



IOMSN
International Organization
of Multiple Sclerosis Nurses



THE CONSORTIUM OF
MULTIPLE SCLEROSIS CENTERS

RiM rehabilitation
in
multiple sclerosis
european
network of ms centres

What is an MS Centre?



multiple sclerosis
international federation

The Multiple Sclerosis International Federation (MSIF)

Established in 1967 MSIF's mission is to lead the global MS movement's efforts to improve the quality of life of people affected by MS and develop understanding and treatment of MS by facilitating international cooperation between MS societies, the international research community and other stakeholders.

It does this by:

- Stimulating and facilitating international cooperation and collaboration in research to better understand the nature of MS, to develop better treatment and rehabilitation of people with MS and inform relevant communication and advocacy initiatives.
- Supporting and encouraging the development of new MS societies and stimulating and supporting existing national MS societies in their work to improve the quality of life of people affected by MS.
- Enhancing and complementing MS societies' efforts to increase awareness, knowledge and understanding of MS and of the needs of people with MS and how to improve their quality of life, whilst being a resource for those people affected by MS who do not have an MS society to support them.
- Supporting MS societies and people affected by MS to have and exert influence on laws, policies and decisions in order to improve the quality of life of people affected by MS and to exert such influence at the international level.

www.msif.org

Rehabilitation in MS (RIMS)

RIMS is a network of MS centres created in 1991 in Milan, Italy to enhance collaboration between European MS centres. RIMS is a dynamic interdisciplinary association affiliating more than 40 MS centres spread throughout more than 20 European countries. Its members are comprehensive MS research and treatment centres, MS clinics and corporations with a special interest in MS. Besides the member states of the European Community, the research and treatment programmes have been opened to research organisations and clinics in central and eastern European countries and the new independent states of the former Soviet Union. www.rims.be

Consortium of MS Centers (CMSC)

Organised in 1986 under the direction of neurologists interested in clinical care and collaborative research in MS, the CMSC has grown to become a multidisciplinary organisation providing a team approach to MS care and a network for all healthcare professionals and others specialising in the care of people with MS. The CMSC includes more than 200 member centres in the United States, Canada and Europe, representing more than 4,000 healthcare professionals worldwide who provide care for more than 200,000 people with MS. www.ms-care.org

The International Organization of Multiple Sclerosis Nurses (IOMSN)

The IOMSN was founded in 1997 to support the professional development and networking of MS nurse specialists worldwide. To date, the IOMSN has more than 1,700 international members. In 2002, the first MS nursing certification examination was offered and currently there are more than 600 MS certified nurses throughout the world. The examination has been offered in English, Dutch, French Canadian, and will be offered in Finnish and Italian in the near future. www.iomsn.org

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Foreword

Multiple sclerosis is a complex disease the cause and definitive cure of which remain unknown. Advanced research is ongoing in many parts of the world, making enormous headway towards finding answers to the many questions surrounding the disease. While medical research is vital to reaching the goal of a world free of MS, there are millions of people living daily with a disease that can be confusing, frightening and unpredictable.

Meeting the challenges of MS on a daily basis is a task that no one should have to face alone. People facing MS should expect reliable information and quality care, based on evidence reported in scientific literature provided by professionals with specific knowledge of the disease. While some people have access to MS centres housing comprehensive care teams made up of health professionals from a variety of disciplines who address the entire continuum of care, in many parts of the world such centres are non-existent.

It is vital that where there are people living with MS, accessible, comprehensive care and services exist to meet their needs.

Fortunately there are a number of model MS centres that can serve as examples of good practice regarding the level of care provided and the organisation and management of its provision. Their experience, shared through international alliances made possible by organisations such as MSIF, CMSC and RIMS, can serve to improve the quality of care for all people living with MS.

Making accessible comprehensive MS care a priority is a challenge for MS societies around the world. While there are differences in the availability of financial resources among countries, high quality care does not necessarily depend on a limitless supply of resources, but more so on the people involved in providing the care.

