

# European Multiple Sclerosis Platform (EMSP)

## Recommendations on Rehabilitation Services for Persons with Multiple Sclerosis in Europe

endorsed by RIMS,  
Rehabilitation in Multiple Sclerosis



european multiple sclerosis platform aisbl

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*Together for Health*

# **Recommendations on Rehabilitation Services for Persons with Multiple Sclerosis in Europe**

endorsed by  
**RIMS, Rehabilitation in Multiple Sclerosis**

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## Foreword

Being a progressive disease that affects the central nervous system, Multiple Sclerosis (MS) is known to affect a wide variety of physical, mental and psychological functions. Although some patterns of disability are evident, in many ways the combination of impacts is unique to each individual stricken by the disease.

Rehabilitation is vital to enabling people to “live with MS”. It cannot alter the course of the disease, but it facilitates the learning of new ways to carry out the day-to-day tasks that allow individuals to maintain a higher level of independence and self-empowerment. Increasingly, rehabilitation programmes seek to exercise body, mind and spirit, recognising that an integrated approach has the most positive effect on overall health and well-being.

In publishing this 2nd Edition of Recommendations for Rehabilitation of MS, the European MS Platform (EMSP) demonstrates its commitment to ensuring that all MS stakeholders – including patients, health professionals and policy makers – have access to cutting-edge information. Indeed, the achievement of critical advances in three aspects of rehabilitation prompted this update:

- Introduction of the International Classification of Functioning (ICF) has expanded the perception of rehabilitation, taking it from the notion of specific treatment of a single symptom to the concept of treating the full range of disabilities and handicaps resulting from the original symptom.
- New insights into the mechanisms of rehabilitation, especially in the area of neuroplasticity, recognise the brain’s ability to actively change its organisation when functions are damaged or lost due to deterioration of neuronal networks.
- Increased recognition of the importance of goal setting and identifying outcome measures for rehabilitation underpin a shift toward rehabilitation programmes designed to help patients address quality of life issues. Considerable scientific data now support the idea that people with MS (PwMS) should take part in making decisions to determine what treatment is best for them in a given situation.

These findings have led to numerous new interventions, which are being studied at least partly under the conditions of evidence-based medicine (EBM), thereby giving the field of rehabilitation a more rigorous and quantitative foundation. This edition emphasizes the importance of defining and monitoring the frequency of the symptom, problem or disability, and presents an overview of most important and/or accepted interventions and treatment techniques.

EMSP has worked closely with Rehabilitation in MS (RIMS) as the European Network for Best Practice and Research and the European Network of MS Centres to develop this publication. Both partners express their sincere gratitude to the many experts who contributed content and to members of manuscript review board for their invaluable input.

This publication supports the European Code of Good Practice in MS, particularly in regard to the fundamental principle that all PwMS throughout Europe should have “equal rights and access to treatment, therapies and services in the management of MS”. We trust that all who read it will assist us in our efforts to disseminate it broadly and to lobby actively at local, national and European level for implementation of its recommendations.



John C. Golding  
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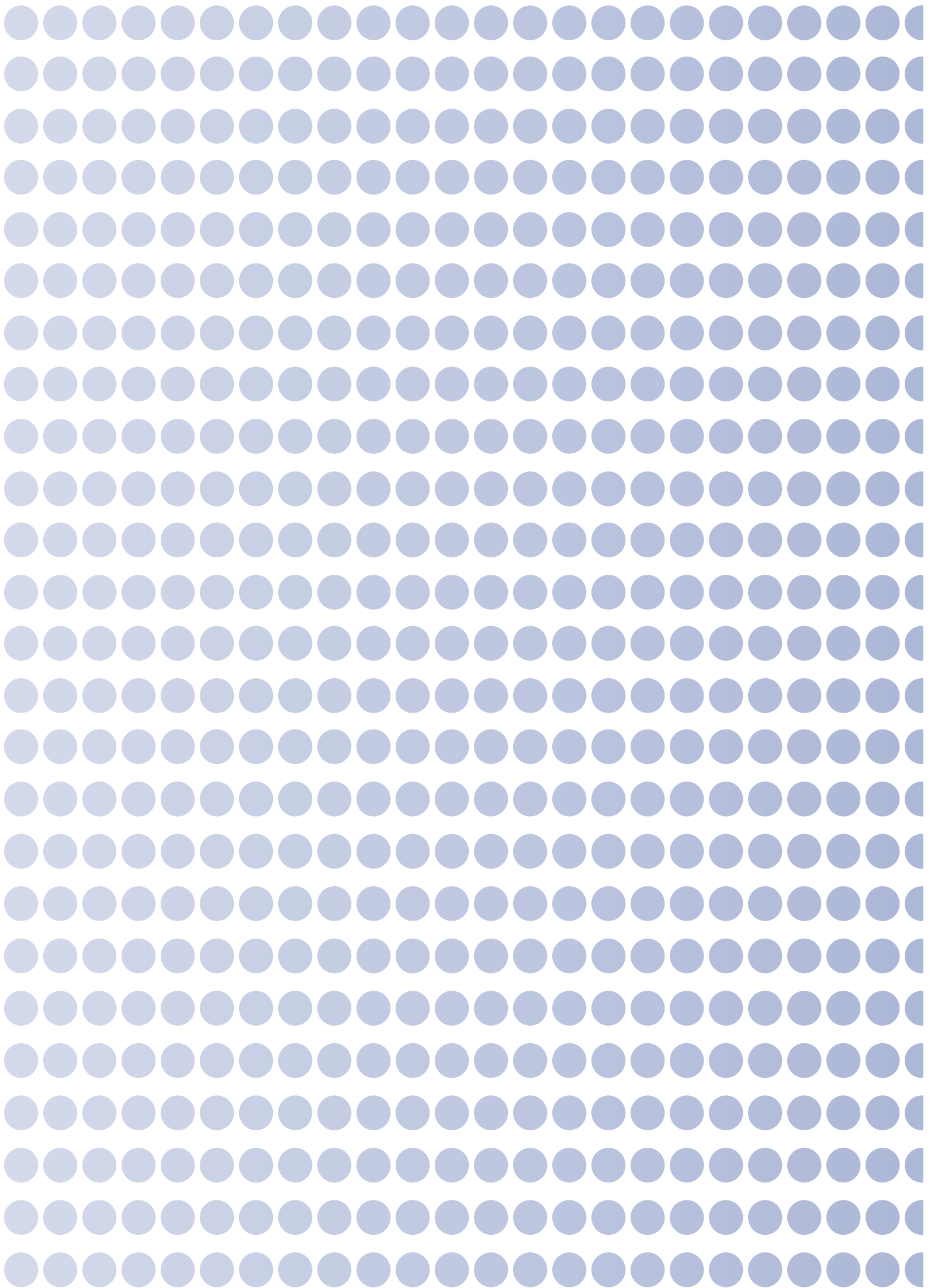


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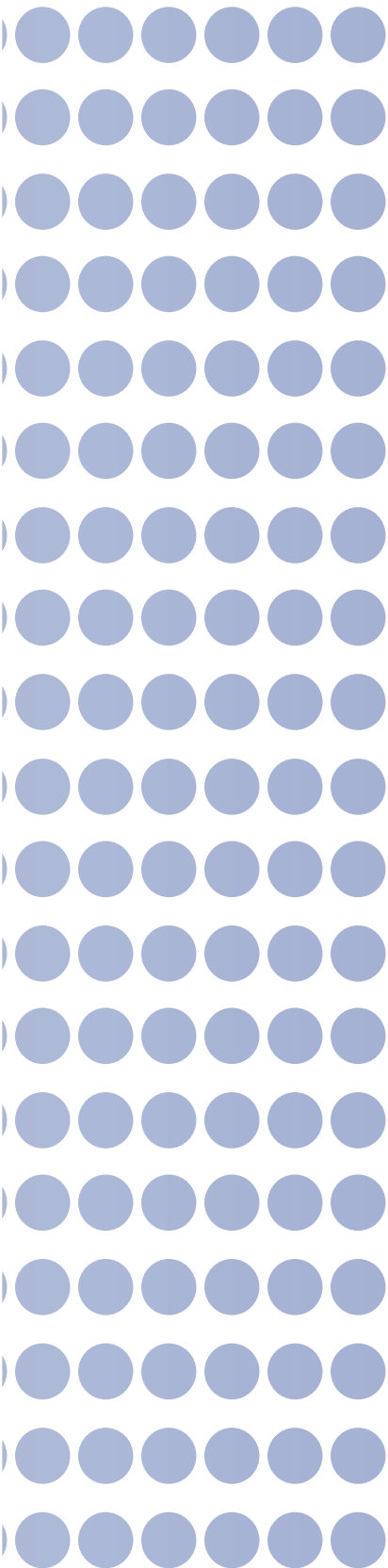


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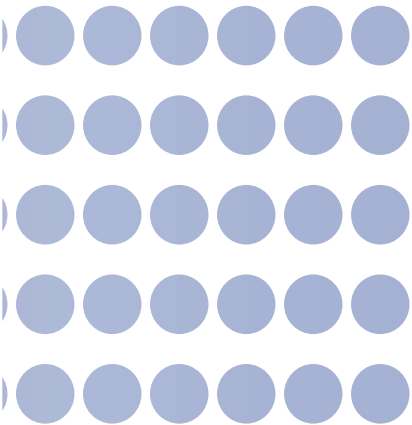
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Part A: Multiple Sclerosis



## What is Multiple Sclerosis?

Multiple Sclerosis (MS) is a chronic neurological disease with an unpredictable course, affecting the insulation surrounding nerve fibres (axons) of the central nervous system (CNS) and the axons themselves. The coating, called myelin, protects nerve cells and allows the efficient transmission of electrical impulses along nerve fibres.

The exact cause of MS is not known, but it is thought to be an autoimmune disease in which an immune system dysfunction produces an inflammatory attack directed against the myelin in a process called demyelination. The results of demyelination are plaques or scars (lesions) along the myelin sheath that interfere with nerve conduction. Conduction failure in demyelinated fibres derives not only from a loss of myelin, but also from the subsequent molecular damage of the fibre itself, which may progressively degenerate. This axonal degeneration is the structural basis of the permanent impairment caused by the disease.

The most common symptoms of MS include (among others) loss of vision and/or double vision, stiffness, weakness, imbalance, loss of co-ordination and dexterity, numbness, pain, problems with bladder and bowel control, fatigue, speech and swallowing disorders, sexual difficulties, emotional changes and intellectual impairment. The type and number of symptoms vary greatly from one individual to another, depending on where the damage occurs in the brain or spinal cord.

MS is the most common cause of neurological disability affecting people in their productive years, between 15 and 55 years of age. The total number of people with MS in Europe is estimated to be more than 600,000. MS affects women twice as much than men. MS is not a classic hereditary disease but, during the last years, some genetic polymorphisms have been defined that could enhance its predisposition.

MS is a disorder of the CNS with a usually slow but uneven progression: the lesions occur not only in multiple areas of the CNS but also as multiple events over time. As a result, the course of MS varies from one person to another and different episodes of demyelination may develop an unpredictable, life-long progression of complex symptoms.

## The Person with Multiple Sclerosis

Current estimates suggest that there are more than 600,000 people with MS in Europe. From the moment an individual receives the diagnosis of MS, she or he is transformed into a “person living with MS”. This label is often given between the age of 20 or 30 years and stays with the individual for life; it can devastate

both the affected person and his or her family. MS is the leading cause of neurological disability in young people, but PwMS can anticipate a near normal life expectancy (reduction of about 5 to 10 years). Thus, the socio-economic impact is significant.

Even in the absence of felt symptoms, PwMS live with the unpredictability and uncertainty that MS brings, as well as the knowledge that they may endure sudden disability with uncertain recovery during a relapse and increasing disability over time. This *not knowing* is often the hardest part.

MS can affect any part of daily function including psychological and mental health. There is up to 50% lifetime frequency of depression at least once over their lifetime. Many of the “silent” or “hidden” symptoms of MS – such as fatigue, pain, depression and cognitive problems – can be as debilitating and disabling as the more obvious functional problems. Moreover, MS can affect every aspect of life; often the life of a young person who is at the beginning of his or her hopes and dreams for the years yet to be lived. Work, education, personal relationships, family life and social participation can be affected by the disease.

Most PwMS will be diagnosed with the relapsing-remitting form of MS (RR-MS), which will transform to secondary progressive MS (SP-MS) in most cases over the following years. Only a small percentage (less than 20%) will have the primary progressive form of MS (PP-MS). It is important to note that at least one-quarter of all PwMS will remain independent and able to walk throughout their lives. Each case is unique in presentation and clinical course.

The hallmark of MS is progression of disabilities and handicap superimposed with early frequent acute episodes that decrease in frequency over time. RR-MS results in relapses (“attacks”) that may cause transient, variable and significant disability, with recovery and restoration of function that is less complete over time. Of all those with RR-MS, about 50% will need some help with walking after a number of years. Chronic neuro-degeneration, as occurs in PP-MS, leads to lasting disability with some PwMS becoming very disabled after a short disease course.

For those who are severely disabled, MS places many challenges upon their lives and the lives of those around them: MS does not affect only the person who receives the diagnosis. People with MS are more likely to be prematurely retired from work, and to be separated or divorced from their partners.

Each attack or relapse may bring a renewed sense of loss and bereavement; each loss of function and sequelae may bring yet more demands to successfully adapt, accept and change. The journey with MS requires courage and endurance to find a positive

response to the negative, often hidden, impact on health and well-being. Not just once, but many times over.

People with MS, their families and friends should be given personalised resources and opportunities that enable them to fully engage with the world about them, and to enjoy full and active lives with a sense of health and well-being. They have the right to self-determination, including that all decisions are equally shared with rehabilitation goals that fully utilise their unique potential to enjoy the positive aspects of living with MS.

## Management of Multiple Sclerosis

The diagnosis of MS will be suspected after a thorough clinical neurological examination followed by magnetic resonance imaging (MRI), which has now become a very important part of the diagnostic process using some broadly accepted MRI guidelines. In contrast to earlier diagnostic criteria, cerebral and spinal MRI are performed twice within 30 days; demonstrating one or more new enhancing (“active”) lesions at the second examination allows a very early diagnosis thus offering the option of an early treatment with immunomodulating agents (discussed below: treatment of the underlying disease). Other tests are mandatory to exclude similar diseases (blood analysis) or to confirm the immunological response within the CNS (cerebrospinal fluid). Evoked potentials, especially visual evoked potentials will also be helpful.

People with only one symptom but MRI findings matching the criteria for MS and/or with the characteristic cerebrospinal fluid results of oligoclonal IgG bands will be classified as having the “clinical isolated syndrome” (CIS).

In most PwMS, the disease runs a relapsing-remitting course (RR-MS) with relapses in very variable frequency and severity, and with complete or incomplete resolution of newly developed symptoms. After a variable period, this relapsing-remitting course will proceed to a slowly progressive phase, often without any relapses (secondary progressive, SP-MS). A minority of patients will suffer a primary progressive course (PP-MS) without relapses but usually slow increase of symptoms and disabilities.

Although there is still no drug that can cure MS, several treatments are available that can modify the course of the disease or ameliorate and/or relieve the resulting symptoms. Fortunately, a great deal of progress towards more effective treatments has been made in recent years, such as the development of the “disease-modifying drugs” (DMDs) that lessen the number and severity of attacks, and slow the progression of the disease.

Treatments in MS can be grouped into three broad categories:

- Management of the acute attack
- Treatment of the underlying disease
- Rehabilitation and management of symptoms

*Management of the acute attack:* The development of new symptoms in people with RR-MS, or the worsening of old ones, may indicate that a new attack is in progress. At such times, the new occurring patches of inflammation in the brain and/or myelin can be reduced through a 3- or 5-day high-dose course of corticosteroid therapy. But not all episodes of new symptoms require administration of corticosteroids: this therapy must rather be decided on an individual basis by the neurologist. Following existing guidelines, severe symptoms that do not ameliorate sufficiently may require repetition of the corticosteroid application in even higher doses. If symptoms continue to persist even so, a course of plasma exchanges may be required.

*Treatment of the underlying disease:* Concerning the underlying disease, in cases presenting with RR-MS, a group of drugs called immune-modulating agents may prevent relapses and can slow the progression of the disease, thereby reducing the severity of disability over the years. These drugs are considered to be more effective if used early, when the first symptoms appear. *Interferon beta* and *glatiramer acetate* are agents of this kind that have to be applied intramuscularly or subcutaneously. For persons with a highly active, progressive and disabling form of MS, immune-suppressive therapies are available, such as the monoclonal antibody *natalizumab* as well as  *fingolimod*, *mitoxantrone* and others. Both categories of drugs, immunomodulating and immunosuppressive agents, alter the disturbed functions of the immune system on which the mechanisms of MS are based. In the near future, some oral drugs will most likely supplement these therapeutic options (MSTCG 2008).

*Rehabilitation and management of symptoms:* At any given time, one or more symptoms, produced by the damage already done to the myelin sheath in different areas of the CNS, may cause numerous symptoms affecting the quality of life (QoL) of the PwMS. Countless symptoms may occur during the course of the disease, in different combinations, with varying intensity, and at different time points. The most often and disabling symptoms are muscular weakness and spasticity, sensory symptoms, bladder, bowel and sexual dysfunction, cognitive impairment, fatigue, pain syndromes, difficulties with swallowing and speech,

and depression. Thus, management of symptoms is as important as the immunological treatment of the disease. This aspect of treatment requires not only a thorough clinical examination of each PwMS, but also an interview in which the treating physician will ask the patient's symptoms, some of which they often do not relate to their disease (such as fatigue or pain), or feel ashamed of (such as problems with bladder, bowel or sexual functions). Moreover, as several symptoms have more than one manifestation (for example, bladder dysfunction or pain), a thorough differentiation of those symptoms is also needed (Henze 2006).

Rehabilitation is another very important and increasingly recognised aspect of comprehensive MS care, which will be discussed to a greater extent in this booklet. Even if symptomatic treatment and rehabilitation do not modify the disease evolution and progression, they have a primary importance for the individual's quality of life.

## Needs of Persons with MS

Individualisation of treatment is presently one of the most important paradigms in medicine. Tools for treatment individualisation already exist in rehabilitation and are used to a variable extent. Focussing individual patient needs is a prerequisite for this patient-centred approach, which also means engaging patients in healthcare decision making as much as possible (i.e. shared decision making) (Charles 1997). Increased involvement presents major challenges to both PwMS (because of increased self-responsibility) and to a similar degree to health care providers (GMC Council 2008).

The needs, resources and support required by PwMS have been studied (Kraft 1986; Ytterberg 2008). But recent establishment of the International Classification of Functioning (ICF, see below) provides a systematic tool to assess needs, monitor interventions and allow comparisons across conditions.

Relevant questions in the area of patient needs are a continuing matter of debate: *Who should define the needs of PwMS? How can the interaction be balanced between patient preferences and their expressed needs on one hand, and observed or diagnosed needs by health professionals on the other? How might PwMS voice needs when they are not aware of deficits, for example in the area of information? How should health professionals treat information-blocking behaviour as a coping strategy?*

Within the scope of coping with their diagnosis, PwMS may sometimes deny obvious needs, be reluctant to develop goals or avoid precise information. As neuropsychological deficits might be a substantial element of these barriers, assessment of patient needs

and rehabilitation goals is not always straightforward. Reflecting on and discussing individual patient needs and understanding needs as a dynamic process is therefore mandatory. Awareness and weighting of needs might be an education issue that should play an important role during MS rehabilitation. Reflecting on the value of bodily functions is as relevant (Heesen 2008) as clarifying areas important for quality of life. Since not every patient is fully aware of his needs – or of the existing approaches to fulfil them – comprehensive information is crucial in assessing individual needs and developing individual goals. Unmet information needs have repeatedly been demonstrated (Solari 2010).

Mental health is an important issue in MS and its management a major need. Especially in the early phase, anxiety and depression are highly relevant and frequent among MS patients. Currently, there is a lack of effective rehabilitation interventions covering hidden symptoms of MS such as fatigue, depression, cognitive dysfunction and pain; addressing these gaps requires substantial scientific efforts (Kraft 2008). Vocational rehabilitation is another important unmet need (Sweetland 2008); strategies for health promotion and increased participation are warranted as well. In palliative care, more information about patient preferences is needed.

In the absence of a cure for MS, as well as its unpredictable, chronic and frequently progressive nature, the amount of care needed by the individual PwMS will be different at different stages of the disease (Ytterberg 2008).

The course of MS may be divided into four stages, although not all cases go through the entire course: the **initial stage** at the moment of diagnosis; the **early stage** with a mild degree of disability; the **later stage** with a moderate degree of disability; and the **advanced stage** with severe disability. The amount and characteristics of needs will depend on the clinical stage of the disease and the degree of disability. Each stage poses its own difficulties related to specific life situations and expressed needs.

### Initial stage

At the **initial stage**, the diagnosis has just been established, usually after a first relapse or because of slowly developing symptoms. PwMS are understandably not familiar with their new disease and coping is in its beginning phase at best. The needs expressed by PwMS are:

- to be aware that making and accepting a diagnosis of MS is a process with different timing needs among individual patients, which healthcare providers should take into account. The two main questions should always be: Is the PwMS ready



for the information a healthcare provider aims to deliver? and What are his/her actual needs?

- to be aware, especially in early stages, that information should be considered an intervention similar to a drug treatment with effects and side effects. Information should therefore follow guidelines of evidence-based patient information (Bunge 2009) and complex interventions (Campbell 2007).
- information delivery on a personalised level, at best with the same reference person throughout the process.
- involvement of family and/or friends in the diagnostic process.
- a low barrier to access for psychological counselling for any newly diagnosed patient.
- Emphasising reflection on the patient's own values and preferences, and developing an individual disease model/concept taking into account the cultural background of a given patient.
- providing different sources of information regarding the disease, its consequences and potential impact on the individual, the family and the social environment. Information may be delivered via print, internet, personal encounter, self-help organisations, group education, etc.
- evaluated MS courses should be offered to PwMS within the first year after diagnosis, covering all aspects of the disease (NICE citation).

### Early stage

During this stage the PwMS suffers occasional relapses of varying severity but usually recovers. The main personal concern may focus on the fear of becoming disabled. Coping with MS and with the need of a long-lasting medical treatment is usually incomplete. Other common concerns are related to the PwMS' relations to her/his family, friends and colleagues.

