, 20(3): 155-163

Rumrill P, Roessler R, Vierstra C, Hennessey M, Staples L (2004). Workplace barriers and job satisfaction among employed people with multiple sclerosis: An empirical rationale for early intervention. *Journal of Vocational Rehabilitation*, 20(3): 177-183

Roessler R, Rumrill P (2003). Multiple sclerosis and employment barriers: A systemic approach. *Work: A Journal of Prevention, Assessment, and Rehabilitation*, 21(1): 17-23

Roessler R, Rumrill P, Hennessey M, Vierstra C, Pugsley E, Pittman A (2003). Perceived strengths and weaknesses in employment policies and practices among people with multiple sclerosis: Results of a national survey. *Work: A Journal of Prevention, Assessment, and Rehabilitation*, 21(1): 25-36

Rumrill P, Hennessey M (2001). *Multiple sclerosis: A guide for health care and rehabilitation professionals*, Springfield, IL: Charles C. Thomas

## Counselling

Chan A (1999). Review of common management strategies for fatigue in multiple sclerosis. *Int J. MS Care*, 2:13-19

Sadovnick A D, Remick R A, Allen J, Swartz E, Yee I M, Eisen K Farquhar R, Hashimoto S A, Hooge J, Kastrukoff L F, Morrison W, Nelson J, Oger J, Paty D W (1996). Depression and multiple sclerosis. *Neurology*, 46(3): 628-32

# MS *in focus*



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MSIF is a non-profit charitable organization 501(c)(3) IRC chartered in the State of Delaware, USA, in 1967. UK registered charity 1105321.

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## With many thanks

MSIF would like to thank Serono for their unrestricted grant which made the production of **MS in focus** possible



Serono is the third largest biotech company in the world. Our products are sold in over 90 countries world-wide. We have been active in the fight against Multiple Sclerosis (MS) for almost a decade and have a fundamental long term commitment to people with MS, by bringing new, innovative and effective

treatments in this area. Serono is dedicated to enhancing patient care and management by constantly improving our patient services. Through pharmacogenomics, we are active in the research towards understanding the genetic basis of MS. Serono is committed to constant research and discovery efforts as we look for even better therapies and hopefully, one day, a cure.

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