The future is to develop opportunities that facilitate exchange between countries, with the goal to create MS centres where they do not exist or where there is difficulty in promoting an interdisciplinary approach. This booklet *What is an MS Centre?* should be the basis for discussion between countries where healthcare professionals and MS societies together are dedicated to improving the quality of the lives of people with MS.

Michele Messmer Uccelli MA, MSCS
Editor, *MS in focus*

Introduction

This booklet answers the question ‘what is an MS centre’ and presents some guidance on best practice in the development and management of MS centres and, to a lesser degree, MS clinics.

The development of a model of care and the management of physical facilities that provide MS services and resulting support are among the most important activities undertaken by those with a personal or professional interest in the welfare of people with and affected by MS. Over a number of years, the MSIF Secretariat has been approached by people with MS, health professionals and others interested in developing such physical facilities with requests for information on what an MS centre should look like, what services it should provide, how it would compare to an MS clinic and who to go to for funding.

To best prepare for such requests and to develop an understanding of global good practice, MSIF approached the Consortium of MS Centers (CMSC), Rehabilitation in MS (RIMS) and the International Organization of Multiple Sclerosis Nurses (IOMSN) with a proposal to collaborate in the development of a booklet that would answer all the questions.

The four organisations established a Work Group comprising individuals with relevant and appropriate skills and experiences. The Work Group created an online survey in English, Spanish and Portuguese, to gather information about people’s perceptions, experiences and opinions of MS centres and clinics. The results from the survey informed the preparation of a draft booklet, which was further developed through consultation with the Work Group.

We hope this booklet will help guide those interested in providing services and support to people with MS from an MS centre.

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Defining an MS centre

An MS centre is both a philosophy of care and a physical space/facility that provides MS-specific services and ongoing support throughout a lifetime of dealing with the challenges of MS.

There are a variety of different models relating to the services an MS centre may provide. These often overlap and complement the services provided by an MS clinic or hospital neurology department. Essentially an MS centre provides all relevant and appropriate non-clinical/medical services, whereas an MS clinic provides all clinical/medical services and support (and in many cases some non-clinical/medical services and support).

An MS centre may be a separate private facility focusing on MS alone or it may share or connect to a facility with other groups or organisations that provide services to people with MS and/or other conditions. Such groups or organisations could include an MS society, hospital or university. In the modern world of information and communication technology, we should acknowledge that an MS centre could also be a web-based virtual facility without walls.

An MS clinic is often an established facility – either a physical or virtual location within a hospital, with a regular outpatient clinic, that is affiliated with an academic teaching hospital.

What services and support can an MS centre provide?

Ultimately, an MS centre should collaborate (and develop formal relationships) with MS clinics, residential homes and other centres, the MS society and other relevant groups and organisations in the country to ensure that the quality of life of people diagnosed with MS is optimised throughout their life. As a hospital/clinical setting is more appropriate for many of the clinical/medical types of services required by people with MS, a direct link between the hospital-based MS clinic and the MS centre needs to be developed and maintained.

An MS centre may specialise in one particular area, such as rehabilitation, or it may provide a variety of different services related to the different stages of the life of a person who has, or is affected by, MS. Such services and support may include:

Patient services – activities that aim to both manage and influence the person's illness:

- Referring to a relevant facility for:
 - diagnosis/second opinion
 - treatment that addresses acute relapses (episodes/attacks/exacerbations) and may delay the progression of the disease
 - treatment of symptoms that are either ongoing or occur intermittently

- Facilitating the management of problems that occur in MS
- Facilitating home visits by a nurse or other health professional
- Enhancing and promoting safe, maximal function, for example, rehabilitation services such as physiotherapy, occupational therapy and speech-language pathology services
- Supporting wellness-focused quality of life, for example, activities that may or may not be medically prescribed, such as yoga, tai chi, relaxation, meditation or aqua therapy
- Facilitating economic support, for example, financial support (grants, loans or discounts) or providing transport (minibus or taxi vouchers) and/or daily living aids and adaptations for the home
- Providing short term temporary respite or relief from the tasks associated with caregiving

Education – through educational programmes and provision of materials that contribute to:

- understanding of appropriate management of the disease and its symptoms by people with MS and their families (for example, information about MS, tools for living with MS and local/national services and support)
- professional training and education of health professionals on a graduate, post-graduate, national and international level
- collaboration with MS societies to provide community-based education initiatives such as courses, classes, seminars, conferences and open days

Both MS centres and clinics should have resources available to provide printed or electronic versions of materials that instruct and inform people with MS and their families about the diagnosis and management of MS.