Key themes responding to the needs at the **early stage** are:

- continuity of service provision.
- provision of support and informed advice concerning the relevance of psychological factors (e.g. stress), relationships, employment, symptoms and impairment, housing and financial planning.
- information about and access to appropriate treatment and management, especially concerning relapse management and immunotherapy.
- information about the evidence of supportive interventions such as nutrition concepts and exercise training.

As MS often affects young adults who have to support young families and are in the early stages of their career, this chronic disabling disease implies major socio-economic uncertainties and risks that must be addressed.

### Later stage

PwMS at the later stage usually suffer from fluctuating or permanent impairment resulting in disabilities and restrictions of activity and participation. They need to maximise functional independence by minimising disability and handicap, and by maintaining their role in the family, workplace and community as long as possible. This will involve inpatient and outpatient rehabilitation services and community care. Based on the concept that rehabilitation is a problem-solving educational process (Wade 1992), and on the idea that health is very much the ability of an individual to adapt (anonymous 2009), adaptation and adjusting one's own expectancies to daily experiences is at the core of rehabilitation at this stage. PwMS usually express their preferences for services provided on an outpatient basis by a multidisciplinary team.

Specific coping strategies should be provided to the patients and their carers. The variety of interacting problems requires the expertise of a wide range of specialists and care providers with an interdisciplinary approach.

Key themes at the **later stage** are:

- responsiveness to needs in relation to significant changes in impairment and disability.
- access to and location of professional services.
- access to multidisciplinary expertise in symptom and disability management and treatment.
- communication and coordination between service providers and care agencies.
- empowerment of PwMS and their carers, enabling them to develop a partnership role within disease management and treatment.
- continued education on disease-management tools, especially in the area of symptom treatment (e.g. intermittent self-catheterisation).

Persons with MS face a considerable array of recurring barriers to employment, education and transportation. The lack of adequate, comfortable and accessible transportation and workplaces has contributed to an unemployment rate among PwMS that is much higher than the average. Focused vocational rehabilitation may substantially increase the number of PwMS continuing employment (Khan 2009). People with MS want to avail themselves of their full rights as citizens. Technology, including any item that could be useful for maintaining or improving functional capabilities, may provide numerous appropriate opportunities.

Ideally, as patients at this stage are in the need of very different medical professions and care providers, they should be treated within a cooperating and well-structured network.

### Advanced stage

At this stage, PwMS have developed a severe disability and are dependent in both mobility and daily activities; this often results in a huge number of challenges for the patients and their carers. Staying at home, with appropriate support and treatment, for as long as possible is a basic need at this stage. If caring and nursing at home is not achievable for different reasons, a nursing home is mandatory and most PwMS (as other severely handicapped people) appreciate to live in settings where they are integrated into normal life as much as possible, especially when living together with other PwMS. Strict attention should be attributed to the needs of the carers, too. Together with formal (paid) care, in most countries informal care has been reported as the most important source of private support and represents up to 70% of a MS person's care (Carton *et al.*, 1998). Expanding support by professional and informal carers will alleviate the time of caring and support in specific everyday tasks and surveillance. Another important need is to teach the carers how to cope with their own physical and psychological burden, and how to best handle any cognitive or behavioural problems that may arise. Furthermore, appropriate equipment such as environmental controls and technical aids is needed to help keep the PwMS less dependent.

Key themes are in the **advanced stage** are:

- providing appropriate palliative care, including short breaks for both the PwMS and the carer.
- providing appropriate long-term facilities, especially in small apartment units.
- access to information about services and community care resources.
- expertise in caring for persons with MS with a severe disability.
- coordination of all services.
- adequate and appropriate community care services, including home adaptations, mobility equipment and aids, health services and (ideally) outpatient rehabilitation services.

The optimal care of the needs of PwMS and their families will be a collaborative effort including the patient and supporting organisations, service providers and researchers, as well as politicians within a well-organised network.

## Quality of Life

*What is the place of "quality of living" within the overall health of PwMS?* Since MS involves a life-long unpredictable course, characterised by the occurrence and progression of several disabling symptoms, the impact on life (and lifestyle) is significant. Quality of life (QoL) can be seen as the sum of all sources of satisfaction minus all threats in life (Mitchell 2005). In general, it is a personal construct affected by health, social, economic, political, cultural and spiritual factors. Consequently, health-related quality of life refers to the individual perception of how a health problem and its treatment affects expected physical, psychological, social and role functioning.

Health-related QoL has become a central concept in evaluating the impact chronic diseases such as MS have on the lives of patients. The full nature of the relationship between MS and QoL is not completely understood but ongoing scientific exploration provides already better insight into factors determining this primary target of comprehensive MS care.

*Opening doors: which are the keys to health-related QoL (HR-QoL) in MS?* Even with impaired mobility being one of the highest concerns of recently diagnosed patients (Sutliff 2010) and physical disability proven to be associated with reduced quality of life (Motl 2009), invisible determinants (the hidden symptoms such as depression, pain and fatigue) seem to affect the well-being of PwMS in a more intrusive way (Zwibel 2009b; Janardhan 2002; Mitchell 2005; Motl 2009; Newland 2009; Shawaryn 2002; Sutliff 2010). Research shows that MS-associated fatigue, pain and depression negatively affect QoL independently of the level of physical limitations. Cognitive impairment is also associated with reduced QoL (Mitchell 2005). In patients with mild cognitive problems and minimal physical disability, this effect was clear for reduced processing speed (Glanz 2010). As cognitive potential becomes more eroded over time, the self-reported impact on QoL and well-being seems to become less pronounced.

The reality of physical burden as a less important predictor of QoL in MS is recognisable for professionals experienced with MS treatment, rehabilitation and counseling. The rationale for this fact nevertheless remains somewhat vague. A possible hypothesis is that, in the majority of cases, disease mechanisms can provide an explanation for physical complaints and limitations. The consequent insight delivers a tool for adaptation, toleration and sometimes even meaning-giving behavior. There is also a larger therapeutic arsenal to relieve physical suffering in comparison to the tools available for dealing with a crisis in the emotional world of an individual patient.

The psychological suffering often associated with MS is a deeply personal confrontation with pain on a more existential level. In contrast with physical limitations, it is much more difficult for people to find a meaning for their psychological misery. How much a human being can endure is an individual characteristic depending on genetics, personal history and contextual factors. Every personal reality has biology at the basis, on which individual psychology is grafted. On top of these two layers, all people carry a (more or less developed) philosophical and spiritual dimension. This subjectivity is the norm in psychological suffering. It is not correlated to muscle weakness or MRI lesion burden; it is not objectifiable through spinal fluid analysis or evoked potentials. As an invisible and intangible part of being a human, one's emotional world is not easily analysed and understood. Since psychological pain is the biggest threat for quality of life, it calls for a careful, open and professional approach systematically integrated into every care pathway for PwMS.

*Catching HR-QoL: why are we trying to measure this most individual aspect in MS care?* Evidence has shown that patients with MS and their treating physicians may not necessarily agree on which dimensions of health are most important. Some physicians generally consider the physical manifestations of the disease to be most concerning, whereas patients often place a high emphasis on vitality, general and mental health. This finding has caused a greater recognition of the importance of the patient's perspective in assessing the outcomes of medical care. For this reason QoL is introduced when it comes to patient evaluations and measurements in comprehensive care for MS. Quality of life endpoints are now also broadly included in therapeutic trials of potential new treatments and in observational studies of the disease (Zwibel 2009a; Jongen 2010).

*Making HR-QoL visible: how to measure?* HR-QoL measures can be subdivided into generic and disease-specific tools (Mitchell 2005). Generic measures such as the Health Status Questionnaire (Short Form-36 or SF-36) were designed to assess patients with diverse medical conditions. Since these assessment tools may not capture all relevant aspects of a specific illness, disease-specific measures have been developed. Many investigators supplement generic HR-QoL assessment with disease-specific measures such as MS Quality of Life-54 (MSQOL-54) and the MS Quality of Life Index (MSQLI).

The SF-36 derives from the General Health Survey of the Medical Outcomes Study by Stewart and colleagues (1988). It has been shown to discriminate between subjects with different chronic conditions

and between subjects with different severity levels of the same disease. The SF-36 has also demonstrated sensitivity to significant treatment effects in a variety of patient populations. This instrument addresses health concepts that are relevant to MS patients from the patient's perspective. SF-36 is a structured, self-report questionnaire that patients can generally complete with little or no intervention from an interviewer. Administration time is approximately 10 minutes. There is no single overall score for the SF-36. Instead, it generates eight subscales and two summary scores. The eight subscales are: physical functioning; role limitations due to physical problems; bodily pain; general health perceptions; vitality; social functioning; role-limitations due to emotional problems; and mental health. The two summary scores are the physical component summary and the mental component summary.

The MSQOL-54 (Vickrey 1995) is a multidimensional health-related QoL measure that combines both generic and MS-specific items into a single instrument. It includes the SF-36 as well as 18 items added to measure specific MS-symptoms such as fatigue, pain, bladder function, bowel function, emotional status, perceived cognitive function, visual function, sexual satisfaction and social relationships. It is a structured, self-report questionnaire that the patient can generally complete with little or no assistance. Administration time is approximately 11 to 18 minutes. There is no single overall score for the MSQOL-54. Two summary scores – physical health and mental health – can be derived from a weighted combination of scale scores. In addition, MSQOL-54 generates 12 subscales: physical function; role limitations-physical; role limitations-emotional; pain; emotional well-being; energy; health perceptions; social function; cognitive function; health distress; overall quality of life; and sexual function. There are also two single-item measures: satisfaction with sexual function and change in health.

The **MSQLI** is a battery consisting of 10 individual scales providing a QoL measure that is both generic and MS-specific (Fisher 1999). The 10 self-report questionnaires can generally be completed with little or no intervention from an interviewer. It is composed of the following individual scales, 5 of which have both a standard and a short form. MSQLI components include: Health Status Questionnaire (SF-36); Modified Fatigue Impact Scale (MFIS); Medical Outcome Studies of Pain Effects Scale (MOS PES); Sexual Satisfaction Scale (SSS); Bladder Control Scale (BLCS); Bowel Control Scale (BWCS); Impact of Visual Impairment Scale (IVIS); Perceived Deficits Questionnaire (PDQ); Mental Health Inventory (MHI); and MOS Modified Social Support Survey (MSSS). The full MSQLI takes approximately 45 minutes to administer; using all five of the short forms, the time can



be reduced to approximately 30 minutes. Individual scales can be omitted to save additional time. Each of the individual scales generates a separate score, and some of the scales generate subscales, such as the SF-36, the MFIS, the PDQ and the MSSS. There is no global composite combining all the scales into a single score.

*Learning from patients: what to conclude about quality of living with MS?* Since quality of life of PwMS depends on physical and psychological well-being, the main goal in comprehensive care is helping every individual to adapt to the changes experienced in different life domains (Khan 2007). Being connected to others is a prerequisite for satisfaction with life and a feeling of happiness. Approaching patients with respect and an open attitude of seeing the person behind the condition helps us to bring professional care as close as possible to the personal lives of patients and their families. In contemporary care, professionals should see each individual with MS as the manager of his or her own health and life. In dealing with changing realities, patients engage professionals to deliver expertise that ultimately enables the patients to maximise the quality in their lives. In facilitating healthy adaptation processes in PwMS, it is our permanent ethical duty to remain hopeful that a satisfactory quality of life is achievable.

## **A Code of Good Practice on the Rights and Quality of Life of People affected by Multiple Sclerosis**

In December 2003, the European Parliament approved a report based upon a petition submitted by Louise McVay, a British citizen with MS. This report was actively supported by the European Multiple Sclerosis Platform (EMSP) and all EU Multiple Sclerosis Societies. Health departments in most EU Member States provided information that was used to assist with the preparation of the report. The contents of the report, presented by Parliament's Rapporteur Uma Aaltonen from Finland and herself a PwMS, analysed the experiences of people with MS in Europe. The official presentation of the "First EU Report on MS" was delivered on 18 December 2003 in the European Parliament in Strasbourg. After the discussion, the MS Report was unanimously adopted by 240 Members of the European Parliament (MEPs).

The report makes clear that, according to Article 152 of the EC Treaty: "Community action which shall complement national policies shall be directed towards improving public health....." It also makes reference to provisions in the Charter of Fundamental Rights on the rights of persons with disabilities. Paragraph 1 of the substantive resolution adopted by the European Parliament in 2003 urges the Ministers

of Health of the European Union to develop a "Code of Best Practice" concerning MS patients.

The *European Code of Good Practice in Multiple Sclerosis (The Code)* was subsequently drafted by EMSP, with inputs from all MS societies, and drawing on European Consensus and reference documents focusing on MS and the United Nations Convention on the Rights of Disabled People.

MS directly affects more than 600 000 people across Europe, but of course the disease affects indirectly many more people who are close to these individuals. To date, no cure has been found for MS.

There is highly robust scientific evidence and expert opinion of the very beneficial – indeed, critical – effects of professional and high standard treatments, therapies and services on the quality of life of people affected by MS and their capacity to continue to contribute to society as workers, consumers and citizens. From a purely cost/benefit perspective, studies have demonstrated unequivocally that the investment this entails is significantly less than the negative economic and social consequences of mismanagement of Multiple Sclerosis (Kobelt 2001; Sobocki 2001; Flachenecker 2003; Flachenecker 2004).

## **Equal rights and access to treatment, therapies and services in the management of MS**

Yet there is huge disparity in the way in which people affected by MS are treated across the European Union, and consequently in their quality of life. This is due, in part, to lack of awareness and information on evidence-based good practice in the field.

*The Code* has been drawn up as a crucial follow-up to a European Parliament Resolution (A5-0451/3003 European Parliament Resolution) and report that identified the root causes of discrimination and inequality for EU citizens affected by MS, and outlined a number of political and programme initiatives needed to address this issue.

*The Code* is a political instrument that outlines briefly the issues of fundamental importance to people affected by MS. It provides a practical framework that describes in general terms:

- The optimal approach in relation to treatments, therapies and services, research, employment, and empowerment of people affected by MS.
- The core reference documents and materials that are endorsed by both the medical and patient community.

Multiple Sclerosis recognises no borders: the needs of people affected by MS are comparable across national boundaries but will be addressed by health



systems, which vary significantly in their organisation, funding and population distribution.

Good practice in four key areas is absolutely critical to the health and quality of life of PwMS. Key issues of the EU Report were calls for good practice – in four key areas being critical for persons with MS, their families and their carers:

- equal rights and access to treatment, therapies and services in the management of MS;
- a shared agenda in MS research;
- employment and job retention; and
- participation and empowerment.

A special key focus is the area of access to therapy and treatment. Some people are fortunate in their access to treatments, therapies and services, but the disparities between the types of care and support available are great both within and among the EU Member States. This must be remedied by raising the level of care provided across the board, bringing about equality of access as a clear objective.

To support the aims of National MS Societies to lobby for achieving these objectives, Care Reference documents have been developed by leading authors and endorsed by many Medical Advisory Boards of MS Societies in Europe. EU consensus documents prepared under the guidance of EMSP include:

- Escalating Immunomodulatory Therapy of MS
- Recommendation on Rehabilitation Services for Persons with Multiple Sclerosis in Europe<sup>1</sup>
- Symptomatic Therapies Consensus Paper
- Palliative Care among People Severely affected with MS (Position Paper)
- Principles to Promote the Quality of Life of People with MS<sup>2</sup>

In late 2008 and early 2009, EMSP undertook to work with European Committee on Treatment and Research in MS (ECTRIMS) and Rehabilitation in MS (RIMS) to update *The Code of Good Practice*, taking into account important new research and consensus papers on palliative care and juvenile MS. This booklet is the update of the “Recommendations on Rehabilitation Services for Persons with Multiple Sclerosis in Europe” which was first published in 2004.

The European Commission has shown its support for the Code and Consensus Papers by making both available on DG SANCO website, through the EU Health Portal:

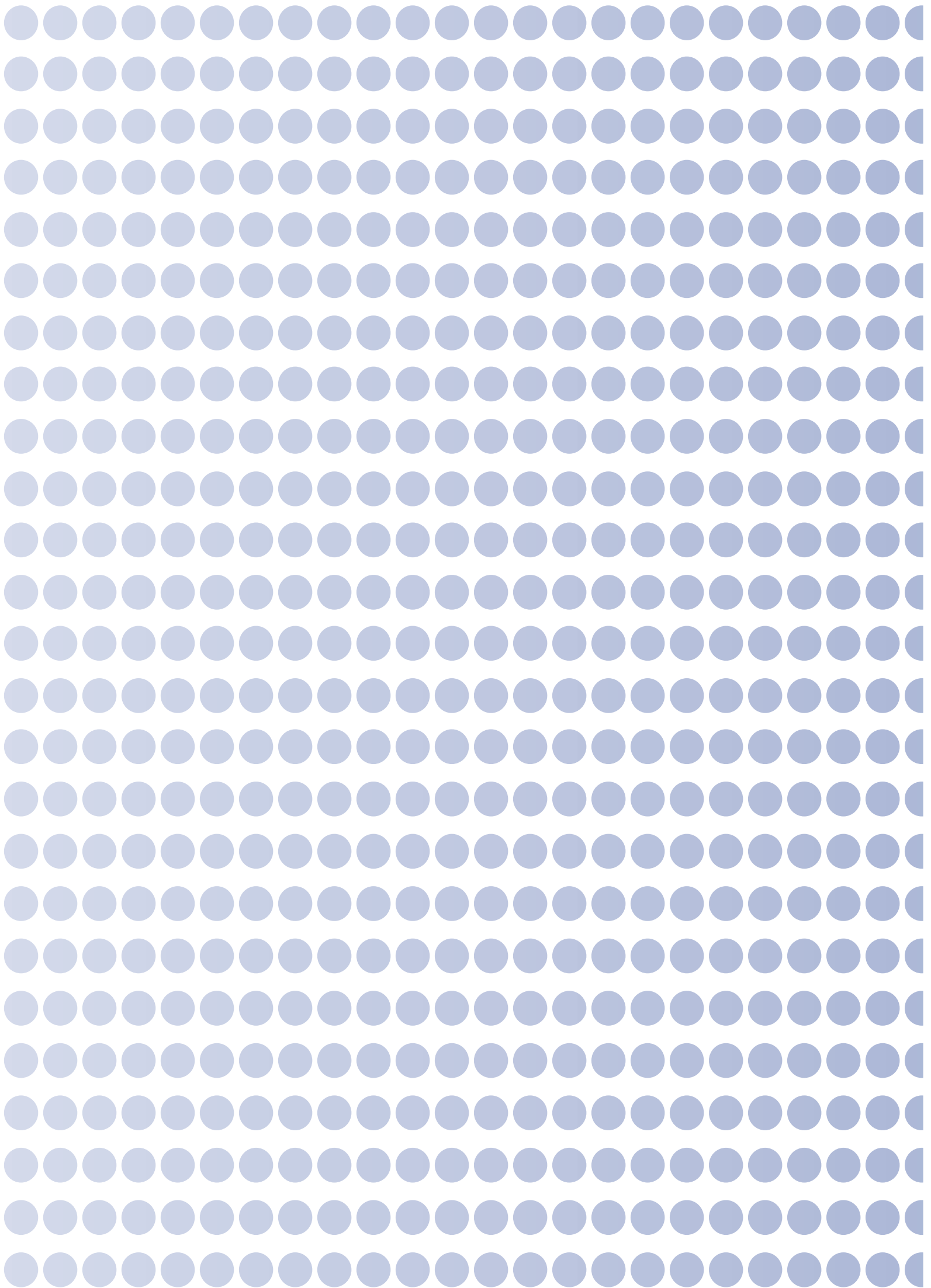
[http://ec.europa.eu/health/ph\\_information/dissemination/diseases/neuro\\_en.htm#monitoring](http://ec.europa.eu/health/ph_information/dissemination/diseases/neuro_en.htm#monitoring)

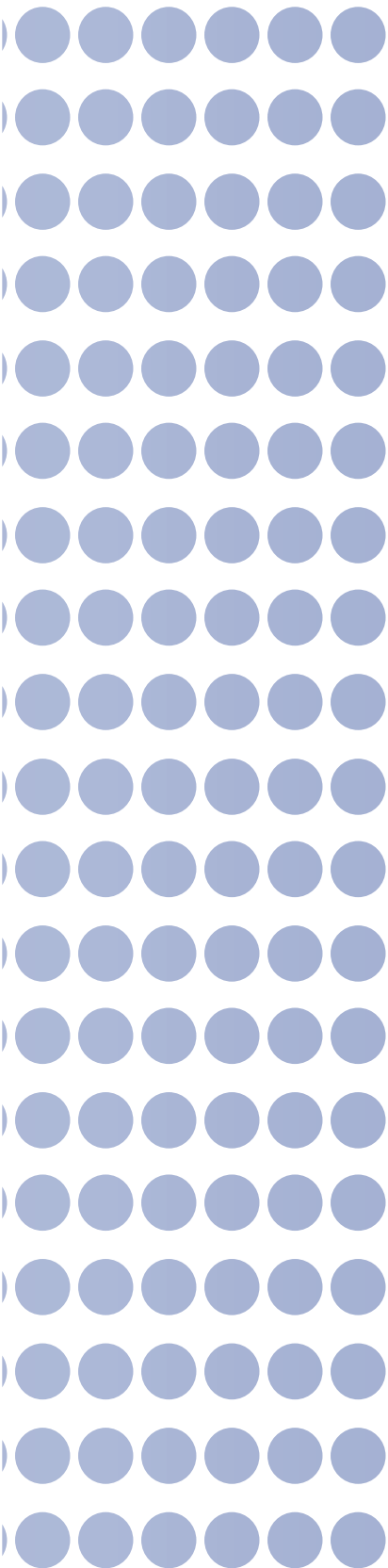
Since July 2008, translations of *The Code* are available via the relevant National MS Society in the following languages: Bulgarian, Croatian, Czech, Dutch, Estonian, Finnish, French, Greek, Hungarian, Icelandic, Italia, Lithuanian, Maltese, Norwegian, Polish, Portuguese, Romanian, Slovakian, Slovenian, Spanish and Swedish.

Although the *European Code of Good Practice in Multiple Sclerosis* focuses on the key needs of PwMS, their families and their carers, we believe that the method of its development can serve model in many European countries to improve the health systems for the benefit of PwMS. The drafting process involved small consensus groups and repeated consultation processes with a network of the leading experts in Europe. The publications reflect widely accepted findings, and undergo regular updates when necessary. Importantly, they have been acknowledged on the political level, with subsequent implementation on the national working level.

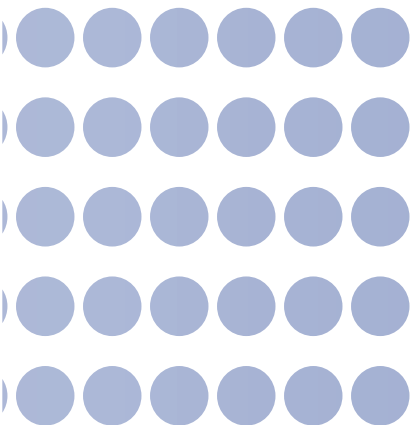
1] Jointly prepared by the European MS Platform (EMSP) in cooperation with Rehabilitation in MS (RIMS).

2] Prepared by the Multiple Sclerosis International Federation (MSIF).





## Part B: Rehabilitation in Multiple Sclerosis



## What is Rehabilitation?

Multiple Sclerosis has physical and psychosocial consequences, which usually have enormous long-term impacts on almost every aspect of the lives of persons with MS and their families. Rehabilitation should therefore improve the ability to perform basic daily functional activities, mobility, occupation, communication and social integration. It is required in many different kinds of impairments and disabilities, especially decreased mobility and dexterity, bladder and bowel dysfunction, communication and swallowing disorders, and cognitive impairment. Rehabilitation “is a problem-solving educational process aimed at reducing disability and handicap (participation) experienced by someone as a result of disease or injury” (Wade 1992). Furthermore, rehabilitation is fundamental for preventing complications of MS and improving the individual’s independence.

As MS can also affect cognition, memory and emotions, rehabilitation should extend beyond restoration of physical ability to also include efforts to ameliorate health-related quality of life and emotional well-being.

Addressing these different aspects of MS requires an interdisciplinary team. Moreover, due to the frequently changing needs of persons with MS (PwMS) and their families, a comprehensive management strategy is mandatory to co-ordinate the individual patient, his/her family (and carers), professionals, hospitals and the community. The aspects mentioned above will be presented in more detail within the following pages.

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

### *International Classification of Diseases (ICD)*

The attempt to classify diseases systematically goes back to 1763 when Carl Linnaeus published his seminal work *genera morborum*. A century later the British medical statistician William Farr proposed the principle to classify diseases by anatomical sites and his idea was concretised in the *International List of Causes of Death* as the register was called when it was first adopted in 1893. The latest edition has maintained the principle, but the list is now titled as the *International Classification of Diseases* (ICD). Currently, we are using the 10<sup>th</sup> edition, endorsed by the World Health Organization (WHO) in May 1990 as ICD-10. In this edition Multiple Sclerosis can be found in chapter VI among the *Diseases of the Nervous System* as G35.

### *International Classification of Impairment, Disability and Handicap (ICIDH)*

By the end of the 20<sup>th</sup> century, the WHO recognised that most people’s health care needs could not be

evaluated on the basis of diagnosis alone and that the ICD (see above) was insufficient to respond to this requirement. This insight called for a shift of treatment focus from acute illness to the management of chronic illness and/or disability. A new paradigm emerged. Instead of cure, functional management of the condition became the goal and outcomes became the standard for measuring the performance of healthcare delivery and its effectiveness. Prompted by the need to measure the consequences of health conditions, the WHO developed the *International Classification of Impairment, Disability and Handicap* (ICIDH). Approved in 1980, this classification of the long-term, non-fatal consequences of disease was structured on three axes, corresponding roughly to experiences at the level of **organ or function** (impairment = 1 009 items), **individual action** (disability = 338 items) and **societal interaction** (handicap/disadvantage = 72 items).

### *International Classification of Functioning (ICIDH 2 / ICF)*

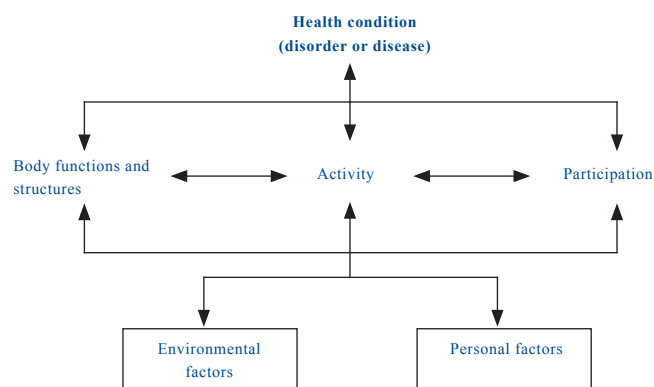
Sensitive to criticisms of existing frameworks, in 2001 the WHO released a major revision of the ICIDH, called the *International Classification of Functioning, Disability and Health* (ICF), which attempted to provide a coherent view of health states from a biological, personal and social (bio-psycho-social) perspective. To avoid the negative connotations of certain terms the original ICIDH used to reflect various dimensions of health-related experiences, the ICF uses a more positive terminology: the word “activities” is used instead of “disability” and the word “participation” replaces “handicap”. Impairments are more specifically described as “impairments of function” and “impairments of structure”.

By addressing contextual factors (e.g. environmental and personal), the ICF framework portrays human function and decreases in functioning as the product of a dynamic interaction between various health conditions and contextual factors. Within the ICF, these contextual factors include aspects of the human-built, social, and attitudinal environment that create the lived experience of functioning and disability. It also recognises that personal factors such as sex, age, coping styles, social background, education, and overall behaviour patterns may influence how the individual experiences disablement.

Within the ICF, the term **health condition** is used to represent diseases, disorders, injury or trauma, aging, and congenital anomaly. According to the WHO, the ICF “gets over” the old concept of health and disablement. The person is no longer classified as healthy or sick, or worse as “bearer of a handicap”, but as a person operating in a more or less suitable way within the various conditions to which the

challenge of life has given rise. By taking into account the environmental factors, the ICF allows classifying and quantifying the components of life as “enabling” or “disabling” and identifies the components that make participation easier or harder. The ICF suggests different ways to find tools that give individuals a chance to keep living an active life in the family, the workplace and the community. When a person with a severe impairment finds it hard to work in a building with no access ramps or elevator, the interventions can be on the person or on the life environment – for example, either by offering aids to help the individual get around or over obstacles, or by removing the architectural barriers.

**Figure 1** The International Classification of Functioning, Disability and Health model, including the theoretical relationships among its factors



### ICF core sets

Activity limitations, restriction in participation and impairment are important drawbacks of MS. The ICF offers the opportunity to rely on a globally agreed upon framework for classifying the problems in functioning of PwMS given the environmental context they face. By splitting different components of function into three categories – *Body Structure and Functions, Activities and Participation, Personal and Environmental Factors* – the ICF arrives at 1 400 categories, admittedly a classification system that is a little too comprehensive for charting the functioning and disability of an individual. To facilitate use of the ICF in clinical practice, it was necessary to develop a selection of those categories considered typical and likely to be most relevant for patients having a particular health condition – the so-called “Core Sets”.

To date ICF Core Sets have been established for a dozen of common, chronic conditions. For each health condition, there is both a *Brief ICF Core Set* (for clinical and epidemiological study) and a *Comprehensive ICF Core Set* (for multidisciplinary assessment) (Coenen 2011). It is hoped that these *ICF Core Set for MS* will form the basis for developing assessment instruments to quantify the severity

of MS, measure change over time and assess effectiveness of interventions. In addition, it is hoped that such research will lead to interventions that improve restoration and maintenance of functioning, and minimise disability among PwMS throughout the world.

## Goal Assessment

### Definitions and central features

Rehabilitation is a process of active change. In this regard, setting of goals is an important component and a core skill of rehabilitation professionals (Wade 2009; Stevenson 2007). It is essential that goal setting involves both the individual with MS and the rehabilitation team. Together, they discuss and negotiate the key priorities for the content of rehabilitation, and agree on performance levels to be attained by the individual for defined activities within a specified time frame (Bloom 2006). A 2009 consensus report on goal setting defined a goal as “how things will be at some specified time in the future and that it is a desired state that requires both action and effort” (Playford 2009).

Rehabilitation goals need to be identified by their time frame. Ideally, goals should be set for the near, mid or distant future, albeit the time frame may vary markedly depending, for example, on the rehabilitation setting (in-patient or out-patient). Long-term goals often include overall rehabilitation aims and should preferably be set at the participation level. Intermediate and/or short-term goals should focus on changes at the level of activity or functioning, and are typically targeted in behavioural change (Barnard 2010).

### Advantages of goal setting

A number of advantages can be achieved through the goal-setting process. Setting goals for a person increases behavioural change and improves adherence to rehabilitation programmes, presumably by increasing motivation. Goal setting encourages PwMS to define their own goals, and thus improves their autonomy and engagement to rehabilitation interventions. Goals are useful to support communication and co-ordination within the rehabilitation team. In addition, identifying goals allows the effectiveness of the rehabilitation process to be monitored in a consistent manner.

### An ideal goal

The success of goal setting depends on the formulation of goals. The acronym SMART has been accepted to specify the characteristics of an ideal (or appropriate) goal, with the letters reflecting that



goals need to be **specific, measurable, achievable, realistic** (relevant) and **timed** (Bovend'Eerdt 2009). However, considerable variation exists in the actual words related to each letter, and every goal does not necessarily need to include all the five criteria. Writing goals in rehabilitation of PwMS may be time consuming and difficult; the SMART acronym offers a practical means to define goals in a concrete manner and is useful to overcome such problems.

### Assessment

Assessment of rehabilitation outcome can be done basically using two alternate, yet complementary, approaches: by evaluating the effects of the rehabilitation process on the individual using standard outcome measures; or by measuring goal achievement. Methods to evaluate goal achievement are important in MS rehabilitation because they provide a person-centred outcome focused on individual's own priorities.

Among the tools introduced for goal assessment, the visual analogue scales are probably the simplest and quickest method. They, however, are susceptible to some bias and ceiling effect. Goal attainment scaling (GAS) is a more sophisticated method for rating goal achievement. It uses the goals themselves to evaluate the individual outcome on a 5-point scale, and has a standardised formula to produce a single aggregated score. In spite of a single numerical outcome, the GAS method allows one to set as many or as few goals as wished (Kahn 2008). Three to five goals is the recommended number of goals to capture the person's key priorities.

### Evidence base

At present, research to evaluate either goal setting or goal assessment methods in rehabilitation for PwMS is scarce. Studies conducted so far have raised some controversial issues related to goal setting in MS rehabilitation. It is, for example, obvious that the person with MS and members of a clinical rehabilitation team do not necessarily agree well on the specific goals set for an in-patient rehabilitation stay (Bloom 2006; Edwards 2002). Furthermore, goal-setting meetings may be guided by professional dominance more than in consideration of patient's wishes as agreed on in written goals. When applied in an in-patient rehabilitation setting, the GAS method has proven to be a responsive and useful outcome measure in PwMS with a wide range of disability (Hurn 2006).

Additional research is essential to strengthen the evidence base of goal setting in rehabilitation for PwMS. Priorities for research could be focused on the impact of goal setting on the individual outcome,

and on approaches to support involvement of PwMS in the goal-setting processes.

The most relevant goals of rehabilitation are mentioned below.

## Service Delivery

The health needs of PwMS are similar and comparable across national boundaries. Yet in reality, these needs must be addressed by national health systems that vary in their organisation, funding and population distribution.

**Fundamental principles:** Certain important qualities should underpin any model of MS service delivery:

- The service must guarantee internal integration among professionals and must also be integrated with all other existing health services relevant for MS (hospital departments, out-patient clinics, community services and self-help organisations), so as to avoid gaps in service delivery and communication.
- Because MS is unpredictable, particularly with regard to relapse occurrence and speed of disability progression, the service must be able to respond in a timely manner without excessive delay and bureaucracy.
- As MS is reflected by a variety of symptoms, disabilities and disease subtypes, services must be flexible and able to adapt to the needs of the patient.
- Services should be patient-centred and available to all patients, and not designed to suit the institution or funders; services must be as close in proximity to the patient as resources allow.
- MS services must be evidence based. This encompasses practicing evidence-based care but also drawing from relevant research in non-MS areas, and collaboration to build the evidence base through research and audit.

### Functions and Components of MS Services:

According to the stage of progression of the disease, MS service delivery will concentrate on multiple areas: provision of establishing the diagnosis; education and shared decision making; relapse management; symptomatic treatment as well as rehabilitation and physical activity; treatment with disease-modifying drugs; counselling; vocational rehabilitation; health promotion; treatment of concomitant illnesses; respite care and palliative care. There is no single model that can be imposed on all health systems. The roles and the range of in-patient, out-patient and community services will vary according to local requirements,

and costs will clearly depend on national systems.

However, there are general considerations regarding resources and capacity:

- Adherence to fundamental principles means that funding must be available for appropriate integration of services, as a PwMS may access in-patient, out-patient and community services to different degrees and at different states of the illness.
- In order to be patient-centred and provide timely services, there must be some uncommitted capacity to treat urgent, unforeseen needs such as relapses or an atypically rapid disease course.
- A good MS service will not allocate all clinical resources to planned patients as it recognises the need to be flexible. In order to improve current and future care, all services need time and support to contribute to research and audit.

### The Interdisciplinary Approach

PwMS may have a wide array of impairments that can lead to relevant problems in activities of daily living. It is important to diagnose the perceived and lived disabilities of each person so that these problems can be targeted and treated specifically and comprehensively. As mentioned above, the content of the rehabilitation process should not depend on the diagnosis of MS but on the dysfunctions, disabilities and handicaps present in the individual patient, as derived from the ICF (WHO 2001).

The ICF does not only allow for classification and quantification of the components of life, but may also facilitate structuring, organisation and documentation of the entire rehabilitation process. It enables all professionals involved in patient care to coordinate their actions in support of helping the PwMS achieve a maximum participation in life even with impairments and disabilities resulting from the disease.

Within the bio-psycho-social framework, the ICF emphasises the importance of a comprehensive care of the needs of PwMS. The promotion of a person's functioning depends upon a full assessment of his medical, psychological and social issues; these diverse needs cannot be addressed by a single therapist but require a team of health professionals. Such teamwork should lead to interventions that improve maintenance of functioning and minimise disability among PwMS.

Teamwork can be applied in different ways. The most commonly applied approaches are either multidisciplinary or interdisciplinary models. Multidisciplinary teamwork applies to models in which efforts of different team members are parallel and discipline-oriented. The result will be the sum of the efforts of all

team members. Interdisciplinary teamwork is based on working together for the same goal: team members are required to have the skills of their own discipline as well as the ability to contribute to a group effort on behalf of the patient. The treatment programme is synergistic, producing more than each discipline could achieve individually. This synergistic approach is obtained formally by regular team conferences.

The teamwork should be based not only on evidence-based methods but also on a person-oriented approach, taking into consideration the client's autonomy and his/her goals in life. Communication and participation are the key words in the teamwork. The team members working with a progressive, life-long disease have to share common values and objectives, which must be adjusted to changing needs over time. Communication among team members should be open, accept different views (both medical and non-medical), and be ready to negotiate and to share values with all team members. The team must be ready to form and develop new values, attitudes and perceptions, tolerate constant review and challenge of ideas, and accept a team philosophy of care. Also, treatment techniques change in response to new research findings; therefore, creativity and problem-solving capacity are very important to an effective functioning of the rehabilitation team.

Effective rehabilitation is tailor-made, flexible, dynamic and depends on the needs of the PwMS. Hence, the rehabilitation team should include a wide range of specialists.

The person with MS and his/her family are the most important part of the multidisciplinary team. They should be well-informed, knowledgeable in MS and accept updated efficient management methods. The PwMS ideally follows the agreed treatment plan once the rehabilitation goals are established. Having specific goals for the rehabilitation and maintenance process allows the effectiveness of both to be monitored. Participation of PwMS in decision making is fundamental in setting appropriate goals and can improve PwMS' adherence to the rehabilitation plan.

The team for MS rehabilitation should include the following professionals, depending on the problems of the person itself:

- A physiatrist (physical medicine and rehabilitation doctor) who is a medical doctor specialised in rehabilitation but also providing medical help. This function may be also be covered by a neurologist experienced in rehabilitation. Moreover, other medical doctors should be available for consultations (e.g., urologist, internal medicine).
- The nursing team provides specialised nursing care, focusing on pain management, patient and family education, and the carry-over of the functional techniques learned during therapeutic sessions.

- The physiotherapist provides treatment interventions to develop, maintain and restore mobility and function throughout life. This specialist is concerned with maximising quality of life within the spheres of promotion, prevention, treatment/intervention and rehabilitation.
- The occupational therapist evaluates and provides treatment for patients with deficits that affect the activities of daily living. This therapist also provides training and adaptive equipment to improve areas of self-care such as dressing, feeding and personal hygiene as well as upper body strengthening to increase independence.
- The speech-language therapist provides therapy for patients with speech and swallowing disorders to help improve communication and the ability to eat and drink.
- The (neuro-)psychologist identifies and addresses psychological, emotional and psychosocial problems, but also detects and treats the different and sometimes disabling cognitive dysfunctions in PwMS.
- The social worker provides support and counselling to the patients and their families in order to solve issues related to social living. The social worker will assist in setting up a successful discharge plan and provides valuable information about services in the community.

Other professions may also be included in the rehabilitation team, depending on the needs of the PwMS: for example, specialists in diet and nutrition, sports and physical activities, adjustment of aids, disease information and education.

The dynamics within the rehabilitation team present distinct challenges to the delivery of effective rehabilitation services. The aim of the team is to achieve the goals of rehabilitation and participation by merging team members' skills and knowledge. The multidisciplinary team sets short- and long-term goals from a patient-centred point of view, plans the rehabilitation processes, delivers the appropriate interventions, and monitors and adjusts them over time according to disease progression and new needs of the PwMS.

## Rehabilitation at Different Stages: A Life-long Process

Rehabilitation is a lengthy but dynamic process. The majority of PwMS have an initial relapsing/remitting course in which remission after attacks varies in quality. After a variable period of time, this may be followed by progressive disability. However, it is important to keep in mind that about 20% of persons with MS do not experience progression in their disability.

### *Initial and early stage*

When receiving the diagnosis of MS, persons usually go through a crisis with feelings of panic, shock and depression; patients typically display a limited capacity to absorb information. In this phase, each patient should have regular appointments with his neurologist and – whenever possible – with a specialist MS nurse in a liaising role. As mentioned above, information delivery on a personalised level using well-structured patient information is mandatory. Many PwMS also need psychological support. The ways in which PwMS are treated at this stage can affect how they cope with their disease in the future. Profound support during early MS is crucial: it may determine the person's quality of life during the later years with the disease. Comprehensive information and advice can empower PwMS to take control.

In the early stages of the disease, PwMS suffer occasional relapses but usually recover well. Nevertheless, fatigue may affect patients even during this phase. Managing this fatigue can be part of the content of an educational and counselling programme. Other themes include symptomatic treatment, adaptation training, motor rehabilitation and physical activity, aids and home adaptation, social and professional consequences of having MS, etc. The socio-economic implications must especially be addressed since the majority of PwMS are young adults supporting young families.

### *Later stage*

In the later stage of the disease, impairment results in both disability and handicap that can lead to a loss of self-sufficiency in the occupational and social life. The lack of adequate means of transportation and accessible workplaces increases the unemployment rate among PwMS compared to the average population. Long-term care programmes for later stage-related problems may be necessary, including treatment of spasticity, bladder dysfunction, gait disturbances, ataxia, reduced vision, speech and swallowing dysfunction, sexual and emotional disturbances, and cognitive impairment. In these cases, neuro-rehabilitation units provide a bridge between the acute hospital and community care. In particular, persons with marked restrictions of mobility and self-help abilities, and/or long distances between their homes and a rehabilitation unit, should be treated in in-patient rehabilitation departments, which are based on integrated, goal-oriented rehabilitation programmes. The alternative, which has been successful in many countries, is the establishment of out-patient day units that have close links with the community, along with professional interventions delivered in the home when needed.



### Advanced stage

In the advanced stage of the disease, PwMS can become totally dependent in both mobility and activities of daily living. The aim at this stage is to maintain, for as long as possible, an independent life in one's own environment. In-patient rehabilitation is required if further deterioration evolves despite ambulatory treatment, or for patients suffering from more than 1 or 2 concurrent disabilities who therefore need a multimodal treatment programme. Even in severely ill and probably bedridden patients, rehabilitation can be important and mandatory, especially when treatment by several medical specialists is needed. Such patients often suffer from heavy and painful spasticity with contractures.

Rehabilitation at these stages also concentrates on installing equipment in the home to allow the person more independence and/or lessen the burden on carers. In this situation, there is an important role in teaching carers how best to cope with their physical tasks and handle any cognitive or behavioural problems that may be present. Appropriate professional support in the home can help maintain quality of life; long-term care facilities may be needed and respite care should, in some cases, be provided.

Effective support at all stages of the disease is known to reduce the number of hospital admissions and improve the general health state and quality of life. Finally, the need of carers should also be recognised and highlighted.

## Selection of Measurement Instruments for Clinicians: General Principles

Numerous measurement instruments are available that can be used in MS. This poses a problem for the clinicians, as it requires quite some research to select a suitable measurement instrument. Therefore, some general principles that can aid the clinician in this selection process have to be discussed (de Vet 2003). Recommendations for specific measurement instruments will be given in the section on rehabilitation interventions.

### Aim of measurement

The first step to select a measurement instrument is to clearly define the aim of measurement. The aim concerns the constructs one wants to measure, as well as the purpose of the measurement. In this context, the ICF model is very helpful for the identification and selection of relevant constructs (see above). Besides choosing the construct of interest, the purpose of measurement should be determined. In general, two purposes can be distinguished:

- to discriminate between subjects at one point in time (discrimination), and
- to measure changes over time (evaluation).

Discrimination is at issue when measurements are used to screen for or to diagnose certain disorders or symptoms. Parameters of interest are sensitivity and specificity. Examples are depression, swallowing disorders or residual volume after micturition. Evaluation is relevant when effects of the rehabilitation treatments are evaluated or when the disease course is monitored. Examples include improvement on the 10-meter timed walk test after physical therapy, changes in fatigue levels after treatment, or increase in neurological impairment during the disease course.