Research:

- A systematic investigation or inquiry to generate new knowledge, or validate existing knowledge, to contribute to the understanding of MS and its effects
- Research may be biomedical or health-sciences related, and either quantitative or qualitative in nature. It may focus on MS as a disease, or as a problem that examines the physical, emotional and psychosocial responses of people with MS and their families
- A database of registered people with MS

In addition, MS centres and clinics can be involved in clinical trials that may generate new approved therapies for disease modification or symptomatic management.

The most successful MS centres, as indicated in our survey, are those that provide as many of the above listed services as possible. The non-medical/clinical services most important to the people who completed our survey were advice, counselling and education.

The services provided by an MS centre can be provided elsewhere and/or in a non-MS specific setting as long as those providing the services have received relevant training and education specifically related to understanding MS. MS is a complex disease that no two people experience in the same way.

Because each person is different, services must be tailored to the individual needs and choices of each person.

MSIF, *Principles to Promote the Quality of Life of People with MS*, 2005

Whatever the setting in which services are provided to those affected by MS, whether an MS centre, an MS clinic or a university/hospital department, the service must be interdisciplinary, with seamless transition between specialised physicians such as neurologists, physiatrists, urologists, orthopaedists, surgeons, nursing professionals, rehabilitation specialists, counsellors, advocates and educators.

As appropriate, people with MS must be offered a broad range of services beyond those provided by physicians and nurses, including physical, occupational, and speech therapy, counselling, and other services. The purpose and potential benefits of those services are to be clearly explained to them.

MSIF, *Principles to Promote the Quality of Life of People with MS*, 2005

Who uses an MS centre and when?

An MS centre can be used by anyone in need of the MS-specific services they provide, including people with MS, people affected by MS and members of the general public.

Considering that an MS centre will be used by people of different ages, gender, religion and sexual persuasion, as well as people with different types of MS at varying stages of the disease, the services provided must consider the specific needs of all those using them.

The services of an MS centre should be provided continually for regular assessment and care as well as utilised at particular stages of the disease, such as at the time of diagnosis, during and after relapses, for advanced disease care and in some cases, at retirement from employment.

MS centres should provide services to people on an ongoing basis determined by their needs while also adopting a formal system whereby people are seen on a monthly, biannual or annual basis, dependent on the type and stage of MS. The length of time spent at each appointment will obviously depend on the reason for the visit, the needs of the individual and the type and stage of their MS. Some MS centres which provide rehabilitation are residential.

After a relapse, a specialised interdisciplinary MS centre seems to be the best place, offering rehabilitation and physiotherapy services to the person with MS. Even if no problem occurs, a re-assessment every six months should be recommended.

European MS Platform, *Recommendations on Rehabilitation Services for Persons with MS in Europe, 2004*

Who provides the services and support?

Once a person has been diagnosed with MS there are a wide variety of health professionals who can provide specific services and support.

The majority of the people who completed our survey suggested that the health professionals who provide services in MS centres should be MS specialists who understand the disease and the challenges of living with it.

In an MS clinic, leadership of services provided should be by an appointed neurologist, with specialist training in MS. Such training ideally includes, but is not limited to, completion of an MS fellowship training programme or regular and substantial consultant work in another MS clinic. In special circumstances, leadership by a non-neurologist physician (for example, a psychiatrist) could be considered if the MS training requirement is met.

Patient-related activities of an MS clinic, including research and education, are often co-ordinated by a registered nurse or equivalent who has had special training or experience in this field. Ideally the nurse will have a minimum of two years' clinical experience and MSCN certification by the International Organization of MS Nurses.

An MS clinic should maintain a defined and formal association with medical or allied health professionals. At a minimum, people with MS must have access to allied health professionals possessing skills in, but not limited to, neurology, rehabilitation and nursing so that such professionals will be integrated, as appropriate, with the clinical staff, and will regularly schedule time to devote to the care of clinic patients. Other health professionals available could include:

- counsellor/social worker
- psychiatrist/psychologist
- neuropsychologist
- psychiatrist/(neuro) rehabilitation physician
- physiotherapist
- occupational therapist
- speech-language pathologist
- urologist
- dietician/nutritionist
- ophthalmologist
- gynaecologist
- alternative therapists (acupuncture/reflexology/yoga)

Different medical service models

In many countries, often there is no integrated interdisciplinary MS centre/clinic model, partly due to a low prevalence of MS diagnosis. If such services are provided they are usually provided as part of the usual general outpatient neurology service, despite being called an MS clinic. In these circumstances the next step is to develop a well defined MS clinic that has a separate identity with an interdisciplinary team and a well maintained database of information. The clinic should initiate interest in neurologists and other healthcare professionals to develop accumulated expertise in the management of people with MS and become a medium for well conducted research.

How are MS centres funded?

The funds to cover the initial costs of developing an MS centre and the ongoing costs of running an MS centre may come from a variety of sources, depending on which individual, group or organisation has stimulated the development, including:

- a group of people with MS
- MS society
- local authority
- government
- private company
- individual donors
- corporate donors
- trusts and foundations

In some MS centres the people receiving the services and support pay a fee. In other MS centres the services and support are provided free of charge to the user or at a greatly subsidised rate made possible by securing alternative sources of funding. Whether or not a user pays for the service will depend on how the MS centre is funded.

People with MS should have access to treatments, programmes and services without regard to their ability to pay.
MSIF, *Principles to Promote the Quality of Life of People with MS*, 2005

To cover the costs and ensure the development of a large, well-resourced centre it may help to collaborate and/or develop strategic alliances with other organisations and develop a centre that provides support and services for people with a variety of neurological conditions, such as Alzheimer's, Parkinson's, epilepsy and stroke.

Relationship with MS societies

The MS society and MS centres/clinics in every country should work in partnership and agree to the following responsibilities:

- The society will provide access to resources available through its national office, chapters, branches, associations and divisions.
- The society may provide funding to support the centres/clinics' services, research and educational activities.

- The centres/clinics will support, where applicable, approved relevant national-driven research projects by providing patient material and data.
- The centres/clinics will provide educational services to its patients, support MS society educational programmes, and provide patients with information to enable them to contact the society.
- The centres/clinics will acknowledge society affiliation/relationship/collaboration wherever possible including in all publications produced by the MS centre/clinic.
- The centres/clinics will participate, as appropriate, in relevant and appropriate activities of the MS society.

The MS society may develop a national certification/accreditation programme to highlight good practice for MS centres/clinics in their country.

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Survey respondents

Thank you to everyone who completed the survey which informed the preparation of this booklet. The survey was completed by 226 people from the following 41 countries:

Argentina	Ecuador	Kenya	Portugal
Australia	Estonia	Latvia	Saudi Arabia
Barbados	Finland	Lithuania	South Africa
Belgium	France	Mexico	Spain
Brazil	Germany	Netherlands	Sri Lanka
Canada	Greece	Norway	UK
Croatia	Iceland	New Zealand	USA
Cuba	India	Pakistan	Uruguay
Cyprus	Ireland	Panama	
Czech Republic	Israel	Peru	
Denmark	Italy	Poland	

Work Group

The following Work Group members include senior staff members of MS centres, health professionals, national MS society staff members and volunteers and people with/affected by MS:

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MSIF Member Societies

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(*Associate Member)

Other booklets in the MSIF *How to* series include:

- *How to Develop a Mutual Support Group*, 2001
- *How to Influence Public Policy*, 2001
- *How to Develop a National MS Society*, 2003
- *How to Work with the Media*, 2005
- *How to Develop a Twinning Partnership*, 2008

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