### Clinimetric properties

Clinimetric properties, such as validity, reproducibility and responsiveness, are the key issues in both the development and selection of a measurement instrument.

**Validity:** A measurement instrument is valid if it measures what it intends to measure. There are many types of validity, but the common aspect of validity studies is the testing of predefined hypotheses regarding relationships of the measurement instrument of interest to other measurement instruments or constructs. The ICF is very helpful in determining whether the content of the measurement instrument or the hypotheses tested in the literature make sense. For example, consider a newly developed questionnaire to measure mobility that contains items about walking short distances, longer distances and climbing the stairs. The first step should be to assess the face validity, i.e. do the items sufficiently cover the construct in which one is interested? In this case, the ICF chapter on mobility may help to assess the relevance of the items.

Two frequently occurring issues can easily be detected when studying the items of the measurement instrument. The first issue is the formulation of items in MS-specific measurement instruments in the form of "Due to MS, I ..." It may be very difficult for patients to attribute a specific symptom, impairment or activity limitation to MS if another potential cause is present for the same symptom, impairment or activity limitation. For example, a patient with a lower leg amputation and MS may have trouble with the question "Due to MS, I have difficulty climbing the stairs". The patient may respond "no", because he feels that the impaired stair climbing is *predominantly* caused by his lower leg amputation. This is a problem. When the aim is to measure the severity of the impact of MS (disease part of the ICF model), the part of the stair climbing activity limitation caused by MS is missed. When the aim is to assess the stair climbing activity limitation, the problem is completely missed.

The second issue relates to the way the use of aids is measured. Valid questionnaires exist to measure mobility problems without the use of walking aids. For example, the answer to the question “I can walk outside without walking aids” will not change even though a rehabilitation intervention successfully provided the patient with the appropriate walking aids that enabled him to walk outside again. However, if the aim is to assess the severity of MS, this question looks valid.

Subsequently, other aspects of validity should be studied by comparing the measurement instrument of interest to other measurement instruments or constructs. A judgement should be made whether the relationships confirm the hypotheses. In the example of the new mobility measure, strong relationships with a 10-meter timed walk test and a 6-minute walk test, moderately strong relationships with ADL measures and no relationship with anxiety would be logical. Because an infinite number of relationships can be tested, validity assessment of a measurement instrument is never completely finished.

Another issue that relates to validity is the question whether health-related quality of life (HRQoL) measurement instruments can or should be used in rehabilitation medicine (Cieza 2005). The main purpose of HRQoL measurement instruments, which often contain different subscales measuring different constructs, is to describe the burden of disease of the population studied. Although this purpose may seem unrelated to the ICF, it has clearly been shown that most of the constructs measured in HRQoL measures can be matched to constructs in the ICF model. So, it is fair to conclude that, although the theoretical concepts behind both models differ, both models measure similar constructs. Thus, measurement instruments developed within both models have potential use for rehabilitation.

**Reproducibility**, the next clinimetric property, is the extent to which repeated measurements in a stable population yield the same results. Sufficient reproducibility is a basic requirement that must be fulfilled before the measurement instrument can be used. An important aspect of reproducibility, especially when the aim of measurement is to detect changes over time, is agreement. Agreement represents the lack of measurement error. For measurement in individual patients, a very small measurement error is obligatory when one wants to safely conclude that the obtained result is correct. This requirement is much stricter than when a measurement instrument is used in groups of patients, because the increased number of measurements reduces the noise (this is the principle of research in groups of patients). Although many parameters are available to quantify reproducibility, it makes sense to search for parameters that express agreement in the units

of the scale of the measurement instrument used (e.g. the Standard Error of Measurement [SEM]). This facilitates interpretation in clinical practice.

**Responsiveness:** The clinimetric property of responsiveness is essential for evaluative measurements, and many parameters to assess responsiveness are available. Currently, there is no consensus on which is best. Nevertheless, the last few years seem to show a small favour for parameters expressed in the same units as the scale of the measurement instrument. Responsiveness indicates whether a measurement instrument is able to measure minimally important changes (MIC) over time. The MIC is the change that is relevant for the patient, and is determined in a group of patients. Once the MIC has been established in research, the same MIC can be used in individual patients and in groups of patients. The MIC does not depend on the reproducibility of a measurement instrument, but it should be related to it in order to assess the usefulness of a measurement instrument (Paltamaa 2008; De Groot 2006).

The agreement of a measurement instrument can be used to calculate the smallest real change (SRC), which is the change on a measurement instrument required to overcome the measurement error. A measurement instrument can be used to measure changes in individual patients only when the SRC is smaller than the MIC. If the SRC is larger than the MIC, one does not know whether the change is relevant or should be attributed to the noise of the measurement. When available, it is advantageous to use MIC and SRC to assess the responsiveness of candidate measurement instruments, because these items they are directly related to the units of the scale of the measurement instrument used.

#### *Practical aspects*

Besides these methodological issues, it is also important to consider practical aspects of measurement, such as how much (treatment) time can be used for measurements, the complexity of scoring the measurement instruments, what is needed to make the scores readily available for clinicians, what are the consequences for the organisation and what costs are allowed. These factors determine whether or not systematic outcome measurement can be implemented in regular day-to-day patient care.

#### *Measurement instruments in rehabilitation medicine*

The theoretical framework of the ICF is very important for rehabilitation medicine because it covers all aspects relevant for clinical practice, as well as their potential interactions. As argued above, the ICF can also be used to guide the selection of measurement instruments. However, the questions “*why measure?*” (purpose) and “*what to measure?*” (construct) remain.

Because the primary focus of rehabilitation is on improving activities and participation, *generic* measurement instruments should be used to measure the overall effect of rehabilitation. Generally speaking, the content of relevant generic measurement instruments for clinical rehabilitation is more activity based, whereas the content of the relevant generic measurement instruments for out-patient rehabilitation is more participation based. These generic measurement instruments do not necessarily have to be developed for MS patients, although it may be that measurement instruments specifically developed for MS patients can be used if they cover the appropriate constructs, and if the items are formulated properly (see paragraph on face validity).

However, the Expanded Disability Status Scale (EDSS) and the MS Functional Composite (MSFC), two frequently used measurement instruments in drug trials in MS research, are not suitable for use as generic measurement instruments in rehabilitation medicine. The EDSS measures neurological deficits and mobility aspects, and the MSFC measures mobility (25-foot timed walk test), dexterity (9-hole-peg test) and cognition (Paced Auditory Serial Addition Test). Although measuring these constructs may be relevant, they do not cover sufficiently the activity or participation domain, which means that they cannot be used as a generic measurement instrument in rehabilitation medicine.

Besides measurement instruments to measure the generic rehabilitation outcomes, it may be very relevant to measure parts of the rehabilitation treatment. These measurement instruments can be tailored to specific symptoms (such as fatigue), specific functions (such as spasticity) or specific activities (such as dressing). These measurements can be used to ascertain whether the patient-specific goals of the rehabilitation treatment have been achieved. They may be used in conjunction with goal-attainment scaling. As argued above, the responsiveness of these measurement instruments should justify application in clinical practice.

In sum, when selecting a measurement instrument, one should first determine the construct that one wants to measure and the purpose of measurement. Subsequently, the clinimetric properties of validity, reproducibility and responsiveness of the candidate measurement instruments should be assessed and compared. Finally, the practical aspects should be addressed. It should be noted that, although good measurement instruments are available, responsiveness at an individual level is the most difficult clinimetric requirement to fulfil.

## Efficacy of Multimodal Rehabilitation

The variety of impairments, disabilities and handicaps in PwMS requires comprehensive neuro-rehabilitation, which can be provided only by multidisciplinary programs (Khan 2007). This approach should be highly effective in:

- improving impairment, disability and handicap of the individual.
- reducing or preventing complications resulting from single or combined symptoms, e.g. lower back pain or disc herniation due to spastic gait.
- providing adaptive strategies to minimise disability.
- providing well-fitted aids, such as orthoses, canes and wheelchairs, to reduce functional dependence.
- providing training skills to improve vocational capabilities.
- counselling to enhance strategies of coping with the disease.
- providing symptomatic management (Putnam 2008; Cohen 2008; Khan 2008; Kraft 2008; Schapiro 2002; Brown 2005).
- improving or maintaining general health and health-related quality of life (Patti 2010).

In general, clinical trials focused on MS rehabilitation are difficult to perform due to the discrepancies between “professional artistry” (which means a very individually and empirically based rehabilitation) and an evidence-based, scientific approach. These problems are related to various factors, such as heterogeneity of MS patients, lack of well-defined control groups or adequate control interventions, concomitant treatment with disease-modifying and/or symptom-related drugs, or lack of appropriate and sensitive outcome instruments (Francabandera 1988; Di Fabio 1997; Freeman 1997; Patti 2002; Patti 2003; Craig 2003; Pozzilli 2002; Stuijbergen 2003). Nevertheless, several randomised and clinical controlled trials for rehabilitation in MS have been carried out (see below).

The most suitable set of rehabilitative intervention for PwMS remains an unsolved question, but it is now very clear that the content of the rehabilitation process is strictly individual and must be narrowly related to the patient’s disabilities and handicaps. Another unsolved question is that regarding the long-term cost-effectiveness of MS rehabilitation.

In general, there are four options for rehabilitation to which the patient may be allocated: home-based therapy, out-patient ambulatory therapy, in-patient hospitalised therapy, and out-patient hospitalised therapy. Specific guidelines aimed at a rationale for allocating PwMS to one of these settings are not available yet.



As mentioned above, the appropriateness and sensitiveness of outcome measures is crucial: unfavourable results from a rehabilitation programme may not reflect ineffective interventions but rather the use of measures that are not sensitive enough to detect relevant variations of performance and abilities of the patient during the rehabilitation process. For example, a long-term exercise programme determined significant improvement on the MSFC, whereas no significant effect was documented on the EDSS regarding the changes of leg function and ambulation (Romberg 2005). A recent meta-analysis showed a significant effect of aerobic exercise on QoL. These effects were statistically significant when using an MS-specific QoL instrument, whereas no significant effect was detected when generic QoL measures were used (Motl 2008).

Several studies have analysed the effects of physical training on impairment, disability and HRQoL of MS patients. Ambulatory MS patients, for example, benefit from aerobic training in terms of fitness, reduced fatigability, and improved QoL perception (Sickness Impact Profile) (Petajan 1996). The amelioration gained from rehabilitation is at least partly maintained after discharge, despite worsening of neurological impairment (Freeman 1997). Carry-over of benefits on disability will last for a further six weeks after a short out-patient treatment, without change in impairment (Patti 2003). Multimodal physical rehabilitation leads to an improvement in disability as detected by the Functional Independence Measure (FIM) motor domains, and has a positive impact on mental components of HRQoL perception. By contrast, all SF-36 domains may significantly improve in a short period (6 months) of a tailored, individualised out-patient rehabilitation programme (Solari 1999). Moreover, an individualised rehabilitation programme will reduce disability as measured by FIM motor domains but will not improve participation and QoL (Khan 2008). In a recent *Cochrane Review*, strong evidence was found in favour of exercise therapy compared to no exercise therapy in terms of muscle power function, exercise tolerance functions and mobility-related activities (Rietberg 2005).

As mentioned before, there are four possible rehabilitation settings to which a PwMS could be allocated. *Which is the ideal one?* Out-patient and home-based rehabilitation programmes using high-intensity treatment may facilitate short-term improvements in symptoms and disability, leading to improvements in participation and QoL. There is also strong evidence that in-patient multidisciplinary rehabilitation determines short-term gains at the levels of activity and participation for PwMS (Khan 2007).

In conclusion, even though MS rehabilitation has no direct influence on disease progression, it is now clear that it improves personal activities and the ability

to participate in social activities, thereby improving quality of life. Treatment should be aimed at the individual patient's needs and the environment in which he/she lives, the needs of carers, and the type and degree of disabilities and handicap.

## Mechanisms of Rehabilitation

One characteristic of MS is the remarkable ability of patients to make an apparently complete recovery from relapses – even if those exacerbations were associated with a severe neurological deficit. Most commonly, these complete remissions occur early in the disease course. Different mechanisms have been advocated to explain their nature.

### *Recovery by resolution of inflammation*

Inflammation, particularly when there is release of nitric oxide, can result in neurological deficit. Yet it has also been shown that removal of nitric oxide or other inflammatory mediators can rapidly restore conduction in an experimental system. Nitric oxide helps to perpetuate the glutamate-mediated damage to oligodendrocytes and neurons during inflammation by both increasing the release of glutamate and suppressing its re-uptake (Rejdak 2004).

The extent which steroids and disease-modifying drugs may dampen this inflammatory reaction – and hence contribute to restore function – is a matter of debate.

### *Recovery by remyelination*

In MS, the oligodendrocytes and the myelin sheath are the major targets of the disease process. Loss of oligodendrocytes leads to loss of myelin sheaths around axons (a process called demyelination). The immediate consequence of demyelination is that the axons become less efficient at conducting impulses. Since myelin appears to be also important for maintaining the health of the axons, the therapeutic promotion of remyelination (a phenomenon by which new myelin sheaths are generated around axons) in situations where it has failed may represent one of the most effective ways of preventing axon loss. Spontaneous remyelination occurs in many MS lesions, but becomes increasingly incomplete and eventually fails in the majority of lesions and patients.

Remyelination seems to occur in two major phases. The first consists of colonisation of lesions by oligodendrocyte progenitor cells (OPCs); the second is characterised by differentiation of OPCs into myelinating oligodendrocytes that contact demyelinated axons to generate functional myelin sheaths. The absence of OPCs is not a common cause of remyelination failure; rather, it can be linked to the

failing of the OPCs to differentiate into remyelinating oligodendrocytes (Fancy 2010). One therapeutic approach could be to support this intrinsic repair process by providing one or more remyelination-enhancing factors or via immunoglobulin therapy.

Another approach is to provide some external help via transplanted cells that are able to produce new myelin. This is called the exogenous or cell-therapy approach. Several cellular candidates have been identified that can mediate repair of experimental demyelinating lesions. Future challenges confronting therapeutic strategies to enhance remyelination will involve the translation of findings from basic science to clinical demyelinating disease.

#### *Recovery by plasticity changes*

Neural plasticity is the ability of the central nervous system to remodel itself and adapt in response to environmental changes such as injury or disease. In patients after stroke and injury, different neuroplastic mechanisms have been described (such as alterations in synaptic strength and changes in neuronal excitability or compensation) in which residual neural substrates are used to perform impaired functions. Finally, the unmasking of previously silent connections or the production of behaviour through neuronal sprouting and dendritic growth can also be seen as plastic changes following injuries of the CNS (Hallett 2005).

Fortunately, the same type of cortical changes as those observed after traumatic or vascular damage of the CNS can compensate loss of function resulting from axonal degeneration in MS. Functional MRI (fMRI) studies have shown that cortical plasticity does play a role in the recovery of symptoms due to MS (Cifelli 2002).

#### *The contralesional hemisphere can take over motor control*

In normal individuals, fMRI activation is largely confined to the contralateral primary motor cortex; by contrast, in MS patients it is also seen in other cortical regions such as the ipsilateral primary motor cortex or the supplementary motor area. Concerning the former area, it is known that there are ipsilateral, corticospinal neural pathways. Although these pathways innervate proximal (more than distal) muscles, these pathways have been shown to be successively involved in the recovery of patients with hemispherectomy and to be also relevant in stroke recovery. In patients with MS, it could be shown that the ipsilateral cortical activation was proportional to the extent of axonal injury, suggesting that the brain tries to maintain a minimal performance level with increasing injury. It is believed that these changes represent an unmasking of existing pathways rather than a novel cortical reorganisation.

A similar compensation mechanism with activation of the ipsilateral hemisphere was observed when MS patients were confronted with a sustained attention task, which they performed as well as the healthy individuals but through activation of more brain tissue (Staffen 2002). When these adaptive changes of the cortex are lost, patients probably advance to disease progression and accumulation of irreversible deficit.

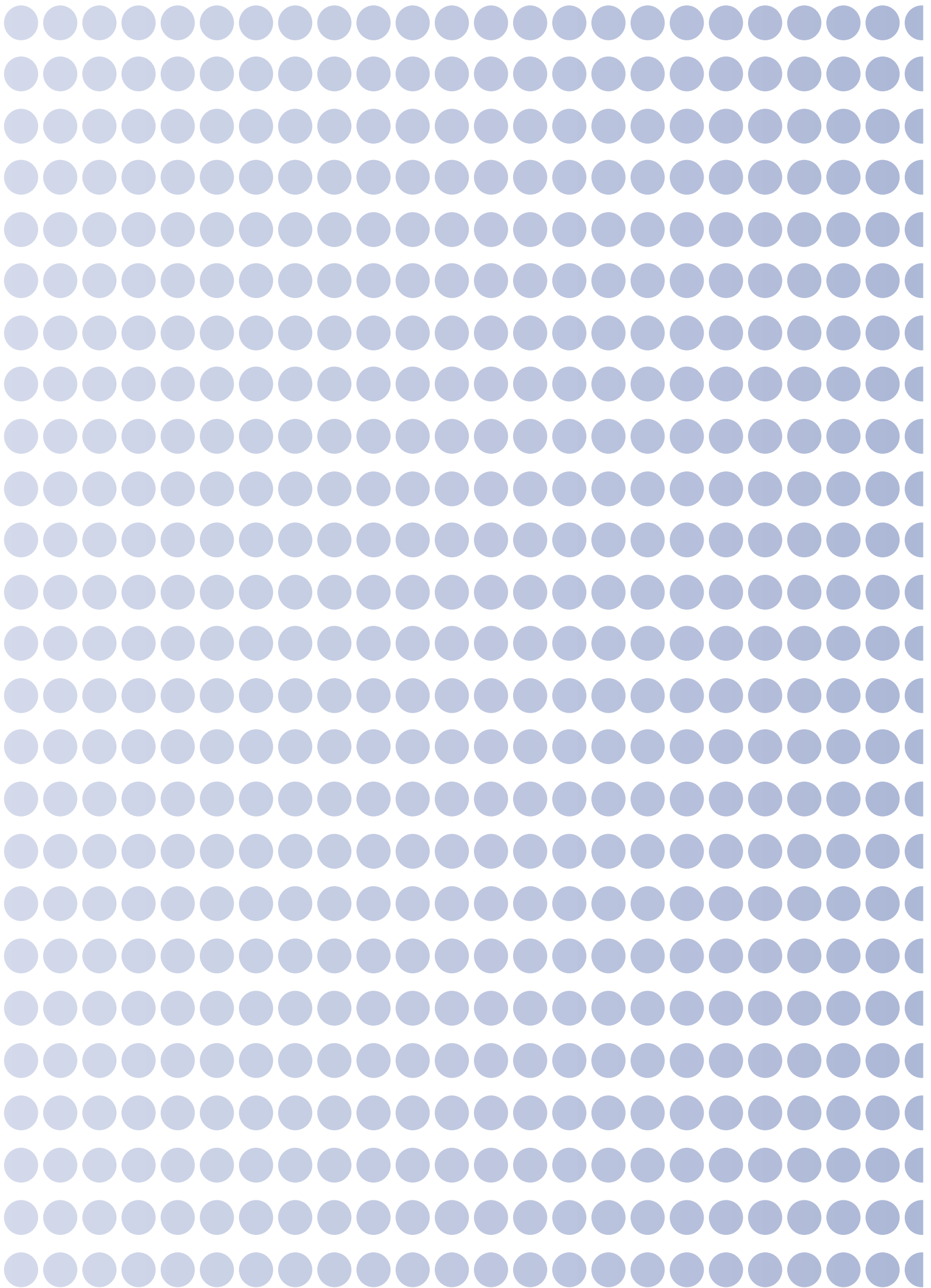
#### *The premotor cortex can substitute for the motor cortex to control motion*

Anatomical and physiological studies show that the premotor cortex contributes to the function of the corticospinal tract; however, the stimulation thresholds of the premotor cortex are higher than those of the primary motor cortex. In a healthy individual, the main output of the premotor cortex is ordinarily to the primary motor cortex; in the case of disease, the premotor cortex can be a source of supraspinal control signals to restore function. This was observed in a study in which MS patients were asked to perform a manual task; researchers found activation in areas outside the usual borders of the hand area involving, in particular, the premotor cortex (Reddy 2002).

Such compensatory functional reorganisation processes may limit the clinical expression of some of the disease symptoms. These neuroplastic processes together with spontaneous remyelination may explain – at least in part – the so-called “clinico-radiological paradox” whereby considerable changes are detected at MRI level in the presence of only weak clinical symptoms.

#### *Future research*

Recent studies have even shown that proprioceptive stimulation by passive limb movement could promote cortical plasticity at the level of the spinal cord. These observations encourage the development of specific rehabilitation methods for enhancing these neuroplastic processes in the right direction, thus delaying the onset of the functional symptoms in patients with MS.





Part C: Symptoms, Disabilities, Handicap  
and Rehabilitation Interventions

## Mobility

Reduced mobility is considered as one of the most common impairments compromising activity and limiting participation of persons with MS (PwMS) (Sutcliff 2010). Some 50% of patients with MS will require some form of walking aid within 15 years from onset of the disease (Flachenecker 1996). Mobility can be separated into different categories including bed mobility, transfers, ambulation, stair climbing, wheelchair propulsion, power mobility and driving. The 12 Item Multiple Sclerosis Walking Scale (MSWS-12), timed 25-foot walking test (T25FW) and the 6-minutes walking distance are recommended to measure walking (Hutchinson 2009). Weakness, tremor, visual disturbances, sensory changes, spasticity or problems with balance and coordination figure among the different symptoms that may affect mobility.

Since multiple factors limit mobility, a multidisciplinary treatment approach is recommended. The proposed treatments to maintain mobility include regular physical exercise, physiotherapy, supplementation with different aids (canes, orthotics and powered wheelchairs) and drug treatment.

## Interventions

### *Encourage strengthening exercise to fight weakness*

Patients with MS face two kinds of weakness; one secondary to deconditioning and one secondary to the neurological disease. Strengthening exercises should be designed to address weakness secondary to deconditioning and should include progressive resistance training, which range from isometrics to resistive bands and to weight training. The optimal resistance is based on muscle power, endurance and functional goals established jointly by the patient and therapist. A recent pilot study showed that strengthening exercises improve mood and reduce fatigue (Dalgas 2010).

### *Exercise to maintain mobility and activities of daily life (ADL)*

Early in their disease, MS patients usually have low disability scores and can use exercise to increase their aerobic capacity. As the disability increases, exercises are modified depending on the degree of weakness, spasticity and diminution in aerobic capacity. A reasonable exercise programme can be prescribed by the physical therapist, regardless of the disability level. Maintaining cardiovascular fitness increases mobility and decreases fatigue.

Exercise programmes should be done three times per week if possible. The exercise programme should be monitored, since excessive exercise may increase the

body temperature and therefore weakness and other MS symptoms. Since fatigue may be problematic, energy conservation techniques are developed by occupational therapists. Furthermore, exercise interventions aimed to improve daily functioning of patients with MS are effective. There is strong evidence in favour of exercise therapy, compared to no therapy, regarding muscle function and mobility (Rietberg 2005).

No single specifically targeted exercise programme has been shown to be more successful than others. Probably a combination of endurance and resistance training will be most effective (see chapter on physical exercise). No deleterious effects were described in the studies published so far. There is some evidence that persons with severely impaired ambulation due to MS can tolerate and benefit from locomotor training using body weight support on a treadmill (LTBWST) or walking with the Locomat®. In addition to improving some measures of disability (such as endurance), LTBWST may influence positively spasticity, muscle strength and balance (Beer 2008).

### *Improving mobility by treating spasticity*

Spasticity is a common symptom reducing mobility in MS patients. Mild spasticity may interfere with normal mobility by making patients feel stiff and causing fatigue when they walk. As spasticity worsens, walking becomes even more difficult. Abnormal gait patterns appear, balance problems occur and falls become more frequent. Some patients report painful spasms, which reduce sleep quality and worsen their ability to transfer or to get in or out of a vehicle.

If spasticity is mild and does not interfere with mobility, rehabilitative techniques such as exercises and relaxation techniques may be prescribed. Exercise programmes will likely include stretching and range-of-motion exercises. Exercise in a cool swimming pool is helpful because the buoyancy of the water makes smooth movements easier. Passive exercise is particularly effective for managing spasticity. Specific positioning can also help to decrease spasticity in bed-ridden patients. If greater problems exist, the additional use of an anti-spastic drug may be beneficial, such as Baclofen (Lioresal®), Tizanidine (Sirdalud®), Diazepam (Valium®), Clonazepam (Rivotril®), Dantrolen sodium (Dantrium®) or Cannabinoids (Lakhan 2009; Wade 2010). Nevertheless, these medications have to be titrated up slowly, to avoid sedation or increased weakness.

When oral drugs are not helpful or produce too many side effects, an intrathecal Baclofen pump is a good alternative for severe spasticity. The pump will deliver steady amounts of the drug, eliminating the variability of oral dosing without having the sedating side effects. For spasticity involving small muscles, injections of



botulinum toxin Type A (Botox®) may be used. These will weaken the muscle, lessening contraction for up to three months. Large amounts cannot be used at any one time, so smaller muscles make better targets. Patients need to follow up with a physical or occupational therapist one week after injections to maximise stretching of the affected muscles.

### *Increasing mobility and participation by providing walking and mobility aids*

Walking aids can compensate for weakness, alleviate pain, improve posture, correct abnormal gait patterns and enable people to walk further and more safely. Moreover, the use of mobility aids can restore confidence, often by signalling to others that the user is unsteady and not drunk.

- **Ankle-foot orthoses (AFOs)** compensate for weakness of the legs. They decrease fatigue and help prevent injury from misuse or overuse of joints.
- **Functional electrical stimulation devices** can improve walking distance and walking speed in people with footdrop.
- **Canes** provide support when balance and/or weakness of the legs are problematic. If one leg is weak, the cane is used in the hand opposite the weak leg. Two canes can be used if both legs are weak.
- **Crutches** give greater stability when weakness is more severe and canes cannot do the job.
- **Walkers** offer stability when the lower body is weak or balance is impaired. Wheeled walkers in bright colours with baskets, brakes and pull-down seats are available.
- **Wheelchairs** or **three-wheel scooters** provide mobility when walking, even with an aid, is fatiguing or impossible. People who are able to walk but need to conserve their energy often use these aids.
- **Grab bars, bed rails** and **vehicle hand controls** can provide the necessary assistance to improve safety and efficiency with overall mobility, particularly for transfer.

### *Drugs to improve mobility*

A recent study showed that some MS patients taking Fampridine SR (a slow release formula of 4-aminopyridine) improved their walking speed (Goodman 2009). In this study, timed-walk responders also showed greater improvement in the MS Walking Scale (MSWS-12) than timed-walk non-responders, providing validation for the clinical significance of the improvements in walking speed. The extent to which anti-spastic drugs objectively improve the walking performance is a matter of debate. Some

drugs proposed to fight fatigue (such as amantadine hydrochloride, 100 mg twice a day or modafinil) may have an influence on mobility when they work.

In summary, limitations of mobility are common among PwMS and are caused by different impairments, which a multidisciplinary rehabilitation team should assess thoroughly. Careful screening that takes into consideration physical, mental, emotional and social factors is essential to determine an appropriate treatment plan. One cannot overemphasise the importance of initiating an exercise programme early in the course of MS and continuing the programme with modifications even as disability increases. Further treatment options range from skilled physiotherapy (such as the Bobath technique) and a growing number of evidence-based mechanical interventions (for example, treadmill training) to the additional use of specific drugs.

## **Arm Function**

Arm or upper extremity function is crucial to independently perform activities of daily life (ADL), which often require a high level of motor coordination, dexterity and a precise collaboration between both hands (e.g. opening a bottle or closing a zip). Unilateral impairment affects functional efficiency and independence, while disability is even more pronounced in neurological pathologies with bilateral impairment such as MS.

Upper limb function in daily life can be impaired in MS due to clinical symptoms such as muscle paresis, spasticity, ataxia and sensory dysfunction, as well as visual and cognitive deficits leading to functioning problems. During the disease course, about three-quarters of PwMS are confronted with reduced manual dexterity while half of all patients experience substantial impact on ADL, in its turn decreasing quality of life (Johansson 2007). Arm dysfunction most typically occurs in persons with overall high disability.

### *Assessment*

Evaluation of arm function in MS is most commonly performed using the nine-hole peg test (part of the MSFC) and Functional Independence Measure (part on self-care). Use of other instruments such as the AMPS (instrumented ADL) and TEMPA are specifically reported (Erasmus 2001; Feys 2002; Mansson 2004). Naturally, other outcome measures, such as those used in stroke, (e.g. action arm research test) are applicable.

### *Interventions*

Treatment can be differentiated in training and compensatory approaches. Training approaches

aim to maximise arm function by practising on motor function and coordination, as well as on performance of task-oriented functional activities.

A common physiotherapeutic practice for improving muscle strength is proprioceptive muscular facilitation, while task-oriented skill training is most often applied by occupational therapists. Devices such as arm ergometers are also frequently used for therapist-independent training of both muscle strength and endurance. Muscle strength is important for active range of movement and stabilisation of the arm during both manipulation of objects and performance of transfers.

Surprisingly, given the functional impact of upper extremity dysfunction, intervention studies targeting arm function in MS are sparse. Different pilot studies have indicated beneficial effects of training on arm function in MS. Resistance training (10 weeks) lead to improved muscle strength in persons with mild to moderate disability, but changes on the activity level were not reported (Taylor 2006). Constraint-induced movement therapy was applied during two weeks in five MS patients with hemiplegic clinical picture, and lead to improved functional capacity as measured with the Wolf Motor Function test and Motor Activity Log (Mark 2008).

Rehabilitation technology is increasingly being applied as this approach may offer a tool for intensive, repetitive training in addition to regular therapy. Training in an enriched virtual environment is increasingly being accepted as an innovative and appropriate intervention given the provision of visual and proprioceptive feedback, and stimulation motor learning and neuroplasticity (Merians 2009). First studies applying technology-assisted arm training programmes, with electro-mechanical or robotic devices, showed improved motor function and coordination in persons with moderate to severe disability level, as well as indications for improved functional capacity (as revealed with the nine-hole peg test, action research arm test, TEMPA, etc.) (Gijbels 2011; Carpinella 2009). However, this additional training remains to be integrated in individual functional goal setting in order to gain meaningful effects for the patient. Besides, motor activity desks have been developed and tested for use by patients living in the community. This type of tele-rehabilitation was shown to be feasible in PwMS and possibly leading to therapeutic effects (Huigen 2008).

Compensatory approaches may consist of optimising arm and hand care by means of correct positioning of arms showing paralysis, mobilisation of the arm and hand to prevent (further) development of contractures and for reasons of hand hygiene. Interaction between healthcare professionals is important to determine the usefulness of additional medical (e.g. botulinum

toxin) or technical (e.g. adapted splints, counselling of ADL equipment) interventions.

## Ataxia and Tremor

Ataxia is a Greek word referring to chaotic movement. In MS, ataxia is typically related to dysfunction in the sensory, vestibular or cerebellar system. Cerebellar ataxia refers to deficits in temporal and spatial coordination caused by lesions or degeneration in the cerebellum and/or brain stem (Hickman 2001; Feys 2005a). It manifests in different effectors such as the limb, trunk and eyes with features such as slowed initiation, spatial dysmetria or dysdiadochokinesia when coordinating multiple limbs and impaired force regulation. It is reported that some feature of ataxia occurs in 80% of persons with MS along their disease course (Mills 2007).

A specific feature of ataxia is tremor, defined as a rhythmic involuntary oscillating movement. In MS, tremor does not occur during rest but while maintaining a position against gravity (postural tremor) or towards the end of especially visually guided goal-directed movements (intention tremor). The prevalence of action tremor is estimated at between one-quarter and one-half of the MS population (Pittock 2004; Alusi 2001). It interferes importantly with the performance of daily life activities (Feys 2004). Besides the direct impact of coordination problems, patients report also emotional and social distress. They often feel embarrassed because of the appearance of tremor and ataxia, with stress often worsening the symptoms (Alusi 2001).

### Interventions

Both ataxia and tremor are known to be difficult to treat with satisfactory results. Medication has so far only limited effect, also due to the occurrence of adverse effects during administration of higher doses (Koch 2007). Neurosurgical interventions such as electrical thalamic stimulation (Nucleus ventrointermedius, VIM) are only indicated for a PwMS suffering from marked tremor given also risk for complications. However, specific (intervention) strategies and compensatory devices have been reported that are useful in daily practice.

Reducing the number of degrees of freedom and moving in so-called "closed chain" is generally known to enhance functional performance. For example, gait can be facilitated by (fore) arm support provided by (partially) wheeled rollators. Stable positioning of a patient with uni- or bilateral elbow support may facilitate the use of the arm in daily life activities. Compensatory aids such as adapted cutlery reduces the need for fine precision while available tools such

as electronic toothbrushes reduce the need for alternating movements (Feys 2004). Orthoses for neck and hand may also restrict the number of joints to be controlled and therefore improve independent activities (Gillen 2000).

A Cochrane Review on treatment of ataxia revealed a lack of randomised controlled (RCT) intervention studies for ataxia (Mills 2007). Physical training programmes may bring some benefit, however adding proprioceptive information by means of air splints was not effective (Armutlu 2001). The use of weights for ataxia has, for many years, been advocated as useful in specific cases, with a recent RCT indicating specific weighting placement on the trunk had effects on functional ambulation outcome measures (Widener 2009).

Additional treatment options for tremor are the application of cooling as well as strategies related to visuomotor performance. Cooling of the limb was shown to temporarily lead to tremor amplitude reduction and improvement of functional arm movements (Albrecht 1998; Feys 2005b). Intention tremor amplitude is also related to deficient processing of visual information. Regarding personal computer (PC) interaction, it was found that persons showed improved PC interaction (and less tremor) when adapted software reduced the represented tremor of the pointer on the screen (Feys 2006; Feys 2001).

Eye movement deficits are frequently present in patients with cerebellar symptoms (Feys 2003). Particularly unsteady fixation after saccadic movements was shown to increase hand tremor amplitude, leading to a strategy of splitting saccadic and hand movements towards a target (Feys 2008). Similarly, saccadic dysmetria had a negative impact on atactic gait (Crowdy 2000). Case reports suggest that training on eye movement accuracy is helpful to improve gait quality (Crowdy 2002).

## Physical Exercise

Up to 79% of PwMS experience loss of mobility as a substantial disease burden (Hemmett 2004) and walking ability in particular is restricted (Myhr 2001). Within approximately 10 years after receiving the diagnosis, 38% of the subjects with MS will have a permanent need for a walking aid (Paltamaa 2006). Thirty years after disease onset, the proportion is 83% (Weinshenker 1989).

Deficits in muscle function and/or balance are major contributors to mobility restriction in MS. Affected lower limb muscle strength, for instance, significantly reduces gait speed (Thoumie 2005). The decreases in muscle strength in MS are more prominent in the lower limbs than in the upper limbs (de Ruyter 2001; Schwid 1999); however, the mechanisms (atrophy

or reduced activation) behind the deterioration of the muscle function may be highly variable (Carroll 2005; Kent-Braun 1997; Lambert 2001; Ng 2004; Rice 1992). Balance deficits are common, and act significantly to an increased likelihood of falling (Peterson 2008). Prevalence rates of 52% to 54% for a recent fall have been reported in MS populations (Cattaneo 2002; Finlayson 2006).

During the course of the disease, the majority of PwMS develops deficits of varying degree in the cardiovascular and respiratory function. Aerobic capacity, in terms of maximal oxygen consumption ( $VO_2$ max), has shown reductions up to 30% among PwMS as compared to healthy subjects (Mostert 2002). The reduction may well be related to neurological impairment, already in early MS (Romberg 2004a). Conversely, no evidence exists about inter-relations between  $VO_2$ max and disease duration, disability or fatigue (Rasova 2005). Respiratory dysfunction is common in MS and respiratory complications are major causes of morbidity and mortality in the disease (Redelings 2006). In particular, expiratory muscle weakness has been observed (Redelings 2006; Buyse 1997). More pronounced reductions in the respiratory function can be seen in advanced stages of the disease (Grasso 2000).

**Consequences of physical inactivity:** MS is associated with a reduction in physical activity participation (Motl 2005). This is caused by the disease *per se* and/or a sedentary lifestyle (Karparkin 2006). Physical inactivity may lead to detrimental effects on versatile levels of health and physical functioning in PwMS. Worsening of symptoms and increased risk of secondary conditions (such as fractures or coronary heart disease, high rates of depression and enhanced fatigue) are examples of documented consequences of inactivity in MS (Logan 2008; Motl 2008; Slawta 2003; Stroud 2009). In turn, these may seriously affect participation in societal interactions and ultimately translate into reduced quality of life (Freeman 2001; Turner 2009).

## Interventions

For many years, exercise therapy was not utilised in the rehabilitation of PwMS because it was assumed to lead to symptom deterioration or to increase fatigue (Sutherland 2001). During the last 15 years, exercise therapy has been gradually recommended more commonly for PwMS, because new studies have shown beneficial effects of exercise (Sutherland 2001; Petajan 1999; Ponichtera-Mulcare 1993). Furthermore, it has been shown that the worsening of sensory symptoms after exercise is temporal, and will be normalised within half an hour after exercise cessation in most individuals (Smith 2006). Various



training modalities are known to target different areas of the physiological profile. As resistance and endurance training constitute the two extremes of basic exercise therapy, most studies have evaluated the effects of these approaches in MS.

### *Resistance training*

Numerous studies have evaluated the effects of resistance training interventions in MS subjects with mild or moderate impairment. None of studies have reported problems related to resistance training, which seems to be well tolerated by PwMS. Current research almost consistently show enhanced muscle strength following resistance training (DeBolt 2004; Gutierrez 2005; Kasser 1996; Kraft 1996a; White 2004; Taylor 2006; Fisher 2000; Aimet 2006; Dalgas 2009). The interventions in most studies (DeBolt 2004; White 2004; Aimet 2006; Dalgas 2009; Harvey 1999) have solely aimed at the lower extremities, but notable improvements (3% to 29%) have also been found in the main muscle groups of upper extremities in the studies applying exercises for these areas (Kasser 1996; Kraft 1996b; Taylor 2006). The effects of resistance training on functional capacity are inconsistent. Some studies have shown to improve chair transfer (Harvey 1999), chair stand (Dalgas 2009), gait (Taylor 2006; Dalgas 2009; Kraft 1996b), stair climbing (Dalgas 2009; Kraft 1996b) and “timed up and go” (Kraft 1996b). But not all have been able to demonstrate functional improvements (DeBolt 2004; White 2004). Resistance training also seems to positively influence fatigue, mood and quality of life (Dalgas 2010).

### *Endurance training*

The effects of endurance training have been studied extensively in MS. Overall, this type of training is well tolerated among persons with mild or moderate impairment. Different types of endurance training have been tested including bicycle ergometry (Mostert 2002; Heesen 2003; Kileff 2005; Oken 2004; Rasova 2006; Schapiro 1988; Schulz 2004; Rampello 2007), arm-leg ergometry (Petajan 1996; Ponichtera-Mulcare 1997; Rodgers 1999), arm ergometry (Marsh 1986), aquatic exercise (Gehlsen 1986; Gehlsen 1984; Sutherland 2007) and treadmill walking (Marsh 1986; van den Berg 2006; Newman 2007). Long lasting (>15 weeks) (Petajan 1996; Ponichtera-Mulcare 1997) but not short (< 8weeks) (Mostert 2002; Rasova 2006; Schulz 2004) interventions improve  $VO_2$ max.

The effects on functional capacity are inconsistent. Some studies examining the effects of endurance training on gait velocity have shown improvements (Kileff 2005; Rampello 2007; van den Berg 2006; Newman 2007); others not (Heesen 2003; Rodgers 1999; Gehlsen 1986; O’Connell 2003). A portion

of the studies have shown that endurance training can positively influence fatigue (Oken 2004; Rasova 2006), whereas others did not find any effect (Mostert 2002; Kileff 2005; Schulz 2004; Rampello 2007; Petajan 1996; van den Berg 2006; Newman 2007). Endurance training seems to influence positively both health-related quality of life (Mostert 2002; Oken 2004; Rasova 2006; Schulz 2004; Rampello 2007) and mood (Petajan 1996; Sutherland 2007). It may also affect beneficially symptoms of depression (Motl 2005). Finally, preliminary evidence suggests that endurance training may have a neuroprotective function via increased production of neurotrophins (Castellano 2008; Gold 2003).

### *Combined exercise: optimal exercise therapy*

While endurance training results in profound adaptations in the cardio-respiratory and neuromuscular systems (Jones 2000), resistance training is known to increase muscle mass and to improve neural activation (Kraemer 2004). Because MS patients have deficits in all these areas, optimal exercise therapy should target all these attempting to maintain and/or normalise these deficits them. From a physiological point of view, this would require the application of both endurance and resistance training for exercise therapy in PwMS. To date, combined (or concurrent) training has been sparsely investigated in MS (Carter 2003; Bjarnadottir 2007; Romberg 2004b). It has been well tolerated and beneficial effects on muscle strength and functional capacity have been observed following a period of combined training. In addition, improvements in  $VO_2$ max have been reported (Bjarnadottir 2007), but this finding is not consistent (Romberg 2004b).

### *Exercise therapy at different stages*

The level of disability, impairments, symptom variation and previous exercise experiences should be taken into account to design an optimal exercise training programme for a PwMS. It is important that the programme is designed and prescribed on an individual basis. Modifications are regularly needed to ensure a variable and appropriate training stimulus. Supervision by a rehabilitation professional (e.g. physiotherapist) is recommended when designing the programme and to support exercise adherence.

### *Early stage*

For persons with minimal impairment, the general training prescriptions may closely resemble those for healthy people. Typically, only competitive sports and very intensive or long-lasting physical efforts are restricted. For persons with some degree of neurological impairment or mobility deficits, combined

training consisting of two weekly sessions of both endurance and resistance training is recommended as the maximal initial training prescription. Endurance training at moderate intensities (corresponding to 60% to 80% of maximum heart rate) is recommended. An initial training duration of 10 to 40 min is adequate; duration should, however, be modified according to the applied training intensity. For previously untrained persons, a convenient starting point for resistance training is 1 to 3 sets of exercises for the major muscle groups with 8 to 15 repetitions for each exercise. Group exercise training may be ideal for many persons. Besides physiological benefits, it enables aspects of socialisation that may be helpful to maintain long-term training motivation.

#### *Advanced stage*

Exercise therapy in advanced MS is often incorporated into conventional physiotherapy programmes. The effects of specific training interventions in this subgroup have been inadequately addressed by research. Persons with severely impaired ambulation may benefit from locomotor training using body weight support on a treadmill (Giesser 2007); clinical experiences support the use of adapted physical aids (such as hand-cycles) on the part of wheelchair-bound subjects. Standardised respiratory training protocols can be recommended to improve pulmonary function in moderately to severely disabled subjects (Gosselink 2000; Klefbeck 2003; Smeltzer 1996). Nonetheless, there is a need to determine the potential of exercise therapy to affect different aspects of impairments and functioning in persons with advanced MS.

In summary, the beneficial effects of exercise therapy in the rehabilitation of PwMS are well established. Exercise modalities such as endurance, resistance and combined training are all well tolerated and capable of improving the functional, psychological and physiological impairments experienced by many PwMS. Exercise therapy should be an integrated part of all physical rehabilitation programmes in MS.

## **Cognitive Impairment**

Some 45% to 65% of PwMS have cognitive deficits with varying degree of severity. MS-related cognitive deficits are highly individual and may be progressive, as the disease itself. As MS lesions have a tendency to affect the efficient functioning of certain neural networks, the most vulnerable cognitive domains are: attention, learning and (working) memory, planning, problem solving, flexibility, mental speed and word finding. Disease characteristics can have an influence on cognitive dysfunction in MS, yet results are often controversial. While some studies report only minor correlation between disease duration, disability and

cognitive performance, more recent actual studies – including larger cohorts and longer observation periods – show at least a closer relationship between mental performance and physical disability. While cognitive deficits may occur very early (at the stage of clinically isolated syndrome) as well as late in the disease course, affecting individuals with only mild as well as persons with more severe physical disabilities, it becomes evident that cognitive deterioration tends to progress over time. In the attempt to isolate clinical predictors, it has recently been shown that incipient cognitive decline seems to be the major risk factor for further disability in the short term as well as in the long term.

Cognitive deficits are more often associated with a secondary progressive disease course and among clinical predictors with a large cerebral lesion load and a more pronounced cerebral atrophy.

**Consequences of cognitive deficits:** Cognitive deficits have major psycho-social (education, work, driving, leisure activities, family and social life) and personal impacts (personal competence, self-esteem, quality of life). Rehabilitation outcome is negatively influenced by cognitive deficits. All PwMS as well as their carers (both professionals and non-professionals) should be informed about MS-related cognitive problems including cognitive fatigue and depression. Both oral and written information, as well as additional information provided by caregivers and significant others, should be available in order to evaluate whether the possible deficits interfere with activities of daily living.

#### *Neuropsychological assessment/evaluation and feedback*

Persons with MS experiencing cognitive problems should undergo neuropsychological assessment, which can help to evaluate the causes of cognitive problems (psychoreactive or organic) as well as find appropriate ways to reduce the consequences of impairment. Cognitive deficits should be diagnosed as early as possible by means of short screening instruments in order to help patients and their carers to cope with the new situation. Thorough feedback about the results should be given, pointing out cognitive strengths and weaknesses.

#### *Interventions and treatment*

Neurocognitive rehabilitation should be offered whenever cognitive deficits are present and whatever the severity. Compensation is needed when there is a gap between the expected and actual levels of functioning. The evaluation methods should be selected on an individual basis. At present, drug treatment

of neurocognitive impairment does not play an important role.

Compensation consists of four elements:

*Remediation* is direct training of a reduced function. In this context, computerised training tools that are targeted towards specific cognitive domains (e.g. working memory, attention, executive functions) might be one important opportunity to stimulate the central nervous system and thereby help the brain to compensate for deficits in terms of activating alternative pathways. However, literature on this topic is still scarce and results are difficult to compare due to different methodological approaches. There is, nevertheless, evidence that cognitive training has beneficial effects.

*Substitution* is the use of other methods to achieve the same result.

*Adaptation* involves adjusting one's own goals and expectations to the actual level of functioning (coping).

*Assimilation* implies adjusting other people's expectations to the actual level of functioning (inform significant others, caregivers, society, etc.). Taking into consideration the high frequency of cognitive deficits in MS and their serious consequences, information about MS-related cognitive problems, neuropsychological assessment and feedback, and neurocognitive rehabilitation should be essential parts of any rehabilitation programme. Rehabilitation starts once the diagnosis is given. Accordingly, the neuropsychologist should be part of the MS team in order to offer competent assessment and treatment to the person with MS.

## Psychology

The diagnosis of MS results in an on-going adjustment process. The PwMS has to live with the unpredictability and uncertainty of future disease progression and thereby advanced disability. So do the close relatives. A psychological crisis may occur, which is characterised by:

- overwhelming strong feelings such as despair, sorrow, anger, anxiety;
- confusion and difficulties in making judgements, keeping control and solving everyday problems;
- a changed picture of oneself (the identity) or low self-esteem; or
- being scared about the future.

Persons with MS may also experience temporary cognitive problems when in such a crisis.

As the early period after getting diagnosed is a very stressful time span for MS patients and their partners, distress and anxiety are very frequent. Even if distress

usually decreases within the first years, high levels of anxiety may remain unchanged in both patients and partners (Janssens 2006).

The lifetime prevalence of major depression disorders following the diagnosis of MS diagnosis is approximately 50%, which is much higher than rates found in other progressive diseases. This high prevalence may have multiple aetiologies. Depression in MS is likely to be an emotional reaction to disease-related psychological stress, but it is also supposed to be linked to specifically located brain lesions or immune dysregulation associated with MS.

A literature survey referring to depression and psychological reactions in recently diagnosed MS indicates that at least 50% of persons with MS are in need of psychological intervention (Goldmann 2005; Tworok 2007).

**Consequences of psychological reactions:** A crisis has a major impact on daily life. It prevents the person from sustaining the routines in family, social activities and work. Thus, psychological problems deriving from an untreated disease may result "not only" in a decreased quality of life for the PwMS, but may also have marked psycho-social consequences such as sick leave, loss of job, broken partnerships and others.

### *Psychological assessment and goal setting*

Careful assessment should be offered when a person experiences psychological problems. The ultimate aim of the assessment is to offer high-quality treatment. The severity of a present psychological reaction must be analysed thoroughly to confirm or to exclude the need of a referral to a psychiatrist, which may be necessary in depression, symptomatic treatment of other symptoms, etc. It is also important to estimate whether a PwMS may profit from the treatment offered since severe cognitive impairment, behavioural changes or profound psychological defence mechanisms (denial) would compromise a successful psychological intervention. Based on the assessment, the goals and framework of the treatment should be planned together with the PwMS. The goals may be set in steps and revised during treatment. Clear frameworks are always an advantage for the outcome of the treatment (Malcolmson 2007).

### *Psychological treatment and support*

Rehabilitation starts when the diagnosis is given, and it is recommended that the PwMS and the close relative are introduced to all members of the MS team, especially including the clinical psychologist and/or the neuropsychologist. Some people need little or no help; others need more. The waiting time for referral



to psychological intervention should be short, and the number of psychological sessions should be planned individually. Feelings, which may be difficult and uneasy to talk about, should be addressed cautiously, and there should be time for “closing down” again (Jean 1997; Lode 2007; McCabe 2004).

The following treatments should be available (Malcolmson 2007; McCabe 2004; Twork 2007):

- Individual sessions and/or sessions together with the close relative (partner, parent).
- Group sessions for homogeneous groups, for example, newly diagnosed persons.
- Groups for relatives without participation of PwMS; relatives also have a great need for sharing their feelings, anxieties and experiences with others.
- Written information about normal psychological reactions.
- Teaching courses on how to live with MS as well as more specific topics such as sexuality, fatigue or cognitive problems and their management.

Regarding the fact that MS is a chronic, progressive disease, and strikes at early ages (20 to 40 years), it is obvious that different kinds of psychological intervention should be offered at different stages of the disease. Offering early intervention will undoubtedly result in increased quality of life for the PwMS and their family, and decrease the need for later intervention and other social services. All members of the rehabilitation team should be able to offer at least some kind of counselling, but psychological therapy should be carried out by specialists (clinical psychologist, neuropsychologist, psychiatrist) who have the sufficient professional background, a profound knowledge about human interactions and defence mechanisms, about MS-related psychological and cognitive problems, and behavioural changes caused by brain lesions.

## Fatigue

Fatigue is one of the most disabling symptoms individuals with MS have to deal with in their daily life (Branas 2000). It is conceptualised as a subjective dimension (i.e. perceived fatigue) and an objective decline in performance and increase of existing symptoms. The definition of the symptom includes two dimensions: 1) subjective feelings of lassitude, tiredness, lack of energy or lack of motivation, which all may interfere with physical or cognitive performance or initiation of intended activities; and 2) the inability to sustain normally expected motor or cognitive performance (Kos 2008).

Fatigue is encountered by 60% to 90% of PwMS; up to 40% of them describe fatigue as the most disabling symptom, even in the early stages of

the disease (Bergamaschi 1997; Stuke 2009; Flachenecker 2002). Fatigue may have a great impact on mobility, personal care, home management, work performance, leisure activities, social relationships and the family role – and may therefore undermine quality of life (Lange 2005). Despite its high prevalence and impact, the pathogenesis of fatigue is still unknown. In line with its unclear pathophysiology, fatigue is difficult to assess and treatment options are limited. This is underscored by findings from the German MS register showing that 64% of all patients complain of fatigue, whereas 79% of patients suffering from fatigue are not treated (Flachenecker 2008b). As the consequences of fatigue may involve many life domains, the approach to manage fatigue should preferably be multidimensional (Krupp 2003).

### Assessment

The most widely used assessment instrument is the Fatigue Severity Scale (FSS) (Krupp 1989; Flachenecker 2002). This scale is heavily weighted towards physical fatigue; it does not cover the cognitive aspect of fatigue and is not sufficiently validated. Therefore, numerous other scales have been developed such as the Modified Fatigue Impact Scale (MFIS), the Fatigue Descriptive Scale, the Fatigue Assessment Instrument and the Multidimensional Assessment of Fatigue. Of these, the MFIS seems appropriate to cover the multidimensionality of fatigue (Kos 2005; Tellez 2005; Kos 2003; Flachenecker 2002; Multiple Sclerosis Council for clinical practice guidelines 1998). Recently, the WEIMuS (“Würzburg Fatigue Inventory for Multiple Sclerosis”) and FSMC (Fatigue Scale for Motor and Cognitive Functions) were validated in large cohorts of MS patients (Flachenecker 2008a; Flachenecker 2006; Penner 2009). Both scales are able to capture the subjective experience of fatigue from the patient’s perspective and can easily be administered in routine clinical settings as well as in research projects. The WEIMuS questionnaire covers symptoms present during the last week and could therefore be regarded as a measure of “state”, whereas the FSMC scale deals more with long-lasting aspects of fatigue (“trait”).

Attempts to objectively measure the degree of both physical and mental fatigue have produced contradictory results (Schwid 2003b; Schwid 2002; Krupp und Elkins 2000; Sheean 1997; Greim 2007), and a universally accepted instrument does not exist yet. More encouraging are the results of attentional testing since the WEIMuS scale values are closely related to the mean reaction times on measurements of tonic alertness (Meissner 2009; Meissner 2007). These findings make it possible to monitor the improvement of fatigue during endurance training (Meissner 2009). Thus, the measurement of tonic alertness with the Test Battery for Attentional

Performance may easily be used for an objective assessment of fatigue.

#### *Interventions including energy management strategies*

A comprehensive screening of the PwMS may detect secondary causes of fatigue (e.g. depression, infection, anaemia, thyroid disease or sleep disorders), which should be treated appropriately (Multiple Sclerosis Council for clinical practice guidelines 1998). If fatigue complaints persist, a rehabilitation approach can be offered, including (a combination of) exercise, body cooling, energy conservation strategies, psychological and dietary interventions (Lee 2008).

Exercise interventions may consist of endurance training (e.g. bicycle or treadmill exercise) (Mostert and Kesselring 2002), strengthening and flexibility exercises, resistance training or aquatraining. The evidence for the efficacy of aerobic exercise or resistance training on fatigue perception is inconsistent and insufficient, partly due to lack of research with high-quality designs and large samples (Rietberg 2005; Rimmer 2010). Relaxation, although used as a control intervention, reduced fatigue (van Kessel 2008) and yoga may show some effect (Oken 2004).

Body cooling can be achieved either by cooling the environment (air cooling), cold bath/shower or using a cooling garment. Wearing a cooling vest may reduce perceived fatigue in heat-sensitive PwMS (Schwid 2003a; Nilsagard 2006).

Energy conservation strategies include setting priorities, activity analysis and modification, balancing rest and activity, ergonomic principles, modification of the environment, proper body mechanics and living a balanced lifestyle (Multiple Sclerosis Council for clinical practice guidelines 1998). These strategies are usually applied by an occupational therapist and show higher self-efficacy and decreased impact of fatigue at short and long term (Mathiowetz 2007; Mathiowetz 2005).

Cognitive behaviour therapy concentrates on changing cognitive attributions and behaviour, and increasing self-efficacy, and may be beneficial for PwMS to manage fatigue (van Kessel 2008).

Other psychological interventions such as group support and a professionally guided self-care management programme, although not specifically developed for fatigue, may decrease subjective feelings of fatigue (Mohr 2003; O'Hara 2002).

Moreover, an electromagnetic therapy, providing pulsing, weak electromagnetic fields, may show some benefit for people with MS-related fatigue (Mostert and Kesselring 2005; Piatkowski 2009).

#### **Pharmacological treatment**

The pharmacological agents used to fight fatigue are amantadine, pemoline, potassium-channel blockers (aminopyridine), anti-depressants and modafinil (Krupp 2003; Branas 2000; Lange 2005). The efficacy of these agents, however, is not fully established, partly due to lack of high-quality research (Lange 2005; Lee 2008; Branas 2000).

#### **Bladder Dysfunction**

More than 80% of PwMS have bladder disorders such as urgency, frequency, nocturia and incontinence. These overactive bladder (OAB) symptoms are mostly present in early MS. As soon as spasticity of the lower limbs becomes obvious, sphincter overactivity might appear as well, leading to symptoms of hesitancy, incomplete bladder emptying or even retention (de Ridder 2005).

Untreated bladder disorders may lead to infections, kidney damage, emotional distress, social isolation and sleep disturbances. They may also increase spasticity and fatigue, increasing the risk of pressure ulcers and thus cause a general loss in the quality of life.

#### *Assessment*

Initial assessment is done by history taking, clinical examination and performing an uroflowmetry with the measurement of the post-void residual by ultrasound. A micturition diary can be used to assess day- and night-time frequency and the presence of nocturnal polyuria (common in wheelchair bound patients). A clinical examination of the pelvic floor muscles can be performed to assess the strength, but also the spasticity of the pelvic floor muscles. This assessment is usually sufficient to start first-line treatment. If symptoms are refractory to this treatment, additional examinations such as urodynamics may be needed. Ultrasound evaluation of the upper urinary tract can be done to exclude kidney abnormalities secondary to neurogenic bladder. The possible presence of a urinary tract infection should be assessed using an appropriate dipstick for nitrites and leucocyte esterase. In the presence of a urinary infection, a urine-culture is useful.

#### *Interventions*

In non-catheterised patients, a urinary tract infection should be treated with appropriate antibiotic treatment. If the patient is performing intermittent catheterisation or has a permanent catheter, diagnosis of a clinical infection is not only based on a positive culture, but also on the presence of symptoms such as pain, haematuria or increased spasticity.



Neurogenic overactive bladder symptoms can be treated conservatively if the post-void residual is normal (<100cc). Pelvic floor exercises, electrostimulation and biofeedback have proven to be successful. In many cases, medical treatment will be necessary. Anticholinergics remain the cornerstone of the treatment of neurogenic OAB in MS. Modern anticholinergics (solifenacin, darifenacin, fesoterodine, tolterodine) have less side effects than oxibutynine. In some countries propiverine and trospium chloride can be used as well. Oxibutynine should be used with caution in PwMS with cognitive dysfunction, since it crosses the blood-brain barrier and might worsen the cognition problems.

In a large proportion of patients, anticholinergics will be unsuccessful in controlling the bladder overactivity. In those cases, detrusor injections with botulinum toxin can be used (according to local regulations on off-label use of this medication). There is also limited evidence on the successful use of sacral nerve stimulation.

Nocturnal polyuria can be treated with desmopressine. This medication carries a risk of hyponatraemia and should be used with care, especially in elderly patients.

Bladder emptying disorders (PVR>100cc) are usually refractory to medical or conservative treatment, although some authors are recommending the use of alpha-blockers. Intermittent catheterisation will usually be taught by a trained specialist nurse and can improve considerably the quality of life and the bladder control. If bladder emptying disorders cannot be treated with intermittent catheterisation (e.g. limited hand function, impaired abduction of the legs, visual deficits or cognitive dysfunction), permanent catheters may be an option. A suprapubic catheter is to be preferred over a transurethral catheter.

In some patients, even urinary diversion surgery can be indicated. The decision to offer this type of surgery to a patient should be based on a wide consultation with the patient, his/her family and the team that is taking care of the patient.

Next to the medical treatment of incontinence, many patients will still need specific aids to cope with the involuntary urine loss. Pads, condom type catheters, etc. should be available and should be adapted to the patient's needs.

## Bowel Dysfunction

Bowel dysfunction (e.g. faecal incontinence, faecal urgency, infrequent or difficult defecation, often combined) occurs in up to 70% of PwMS and causes significant disability. The key mechanisms of constipation are obstructed defecation, weak

abdominal muscles, impaired rectal sensation, delayed colonic transit time and paradoxical contraction of the puborectal muscles. Faecal incontinence results predominantly from impaired anal sphincter control, uninhibited rectal contractions, alteration of anal inhibitory reflex and impaired rectal sensation. Impaired mobility, reduction of fluid intake, altered diet and behaviour, psychological disturbances or adverse effects of anticholinergic and anti-spastic drugs may further aggravate bowel dysfunction. An additional slow gastric emptying rate can delay the onset of action of oral drugs in MS.

These symptoms are likely to result in social retirement, depression, reduction of sexual activity, increased spasticity and nursing effort, abdominal pain, adynamic ileus, skin infections and pressure ulcers.

### Assessment and goal setting

Specific evaluation is required in individual cases. Faecal incontinence is seldom reported spontaneously. Standardised questionnaires including dietary habits and fluid intake, posture and place during defecation, a faecal diary and scoring of symptoms (e.g. Wexner scales for constipation and for incontinence) are recommended. Several scales address the impact on quality of life such as the Fecal Incontinence Severity Index, Fecal Incontinence Quality of Life (FIQL) scale, and the Gastrointestinal Quality of Life Index (GIQLI). A thorough clinical investigation is mandatory, including anorectal reflexes, tone and voluntary control of pelvic floor muscles, anorectal sensibility and – rarely – faecal analysis. Electromyography of the external sphincter and pudendal evoked potentials help to identify lesions of pelvic nerves and muscles. Abdominal and anal sonography, anorectal manometry, defaecography (MRI or X-Ray), measurement of bowel transit time and colonoscopy can be useful in special cases, in particular to identify structural changes and differentiate colonic hypomotility from outlet obstruction.

### Interventions

Since scientific data concerning treatment of bowel dysfunction are scant, recommendations for PwMS are predominantly empiric or based on expert opinion. Physical activity, adequate fluid intake and a high fiber diet are mainstays for treatment of constipation. Oral laxatives, in particular macrogols, are useful to soften a hard stool, but should be handled with care when rectoanal sensibility or sphincter control is impaired, to avoid an increase of incontinence episodes. There is limited evidence that antidiarrhoeal drugs such as loperamid may reduce faecal incontinence in patients with liquid stools. These drugs should be used carefully, as most of the patients have concomitant constipation. Abdominal massage increases the

frequency of defecation and reduces colonic transit time in patients with neurogenic bowel dysfunction. Scheduled emptying using laxatives, digital stimulation, suppositories, micro-enema or enema is often helpful in constipation and incontinence. If this approach is insufficient, transanal irrigation can be valuable for managing neurogenic bowel disease reducing constipation and improving anal continence, and therefore symptom-related quality of life. An individual selection of different absorbent product designs (e.g. for day/night, going out/staying in) is advisable and may be more effective and less expensive than using one design all the time. Individually selected anal plugs can be helpful as an adjuvant treatment option, but are sometimes difficult to tolerate.

Electrical stimulation of the pelvic floor may be helpful in the management of faecal incontinence. Also S3 TENS is a promising non-invasive method to treat faecal incontinence. A response to behavioural therapies, pelvic floor training and biofeedback is more likely in patients with limited disability and a non-progressive course of the disease.

Surgery should only be performed if all medical options have failed. Sacral nerve stimulation (SNS) is only minorly invasive, nevertheless an effective and safe long-term treatment option with success rates up to 80%. It appears to be more effective than optimal medical therapy for severe faecal incontinence, and reduces symptoms even in some PwMS with constipation. The clinical outcome seems to be stable over time. Quality of life among patients with neurogenic bowel disorder, who received a permanent implant, increased at 12 and 24 months after operation. Nevertheless, at present SNS in PwMS is still experimental and it is often difficult to identify exactly those who will benefit from it. More invasive irreversible procedures, including artificial sphincters, should be indicated thoroughly and only in specialised interdisciplinary centres. Stoma formation remains an option for patients refractory to other approaches; especially when faecal incontinence is associated with severe decubital ulcers.

In summary, in neurogenic bowel disorder an individual interdisciplinary rehabilitative approach using different physiotherapeutic techniques and drugs is advisable in most patients to reduce bowel dysfunction and improve quality of life.

## Sexual Dysfunction

Up to 75% of males with MS and 55% of females will experience sexual difficulties and the negative effect these can have on quality of life, but it is a symptom that receives insufficient attention. MS is diagnosed in sexually active young adults and the sexual problems experienced can cause great distress for

both the individual and the partner. For those not in a relationship, disability can often act as a barrier to meet potential partners and form relationships (Bronner 2010; Kessler 2009).

Many people are unwilling to discuss any sexual difficulties they are experiencing for a variety of reasons. It is known that many healthcare professionals do not openly ask about sexual difficulties. This may be due to embarrassment or lack of confidence, lack of training or considering questioning too intrusive and sensitive an area for patients.

The effect of MS on sexual function may be categorised into:

- **Primary sexual dysfunction** is the result of MS-related changes within the central nervous system that directly impair sexual feelings and/or the sexual response. Symptoms include decreased frequency or intensity of orgasms, low libido, altered genital sensation, decreased clitoral engorgement, decreased vaginal tightness, lack of lubrication (females), and erectile dysfunction and some ejaculatory difficulties (males).
- **Secondary sexual dysfunction** denotes neurological symptoms that indirectly affect sexual feelings and/or response, and includes symptoms such as bladder or bowel dysfunction, fatigue, sensory changes, spasticity, tremor, pain and side effects of medications.
- **Tertiary sexual dysfunction** is defined as the disability related psychosocial and cultural issues that affect the sexual response or performance. They include demoralisation and grief, clinical depression, social isolation, financial difficulties, performance anxiety, role changes/conflict as well as cultural beliefs with inhibiting expectations and judgments.

### Assessment

Addressing the topic of sexual difficulties is essential if there is to be provision of a high quality, holistic approach to the care of PwMS. There may not be an ideal assessment tool available, but there are a variety of strategies that may make all the difference. Even providing an opportunity to discuss sexual problems is often both positive and therapeutic.

*Before the assessment* begins, the healthcare professional needs to discuss and assure confidentiality and non-discrimination with the patient, obtain patient consent, and establish how much of the consultation could be recorded in notes, letters and so on. The healthcare professional needs to be aware of relevant therapeutic options, resources and referrals. Moreover, he must ensure privacy, plan sufficient time for the appointment and decide if he will utilise a formal assessment tool.

*During the assessment* it is mandatory to ensure using language the patient understands and that questions are asked in a matter-of-fact but sensitive, way. Start with the least intrusive questions before asking ones that are potentially more embarrassing. It is important, too, to establish with the patient the sexual problems being experienced, to avoid unnecessary and intrusive questions, and to evaluate the goals of the patient for this assessment as well as her/his sexual knowledge and provide sex education as needed. Further assessment may include a baseline history, underlying medical disorders or medications, past experience of sexual dysfunction, and the current or “usual” level of sexual activity. Once the problems are established, the healthcare professional must decide if the dysfunctions are primary, secondary or tertiary, and whether the patient and her/his partner are willing and ready to change thoughts, behaviour, etc. Then an action plan should be set, together with the patient.

Useful formal assessment tools include the MS Intimacy and Sexuality Questionnaire-19 [MSISQ-19] and the Female Sexual Function Index. It is helpful, too, to use Foley and Werner (2000) framework for defining categories of sexual dysfunction for PwMS.

### Management strategies and interventions

Management of primary sexual dysfunction for males and females includes counselling interventions to enhance intimacy and communication as well as sexual aids such as vibrators or other devices. The use of fantasy may also enhance orgasmic response. Other options are body mapping to find alternatives to penetrative sexual intercourse or experimenting for positioning that enhances sexual pleasure.

Management of primary sexual problems in men: for erectile dysfunction predominantly includes oral medications (all have to be prescribed) such as Viagra, Cialis and Levitra. Alternatively, intracorporeal injection therapy (prostaglandins: Caverjet or Viridal), penile injections, suppositories or vacuum erection pumps, or – in rare cases – a penile prosthesis may be used.

Management of primary sexual problems in women: A vibrator may compensate for loss of sensation. This can be used clitorally, vaginally or in the anal area. It is important that the vibrator has a hertz speed of 20. For lubrication, water-based lubricants should be used liberally. Pelvic floor exercises may enhance orgasmic response. Oral sex may be more likely to achieve an orgasm.

Management of psychological and emotional issues for males and females: the couple need to discuss what feels pleasurable or not. They should experiment with different sexual positions and be creative in

finding ways to give and receive pleasure.

A healthcare professional may encourage the couple to agree when and where it is most comfortable to talk about sex and suggest that they use books, publications or videos to initiate discussion. Any accusations, criticisms or blame should be avoided. He also should educate on myths and misconceptions regarding sexual intercourse and sexual activity, and encourage the couple to maintain intimacy by touch such as cuddling, caressing or massaging. Moreover, there may be a need for psychosexual counselling (Foley 2001; Bronner 2010; Kessler 2009).

### Dysfunction of Speech and Communication

A reduced ability to communicate due to dysarthria is frequent in MS, but often underestimated. It may lead to social isolation, depression and loss of independence (Melfi 2008) and has a high impact on other relevant aspects such as employment and social life (Bringfelt 2006; Chiaravallotti 2008; Simmons 2010). Cognitive and behavioural impairment, fatigue, pain and emotional disturbances, as well as visual and mobility restrictions, may further influence communication negatively (Yorkston 2001; Bringfelt 2006; Baylor 2009). Moreover, some common drugs in MS (e.g. benzodiazepines, baclofen and tizanidine) can cause weakness, fatigue and cognitive impairment, and thus may impair communication.

Dysarthria, including spastic and ataxic components (Hartelius 2000), is the most frequent communication disorder in PwMS, with a prevalence rate of 40% to 50% (Mackenzie 2009). If mild, it affects intelligibility only in problematic situations such as in noisy environments or pronounced fatigue (Yorkston 2003; Bringfelt 2006). However 9% of PwMS experience moderate to severe dysarthria (Yorkston 2003). Respiratory and phonatory dysfunction (Yorkston 2003), impairment of tongue function, and oral and verbal diadochokinesia (Hartelius 2003) may influence voice, articulation and prosody.

Some 63% of PwMS may experience high-level language disturbances (Klugman 2002), including word-finding problems and difficulties to manage expressive and comprehensive subtleties of language, both oral and written (Lethlean 1997; Arnott 1997). These disturbances are closely related to cognitive changes such as slowed information-processing speed and disturbances in attention, memory and executive functions (Chiaravallotti 2008; O'Brien 2008). The presence of cognitive-linguistic impairment may reduce the capability to benefit from rehabilitation (Langdon 1999). Aphasia is rare in MS but may appear in some cases, mostly in the context of severe cognitive impairment (Staff 2009).



## Assessment

Evaluation of dysarthria should include a neurological examination of the structures and functions involved and a perceptual and/or acoustic evaluation of voice, articulation and prosody (Murdoch 2000). Recent studies highlight the need to assess intelligibility of speech in adverse conditions and to measure listeners' efforts and adequacy of communication in natural settings (Yorkston 2008). Furthermore, results of the neuropsychological evaluation must be taken into account and related with performance in high-level language functions (Book: Murdoch).

There is lack of instruments in speech-language pathology devoted to measure solely communicative participation (Eady, 2006). However, some tools may approach this fact indirectly (Worrall 2001; Book: Murdoch) by providing information on the intelligibility of speech (Mackenzie 2009), functional communication and communication-related fatigue (Hartelius 2004), satisfaction with communication and quality of communication life (Yorkston 2007a; Klugman 2002), as well as cognitive self-evaluation (Benedict 2003). The perspectives of both patients and caregivers are important (Yorkston 2001; Bringfelt 2006; Hartelius 2008) and should be documented systematically (Hartelius 2008). A recently developed approach to functional assessment of PwMS may represent a line to the future (Goverover 2010). A Core Set for MS of the ICF (Kesselring 2008) is being validated among speech and language therapists, and may become a useful framework for interventions in communication disturbances in PwMS.

## Interventions and treatment

Treatment of restricted communication in PwMS should take a broad perspective and consider all the facts mentioned above in a holistic way (Bringfelt 2006; Mackenzie 2009; Foley 2009). Unfortunately, only weak evidence-based data on the efficacy of single interventions are available at the moment. Nevertheless, treatment should include interventions directed to improve awareness of the existing problem and of the available strategies to address them, both for patients and caregivers. Moreover, approaches directed to improve social and vocational life (Khan 2008; Khan 2009), taking into account the personal, functional and social situation of the patient and relatives, are crucial to achieve a satisfactory level of participation in communication. Informative booklets (Ref booklet RIMS), education groups including caregivers (Figved 2007) and telephone counselling (Bombardier 2008) are useful tools to introduce coping strategies and to promote a better emotional basis for treatment. Treatment should start early to prevent the development of further communication problems and maintain communicative participation (Yorkston 2003; Yorkston 2007a; Chiaravallotti 2008).

**Dysarthria:** Scientific evidence on treatment of dysarthria is still scarce and inconclusive, so some data related to interventions in other pathologies have to be taken into account. The main goals of the intervention are to increase intelligibility and functional communication, depending on the stage of dysarthria (Melfi 2008). General advice may include awareness of the body posture, reduction of background noise, facing the partner while communicating and speaking half words on each breath (Ref MS Trust).

**Respiratory and phonatory function:** An intensive respiratory-phonatory treatment programme, the Lee Silverman Voice Treatment, has recently demonstrated to be highly effective in improving loudness and some articulatory features in Parkinson disease (Ramig 2007). Applicability of this behavioural programme has been reported in PwMS with dysarthria characterised by vocal weakness or fatigue and reduced vocal loudness (Sapir 2001). Furthermore, several other interventions are used to improve respiratory and phonatory functions such as a combined behavioural programme (Hartelius 1997), expiratory muscle strength training (Chiara 2007), breath control exercises, accent method and breath pattering (Book: Murdoch), and music therapy (Osterman 2006). Referral to an otolaryngologist has been suggested for patients with laryngeal dysfunction (Woodson 2008).

**Rate, prosody and articulation:** In some patients, adjusting speech rate may revert into improvement of intelligibility (Van Nuffelen 2009; Yorkston 2007b). A variety of techniques has been used with some success, including external pacing devices, computer training, behavioural instructions and biofeedback (Yorkston 2007b). Several interventions for prosody impairment may be applied but their efficacy is not yet clear (Yorkston 2007b).

Alternative and augmentative communication, using letter or communication boards as well as micro-computers with synthetic voice output, should be considered in PwMS with severe dysarthria. Depending on the mode of input, letter- or symbol-oriented devices may be used. A special journal informing on this rapidly growing topic can be read (*Augmentative and Alternative Communication*). In any case, there is a need for a very intensive training with these devices; best candidates are PwMS with severe dysarthria and relatively preserved cognitive, pragmatic and motor functions (Hanson 2004).

Drug treatment, using only botulinum toxin A (Jost 2006) or anticholinergic drugs like amitriptyline, in small amounts can be useful for treatment of hypersalivation, which may otherwise compromise speech and social contact.



## Dysfunction of Swallowing

Oropharyngeal dysphagia is frequently present during the course of MS and affects between 30% and 65% of patients depending on the criteria used to define dysphagia, evaluation methods and severity of neurological impairment. Usually dysphagia worsens progressively and is most frequent in patients with a high EDSS, but about 15% of PwMS with only mild disability may also suffer from dysphagia. Swallowing dysfunction is associated with increased morbidity and mortality, due to severe and sometimes fatal complications such as malnutrition and bronchopneumonia (Giusti 2008).

### Assessment

The diagnostic procedure should identify the anatomical or physiological anomalies that cause difficulty swallowing and evaluate the efficacy of interventions used during treatment. The assessment comprises a bedside or clinical examination as well as videofluoroscopy, flexible endoscopy and, in specific situations, esophageal manometry (Tassorelli 2008; Prosigel 2004).

**Clinical swallow evaluation** includes a medical and a specific nutrition history, a physical examination of oral-motor anatomy and function, as well as an observation of swallowing. The information obtained in this evaluation serves as the basis for later treatment strategy recommendations. The diagnostic exploration is based on:

- specific questionnaires such as the DYMUS (Dysphagia in Multiple Sclerosis) with a narrow correlation between swallowing problems and EDSS (Bergamaschi 2009).
- a bedside evaluation providing important information with regards to the risk of aspiration and can evaluate different viscosities and bolus volumes. Aspiration is diagnosed if the patient chokes or coughs, and laryngeal penetration is present if any alteration of the voice occurs. However, it is worth noting that patients with silent aspiration may show no signs of aspirations.

The clinical symptoms resp. sufficient predictors of whether patients are likely to aspirate or not are dysphonia/aphonia, wet phonation, abnormal/absent laryngeal elevation, wet spontaneous cough, abnormal palatal gag, some or no swallowing of secretions, and unexplained recurrent fever.

**Videofluoroscopic examination** involves an X-ray examination using low irradiation; it allows for real-time analysis of the bolus propulsion from the mouth to the esophagus and for detection of dysfunctions

during the oral and pharyngeal phases of swallowing. Different consistencies (liquid, nectar and pudding) and different volumes are used in a lateral and in anterior-posterior views.

**Flexible endoscopy** most often uses the Flexible Endoscopic Evaluation of Swallowing (FEES), which enables examination of the anatomy and sensibility of oral cavity, pharynx and larynx. Standardised FEES includes examination of swallowing food of different consistencies and observation of therapeutic interventions. It allows identifying delayed initiation of swallowing, penetration, aspiration and post-swallow residue.

**Esophageal manometry** is a test to assess motility of the upper esophageal sphincter (UES), esophageal body and lower esophageal sphincter at rest and during swallowing. In oropharyngeal dysphagia esophageal manometry may especially give information as to whether difficulty swallowing is caused by increased UES pressure.

Clinical examination and FEES can be done repeatedly, and are therefore highly suitable to follow the course of treatment and to evaluate the efficacy of therapeutic strategies used whereas videofluoroscopic examination is the most meaningful examination at the beginning of treatment.

### Interventions and management

Treatment of dysphagia is clearly aimed at preserving at or returning PwMS to a normal diet, improving her/his nutritional status, and reducing the morbidity and mortality associated with aspiration pneumonia (Giusti 2008; Terré-Boliart 2004; Singh 2006). Interventions can be differentiated into restituting, compensatory and adaptive strategies. Nevertheless, scientific evidence of efficacy of dysphagia therapy is still scarce. Several of the therapeutic interventions require intensive cooperation and motivation, as well as preserved cognitive function.

### Restituting interventions

- stimulation of face, mouth and tongue (stretching, pressure, brushing, thermal stimuli, vibration).
- mobilisation techniques at face, mouth and tongue.
- functional exercise of tongue and lips; speech, breathing and vocal exercises; Masako manoeuvre (tongue holding).
- thermal stimulation for triggering the swallowing reflex (cold stimuli), sometimes in combination with mechanical and gustatory stimuli (Sciortino 2003).

- head elevation exercises to facilitate the function of UES.

### Compensatory strategies

- postural manoeuvres to modify the pharyngeal dimensions and redirect bolus material, thus preventing aspiration.
- changes of head posture to facilitate transport of food to the esophagus.
- training of special swallowing techniques, especially regular clearing one's throat and repeated swallowing ("double swallow"); effortful swallowing; and Mendelsohn manoeuvre in uncoordinated swallowing, which maintains laryngeal elevation and thus upper esophageal sphincter opening and airway closure.
- delivering food to the functional better half of the tongue.

### Adaptive strategies

- diet adaptation such as mashed food, thickened beverages, smaller bolus size, and no milk and sweets (which provoke increased production of mucus). In general, food of higher consistency prevents aspiration while thin liquids facilitate it.
- supportive devices for eating and drinking.
- upright positioning of body and head, take up time for eating, breaks, emptying one's mouth before next bite, and regular swallowing of saliva.

### Other swallowing therapies

- *pharmacological*: salivation can be treated with anticholinergic drugs or drugs with anticholinergic side-effects (amitriptyline, oxibutynine) and with botulinum toxin A injection to the parotid and submandibular glands. Botulinum toxin A injection into the UES may be used for treatment of oropharyngeal dysphagia in patients with incomplete sphincter relaxation (Restivo 2010)
- *Tube feeding*: In advanced phases of MS, enteral feeding tubes may be used when oral intake is not deemed sufficient for nutrition and hydration purposes. Nasogastric tube feeding should only be used for short periods whereas percutaneous gastrostomy (PEG) is recommended in chronic cases.

## Occupational Therapy

Multiple Sclerosis affects the everyday lives of PwMS and their partners and children. Many PwMS encounter difficulties in fulfilling their roles related to all aspects of daily life, such as personal care, employment, education, child care, leisure and functional mobility. The symptoms caused by MS may change the ability

to participate and engage in desired activities in an ongoing process.

Occupational therapists (OTs) help clients to increase participation in the activities of their daily lives by making the performance easier. This can be reached either by increasing the power (physical and/or mental) of the client or by decreasing environmental barriers (Steultjens 2003; Finlayson 1998).

Occupational therapists often use life domains as the basis for the treatment (Baker and Tickle-Degnen 2001). Together with the client, the OT will explore the most relevant occupations (roles) and detect threatening factors influencing performing daily activities. OT focuses on activities of daily living (ADLs) because they are essential to independent living. Personal ADLs (pADLs) include eating, dressing, bathing, grooming, toileting and transferring (e.g. moving between the bed, chair and bathtub or shower). Instrumental ADLs (iADLs) include preparing meals; communicating by telephone, writing or computer use; managing finances and daily drug regimens; cleaning, doing laundry and food shopping; and functional mobility (pedestrian or using public transport) and driving. IADLs require more complex cognitive functioning than pADLs. Other possible occupation areas include employment (paid or volunteer), leisure activities, education, care for others and social activities.

Preferably, the OT will train skills in the authentic situation, thereby ameliorating physical, mental or social capacities. For example, when a PwMS envisages problems in preparing food, the training will take place in the kitchen and includes preparing a meal. When physical, mental or social abilities are inadequate to complete tasks, the OT may advise alternative strategies to compensate for the limitations (compensation strategy). For example, if standing for a certain time is not possible due to muscle weakness, clients may use a chair to perform the task (either during personal ADL, preparing meals or gardening).

OTs may also advise modified or assistive devices or house alterations to engage in occupations adequately (e.g. thicker knife, inclination of a mirror, communication boards, wheelchair use indoor and outdoor). Training in the use of suitable equipment is required.

Occupational therapists can help clients to return to or stay at work by collectively assessing possibilities and needs of the client, the workplace and the employer (Dyck & Jongbloed 2000). Clients may be taught new skills or modifications of previous skills. Therapists may evaluate the workplace and collaborate with the employer to modify the environment or work regimen so that clients can work more easily.

Occupational therapists are skilled to facilitate social and leisure activities such as how to travel safely

to friends with or without a walking aid, how to go shopping without having urinary accidents or how to make cinema visits possible. Therapists may suggest new activities such as taking a computer course, volunteering in library or for community services). One important aspect is improving or compensating writing skills, either by writing exercises, using special pencils or techniques or training in computer use.

The prevention of injuries or falls is an important issue that includes both an assessment of the individual and his environment (home or workplace). For example, the OT may advise to use a bath chair and grab rails to use the bathtub safely, or improving lighting in driveways and hallways. The use of a walking aid may also contribute to reduce the risk of falls, or a thermostatic tap may be useful to prevent burning injuries.

Sometimes, symptoms are used as starting point for therapy: in a fatigue management programme, for example, the OT assists in exploring the impact of fatigue on the person's ability to engage in relevant occupations. Following this, energy saving strategies is skilled by modifying performance, balancing rest and activity, rearranging environment in an ergonomic way, etc. (Kos 2007; Mathiowetz 2005). In a cognitive intervention programme, the focus will be on managing with cognitive problems in everyday life. In all cases, a combination of personal and environmental strategies is included.

Hand function training is frequently part of occupational therapy in order to reduce limitations in performing fine motor skills. Another common approach is training (or maintaining) cognitive capacities, using paper exercises or computer programmes and games.

- In summary, the following activities are main objectives in occupational therapy:
- Functional training of physical, mental or social abilities (either strengthen or compensate limitations) in relevant occupations identified by the client.
- Advise and instruction of assistive devices or house alterations.
- Educate family or care givers.
- Advise on wheelchair and functional training wheelchair use indoor and outdoor.
- Fatigue management.
- Cognitive intervention.
- Prevention of falls and injuries (safety management).
- Hand training.

## Vocational Rehabilitation

Work contributes to adult identity (Dyck 1995), confers financial benefits and status (Catanzaro 1992), can improve quality of life (Aronson 1997) and reduces ill health (Waddell 2006). Being part of the world of employment enhances social contacts and facilitates an individual's development.

At diagnosis most people (~ 90%) with MS are in work. As the condition progresses, however, the number of people able to remain in work decreases. Estimates of work retention vary between 20% and 30% employed by 5 to 17 years after diagnosis (Aronson 1997; Larocca 1985); at any one time, only 50% of the MS work is in employment (Julian 2008; Simmons 2010). Typical "invisible" symptoms that lead to difficulty working include fatigue, anxiety and depression associated with concerns about memory and concentration. As the disease progresses, PwMS report greater physical disability including mobility limitation which makes access to work difficult and movement within the workplace effortful. It also results in poor dexterity affecting handwriting, keyboard use and other manual tasks, and visual impairment resulting in difficulty with reading both written and on computer screens. Other effects include urinary and faecal frequency and urgency, with fear of incontinence and dysarthria resulting in difficulty using the phone, general communication and poor presentation skills.

It is important that when individuals stop working due to a relapse or disease progression that they are supported to return to the workplace as soon as possible. A Belgian project showed that two years of sick leave represents the maximum for a return to the job (Interreg III "Neurological Re-integration Programmes" Euregio Benelux middle area, project with financial support of the EU 2003-2006).

Many PwMS withdraw from the workplace citing lack of information about legal rights and the support available, poor support with job retention through workplace accommodations, inflexible employment structures and lack of employer/colleagues support, which may develop into active discrimination.

Some PwMS decide not to disclose their diagnosis to employers or colleagues for different reasons. They feel their condition is part of their privacy or fear that disclosure might cause negative consequences for their employment or career.

### Assessment

The vocational needs of PwMS can be addressed properly by analysing all the factors that contribute to the employment problems including cognition, physical abilities, fatigue and mood disorders, as well as the disabilities mentioned above. Assessment is



best performed by a multidisciplinary team, but the roles of occupational therapy and neuropsychology are crucial. Ideally services should also have access to employment specialists.

There is a perceptible change of attitude, in the MS population as well as in the medical and other professional accompanying staff, resulting in a much more balanced view on employment and MS. Most PwMS have a specific education, job capacities and/or work experience, and thus have value on the labour market. Continuing to work, even with MS, can be challenging but can also be a source of frustrations when the symptoms of the disease interfere with the requirements of the job.

### Interventions

The vocational rehabilitation service should intervene early, respond rapidly and have open access. The aims of the service should be to empower the individual, often through education and support. Once the evaluation is complete, the occupational or vocational rehabilitation specialist will work with the PwMS to:

- educate them about relevant legislation and how it applies to them, including the nature of “reasonable accommodation”.
- support with disclosure, communicating needs and concerns to the employer, requesting accommodations if there are difficulties and using support systems such as co-workers when help is needed.
- offer counselling to support people to adapt, adjust and resolve complex issues and manage the stress and demands of the job.
- manage symptoms that have impacts on work performance; for example, in the case of fatigue, application of energy conservation strategies, additional breaks, etc.
- encourage PwMS to organise the workload, set priorities and pace themselves.
- plan work, making changes to the work environment including job modification and technological support to minimise the physical demands.

It is important to overcome the job barriers with creativity, to identify options and communicate openly with the employer.

### Rehabilitation Nursing

MS will place many challenges upon the individual, his/her family, friends and colleagues. It will test the capacity of all involved to adjust to, and accept, the problems and limitations imposed on daily life. It may evoke many different emotional responses and

bring subtle problems such as cognitive impairment, persistent fatigue, depression and pain as well as the more overt problems of functional ability.

PwMS may perceive and experience their role in life is much altered and requires adaptation as part of a process toward renewed confidence and restoration of their sense of self. Family and friends may also undergo adaptation and adjustment to their roles and their responses to problems that MS may bring.

Supporting the person with MS toward hope, self empowerment, self efficacy and the experience of health and well-being are at the core of rehabilitation nursing. The MS rehabilitation nurse is pivotal to the cohesive and 360° view of multidisciplinary team (MDT) interventions. The Kings Fund describes rehabilitation nursing as providing advice and counselling as “...a process aiming to restore personal autonomy in those aspects of daily living considered most relevant by patients or service users, and their family carers” (King’s Fund 1998).

The key elements of MS Rehabilitation nursing are to:

- work in partnership with PwMS, and within an environment of mutual trust, to explore the impact of MS upon their and their families’ lives.
- work in partnership with PwMS to identify and prioritise the problems felt and experienced. This may also include problems with social or family relationships, physical comfort, mental well-being, nutrition and fluids, breathing, moving and continence.
- work in partnership with PwMS to identify areas that require specific nursing expertise, share solutions and agree on interventions.
- review and revise any rehabilitation nursing interventions in the light of new evidence or change in the patients’ needs or wishes.
- use critical analysis of presenting problems to determine possible causal links. For example, excessive daytime sleepiness/fatigue may require a bladder training programme at night rather than medication or afternoon resting.
- encourage the PwMS to set goals that are meaningful and facilitate self-management while respecting their right of refusal and self-determination.
- identify any learning needs or barriers to self-management and create educational programmes that respond to those needs (such as fatigue or stress management) with provision of evidence-based educational materials that are timely, appropriately paced and allow the PwMS to make their own informed decisions.
- facilitate carryover of new skills and adaptations learnt with MDT into an everyday environment



and encourage the PwMS to complete self-evaluation.

- provide a space for PwMS for a shared review of positive and negative coping behaviours. Work in partnership with PwMS to discuss those feelings and thinking patterns that may motivate behaviours and response shift.

The MS rehabilitation nurse should have knowledge of rating scales used in MS rehabilitation and understand the significance of reliability and validity data related to outcome measures and translate this information and how it applies to the PwMS. He/she should take a lead role in communicating with all relevant members of the healthcare team, family members and carers to ensure there is open exchange of information with shared understanding, mutual goals and agreed consensus with PwMS.

## Social Counselling

Unrestricted participation is the ultimate goal of every multidisciplinary rehabilitation treatment in PwMS. Since MS affects the person and his entire social environment, all actors should be involved in the management of care. PwMS and their partners and families demand an active role in the management of the disease, and have a strong need for information and support to overcome social barriers built by MS and to improve or at least maintain their roles in society.

The social worker is a crucial part of the multidisciplinary rehabilitation team. He covers a broad range of socio-administrative and psycho-social competencies since he has to deal with very different domains such as family relationships, social role issues, work and occupation, finances and social security systems, housing, professional and non-professional home care (with special attention to the burden and needs of non-professional caregivers), leisure activities, and professional health care in the community (including outpatient rehabilitation programmes). Continuity of care and communication with homecare professionals are cornerstones in the long-term management of MS. All social work rehabilitation activities must take place in consultation with the PwMS and his family, enabling them to make individual decisions within their own and specific situation at that specific stage of the disease.

### *Assessment, goal setting and outcome measures*

Assessment tools in the field of social counselling should identify resources and threats to a PwMS's social support system and to his participation in general. A standardised social file for internal use in the rehabilitation centre should be used. Unfortunately, at present no generally accepted tool exists.

The Environmental Status Scale (ESS\*) is used frequently but remains quite unsatisfying as do the London Handicap Scale (LHS\*) and the Inventory of Participation and Autonomy (IPA\*). The development of ICF-based, MS-oriented screening tools might give new impulses.

A valuable instrument for goal setting is the Rehabilitation Activities Profile (RAP) (van Bennekom), which strives to a multidisciplinary description of rehabilitation goals. Most of the social counselling goals are situated in the domains of "daily occupation" and "relationships". Special attention should focus on the needs of caregivers. Satisfactory results may be reached using the Caregiver Burden Inventory (CBI\*).

### *Information, counselling, support and guidance: meeting social problems*

First the PwMS, preferably together with his partner or family, has an extensive and detailed interview with the social worker of the rehabilitation team involved. This gives them the opportunity to ask questions about and to express their feelings and concerns towards the care programme, and may help to reduce tenseness and anxiety. During the interview, some basic information about cultural, religious, financial or relational aspects can be documented which might be crucial for the course of the rehabilitation programme.

- **Relationships and family issues:** Sustained efforts are made to involve the partners and key persons of a PwMS in the rehabilitation process. They are encouraged to express their feelings, needs and concerns. Information directed towards partners, counselling, support and guidance can be very important throughout rehabilitation. A close collaboration with other members of the rehabilitation team is mandatory.
- **Work and occupation:** First, PwMS may often need extensive information to make the right decision concerning disclosure of their diagnosis to their employer. Then, they need help to find appropriate governmental programmes to support them in staying at work, and may need information about their legal rights or search for advocacy towards their employer. Giving up a job usually has a lot of financial and social consequences that need to be discussed extensively before a decision can be made. Therefore, it is recommended to have a vocational referral person in the social work department of a MS rehabilitation centre.
- **Homecare/professional health care in the community:** Availability and (financial) accessibility of homecare services are not necessarily compatible with the needs of PwMS and their caregivers. Moreover, evaluation of the needs of a PwMS may demonstrate that these are not always consistent with those of partners and caregivers. Differences

should be taken into account and adjustment may be necessary. Advocacy toward community services can be required and is part of the social worker's tasks. In order to avoid problems in the long term, it is necessary to clarify the services that can be provided by an organisation and to match these with the needs of the user. **Financial and social security interventions:** Social policy is not always very transparent and PwMS often do not automatically obtain the social services for which they are eligible. PwMS and their families very often appeal to the social worker to give support and practical help with applications for different social benefits to different governmental departments, resulting from various and very different legal regulations. It is not always easy to balance empowerment and self-management of PwMS against providing sufficient assistance to facilitate claiming their rights and getting the financial and administrative interventions. Advocacy towards legal authorities can be required.

- **Housing, technical aids and home adaptations:** Home adaptations and technical and mobility aids should be planned in close collaboration with the occupational therapist, taking into account the financial implications and legal interventions, expectations, resistance and aversions of the PwMS and their families. It should also

consider their coping strategies and the long-term management of the disease. If indicated, homecare professionals can be involved in decision making.

Since MS is an unpredictable but mostly progressive disease, the extent and content of the social worker's interventions will depend on the stage of disease and the resulting disease burden, ranging from newly diagnosed patients with only low disability up to PwMS living in respite care.

The social worker should have regular contacts with the PwMS, his partners and, if indicated, the professional home caregivers either by telephone/e mail, by organising meetings in his office or by home visits. Continuity of care is an ongoing challenge, as is networking among the members of the rehabilitation team and the professional homecare in the community.

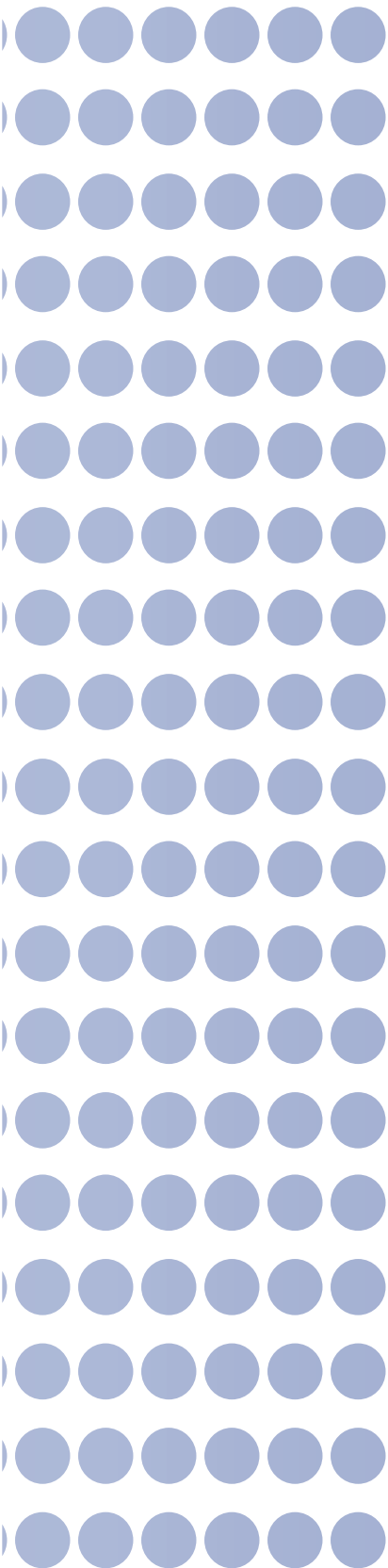
\*ESS: Environmental Status Scale, Minimal Record of Disability, IFMSS 1985.

\*IPA: Impact on Participation and autonomy, Dept. of Rehabilitation, University of Amsterdam 2001.

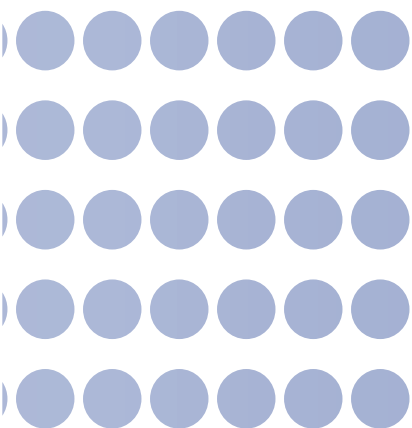
\*CBI: Caregiver Burden Inventory, Novak et al 1989.

\*LHS: London Handicap Scale, Dept. of Health Care of the Elderly, University of Nottingham 1995.





Final Recommendations





## Final Recommendations

### Recommendations for Rehabilitation in MS

Persons with MS should be referred to a specialist neurological rehabilitation team which should recognize the varying and unique needs and expectations of each person with multiple sclerosis.

The rehabilitation team should include health care professionals from the following disciplines, as integral members: neurology, rehabilitation medicine, nursing, physiotherapy and sports, clinical psychology, social counseling, occupational therapy and speech therapy. The functional treatment methods used should include the rapidly progressing knowledge of the mechanisms of neuroplasticity.

The rehabilitation team and other health care professionals working with the person with multiple sclerosis and the family should work together towards common goals covering short-term and long-term outcomes. According to the degree of impairment and disability these goals should be evaluated in the initial, early, later and advanced stages of the disease.

At the moment of diagnosis information should be available regarding the disease and its effects and potential impact on the individual, the family and the social environment. Educational programs should be instituted to address these areas and to increase the patient's self-responsibility as well as his ability for shared decision making. Moreover from the moment of diagnosis each person with MS should benefit from emotional support provided by a clinical psychologist. During the early stage, provision of support and informed advice about relationships, employment, symptoms, housing and financial planning should be available.

When, at a later stage, the person with MS experiences greater impairment resulting in both disability and handicap, access to a focused symptom and disability management program must be available.

Recurring barriers to employment, education and transportation should be eliminated, avoiding discrimination on the basis of disability.

At an advanced stage persons with MS may develop severe disability and become dependent in both mobility and activities of daily life. Adequate and appropriate community care services including home adaptations, assistive technology, including mobility equipment and aids for activities of daily living should be available. For the most disabled long-term facilities should be an option. Provision of respite care and carer support will lessen the burden on family members.

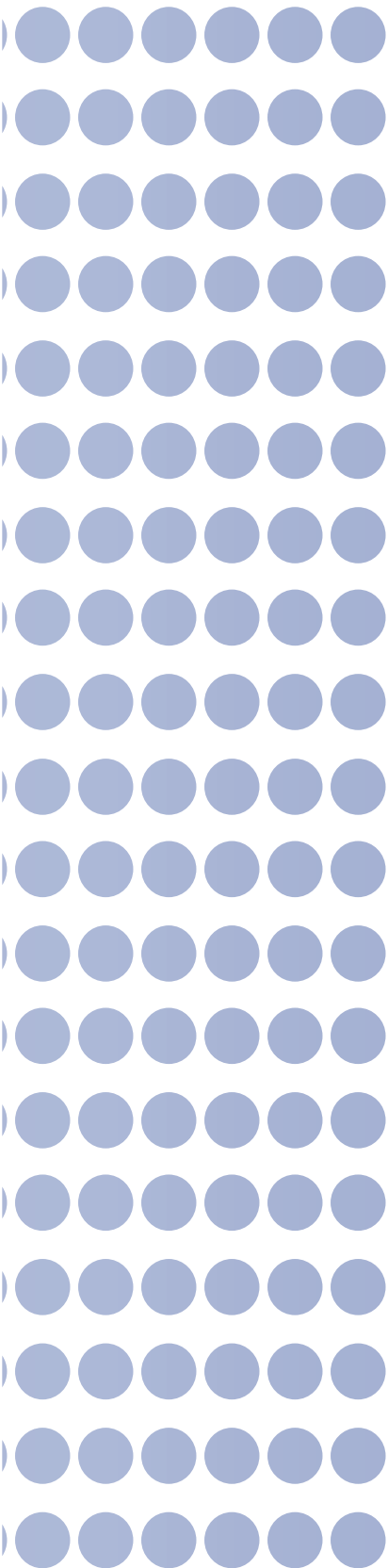
The health needs of persons with MS, which are comparable across national boundaries, should be

addressed in different nations based on health systems which vary in their organisation, funding possibilities and population distribution.

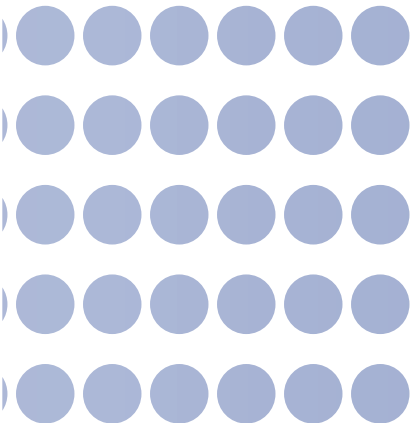
The rehabilitation service must guarantee internal integration among professionals and must also be integrated with other existing health services relevant for MS (hospital departments, outpatient clinics, community services), since a person with MS may access inpatient, outpatient and community services to different degrees, at different stages of the illness.

Service delivery must be high quality, as accessible as possible, continuously adapted to the needs of the person with MS, as well flexible, timely and evidence- and experience-based.

Service delivery for people with MS and their carers must be regionally equal and home-based, when a high level of quality can be guaranteed.



## Appendix



## Appendix

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## The process for establishing the Recommendations

During fall 2009, EMSP decided to publish a new version (2<sup>nd</sup> edition) of their “Recommendations on Rehabilitation Services for Persons with Multiple Sclerosis in Europe” which had first been published in 2004, since a great body of new scientific knowledge of the mechanisms of rehabilitation had appeared together with numerous new topics, for example quality of life, the ICF classification, or shared decision making, as well as a great number of new rehabilitation techniques.

The former Table of Content was completed with several new chapters. Numerous European specialists in MS Rehabilitation, a lot of them organized with-in RIMS, were then asked to contribute. Their manuscripts were reviewed by the 2 members of the Reviewer’s Board and the final version was completed during the following months.

## Malta Declaration

### *Declaration*

by the participants of the Meeting of the European Multiple Sclerosis Platform, Malta, May 2003

Acknowledging the dramatic differences across Europe faced by citizens by multiple sclerosis, we, representatives of EMSP, call for treatments and services that

- Recognize personal dignity
- Seek to maximize personal potential
- Enable people affected by MS to be fully involved in and influence decisions about service provision
- Take account of the full range of physical, cognitive, emotional and social implications of being affected by MS
- Meet agreed upon European quality standards
- Are subject to continual evaluation and improvement
- Are accessible and timely
- Are delivered by appropriately skilled and experienced professionals
- Are provided equitably and efficiently, irrespective of geography or organizational or professional boundaries

To achieve these goals, we affirm our commitment to:

- working collaboratively with the European Institutions’ programmes and policies on health, social inclusion and non-discrimination to promote the principle and practice of equal treatment and services for people affected by MS across Europe
- supporting concerted action and co-operation with relevant European medical NGO’s and governmental agencies for the implementation of “European Wide Guidelines on Therapies for People affected by MS”
- holding high-level discussions with EU Institutions to explore, in the framework of the Convention on the future of Europe, new EU competencies that can advance our endeavours for:
  - more MS-related research on national, European and world-wide levels
  - better awareness on the importance of continued employment for persons with MS
  - achieving high-quality, equitable treatment and services for all Europeans affected by MS
  - universal access to public buildings and services throughout Europe
  - engaging in a major awareness campaign across Europe to ensure stakeholders at all levels support our drive towards a better quality of life and brighter future for every European affected by MS

This declaration was adopted on May 3<sup>rd</sup>, 2003 in Malta

It constitutes the central message from 29 national MS Societies represented by the European MS Platform to fellow Europeans in this, the European Year of people with Disabilities.



## European Multiple Sclerosis Platform (EMSP)



Information exchange and dissemination  
Advocacy and awareness-raising

### A united membership that spans the continent

Founded in 1989, EMSP is the umbrella organisation for 38 MS Societies operating in 34 European countries.

**EMSP full members** are the following: Austria, Belarus, Belgium, Bosnia, Bulgaria, Herzegovina, Croatia, The Czech Republic, Denmark, Estonia, Finland, France (LFSEP), Germany, Greece (GMSS), Hungary (MSMT), Iceland, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, The Netherlands, Norway, Poland, Portugal, Romania, Russia, Serbia, Slovakia, Slovenia, Spain (AEDEM-COCEMFE), Sweden, Switzerland, and the United Kingdom.

**EMSP has associate members** in France (UNISEP), Greece (Hellenic Federation of Persons with MS), Hungary (SMBOE) and Spain (FELEM).

### A European Strategy that reinforces national action

EMSP lobbies at the European level to uphold the rights of people with MS. Its activities derive from a mission comprising five main objectives:

- Encourage MS research through recognised organisations;
- Exchange and disseminate information relating to MS;
- Promote collaborative programmes among national MS Societies in Europe;
- Facilitate interaction between institutions of the European Union, the Council of Europe and other organisations; and
- Propose new measures to advance the rights of People with MS and ensure their participation in society.

### Activities and projects to make a real difference

*The Multiple Sclerosis Barometer.* In 2008, EMSP provided data on the general management of the disease and the quality of life of people with MS through a valuable benchmarking tool, the so-called MS Barometer. This consists of a series of questions in seven key areas completed by the national MS Society and endorsed by the society's Medical Advisory.

Board: access to treatment and therapies, research agenda on MS, employment and job retention, empowerment of PwMS, reimbursement of costs related to MS, accurate data collection on MS at national level, and medication coming on the national market. The MS Barometer allows the tracking of yearly progress within a given country and across Europe.

*The European Register for Multiple Sclerosis (EUReMS) project*, co-financed by the European Commission (EC) under the Public Health Programme aims at establishing a European wide platform for systematic collection, exchange and analysis of longitudinal (epidemiological, medical and socio-economic) data on multiple sclerosis. This project follows-up with the EC Communication on health issues aiming at improving quality of healthcare and treatment, thus ultimately the quality of life of people with MS.

*The Multiple Sclerosis – Nurse Empowering Education (MS-NEED).* There is no current internationally recognised nurse speciality status of MS nurse professional certification process. The MS-NEED project aims at developing a European consensual nurse curriculum.

*The UNDER PRESSURE project.* It expresses in a photo-journalistic language the results of the Multiple Sclerosis Barometer 2011. Over a 10-day period, the photographers followed people with multiple sclerosis into a variety of settings that are typical to all people with multiple sclerosis, with the aim of ultimately showing contrast between countries in terms of:

- General conditions and specialised facilities in health care and rehabilitation centres;
- Ability to live at home (including adaptation measures) or having to reside in a care facility;
- Ability to remain in the workforce (including adaptation measures) or being unemployed or forced to live on social assistance; and
- How daily living situations make multiple sclerosis more/less difficult in relation to other countries.

For more information on EMSP, please consult: [www.emsp.org](http://www.emsp.org)

## Rehabilitation in Multiple Sclerosis (RIMS)

RIMS (Rehabilitation in MS) is a European dynamic network for MS health care professionals and researchers across Europe founded already in 1991.

With membership in over 35 European MS centres and hospitals as well as universities and individual members, RIMS is an interdisciplinary group, bringing together experts in MS practice and research for traditional RIMS annual conferences, workshops, guidelines writing and collaborative research.

RIMS Special Interest Groups (SIG's) organises seminars and multi-centre research projects on specific topics of interest for clinical and rehabilitation specialists. Current Special Interest Groups include Mobility,

Bladder, Bowel and Sexual Disorders, Psychology and Neuropsychology, Communication and Swallowing, Patient Education, Occupation and Social Participation. SIG's meet at annual conferences and also during separate in-between meetings at different locations in Europe.

The International Journal of MS Care is the official journal of RIMS, in partnership with the Consortium of Multiple Sclerosis Centres.

RIMS also offers a newsletter Network and an informative website for its members.

More information on RIMS: [www.rims.be](http://www.rims.be).

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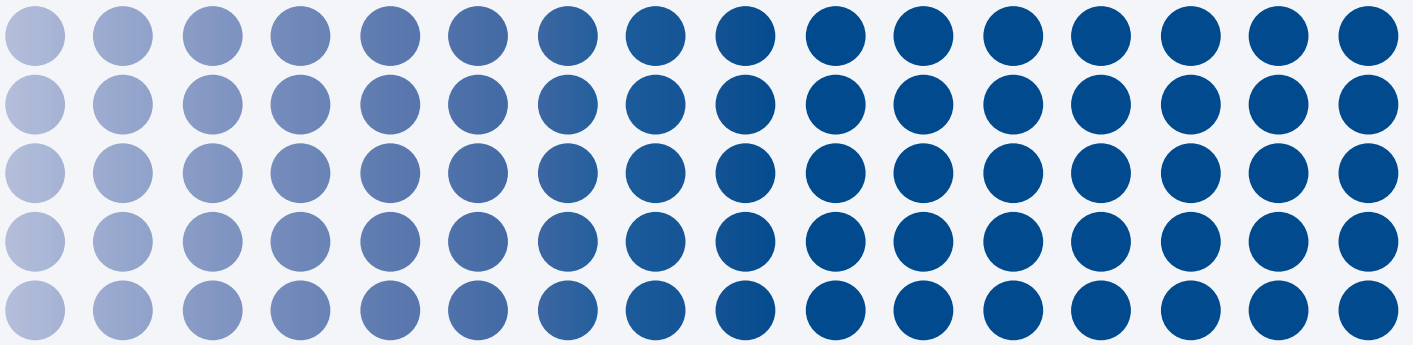
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