# MS and Fitness

Guide for people with multiple sclerosis



"The feeling of fellowship in our group is amazing. Every week, we go out for coffee together after our exercise class."

- Mary

"Before my wife got sick, we used to love ballroom dancing. It's extraordinary because now, despite multiple sclerosis, we're able to waltz or tango again."

- John

"My exercise class is also a social get-together, and I wouldn't miss it for the world!"

- Stewart

"Exercise in a group is good for my mood as well as my body. It's a very dynamic, stimulating environment." - Pam

> "Every success makes me proud and happy."

#### - Cindy

"I couldn't do without physical activity. Thanks to my exercise, I can now do my grocery shopping standing up and leave my wheelchair in the supermarket lobby."

- Cherryl

"Now I can play with my grandchildren. I should have started exercising much sooner!" - Paul

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# Never mind the myths – just get moving!

Multiple sclerosis (MS) is the most common disease of the central nervous system among adults in Ireland. Its symptoms are unpredictable and their severity varies from one person to the next. These symptoms may include extreme fatigue, tremors, loss of balance, and sometimes even paralysis. Most people with MS, however, still continue to lead a relatively normal life many years after their diagnosis.

Physical activity is probably the last thing on the mind of someone who has just been diagnosed with MS. Moreover, as time passes, many people with MS experience decreased motor skills, muscle strength and endurance, which may unfortunately lead them to believe that physical activity is inappropriate, or even prohibited, for them. And it must be admitted that until recently, people with MS were advised against taking up activities they were likely to find tiring.

Today, however, it is generally acknowledged that we must change our way of thinking. A better understanding of this disease and of the related therapeutic process prove without any shadow of a doubt that inactivity must be shunned. There are many ways to do this. Of course, physiotherapy, kinesiology and occupational therapy can play a role. But more and more other activities are now available for people with MS who want to keep fit: walking, weight training, swimming, aerobics and dance, to name only a few.

## No more inactivity

It is important to remain physically active, as much to preserve, and even improve, your abilities as to combat the harmful effects of inactivity. Exercise – regular efforts at a certain intensity level – is the key in this new approach to activity for people with MS.

It has been proven that movement in itself is not enough to achieve rehabilitation. Rather, one must promote the learning of new motor skills, in particular by engaging in regular physical activity.

More than ever before, physical exercise is now open to people with MS. Everything is possible because training methods are now adapted to each person's specific condition. Moreover, many of the physical activities and sports suggested for people with MS take place under highly professional supervision, in cooperation with many specialists.

Today, no detail or effort is spared to make regular physical activity an effective and pleasant practice. We encourage you to get moving! In the following pages, you will find some simple suggestions that will motivate you to do so.

Physical activity programs vary from one region to another. Contact your local physical rehabilitation centre, another professional rehabilitation resource (physiotherapist, physical educator or kinesiologist, for example) or your local MS Regional Office to find out what is available near you. (Check out page 17 for list of contacts).

# Make physical activity part of your life!

# Being physically active: A priority

Physical activity always constitutes one of the foundations of quality of life for human beings, regardless of how healthy they are.

This statement is just as true of people who have a physical disability.

Specialists say that when a disease is accompanied by one or more motor disabilities, they can have a harmful influence on a person's body identity, and may even cause that person to reject their own body. Reconciliation with the body therefore constitutes an important phase in the rehabilitation process. It is well known that sport and dance are excellent ways to accomplish this. In addition to enhancing strenght, endurance, cardiorespiratory capacity and mobility and avoiding certain medical complications that may be associated with inactivity in people with MS, as we will see below, physical activity can also contribute to a better lifestyle.

#### Avoiding social exclusion

The MS disease process can easily lead a person to remain hidden at home, to feel isolated and avoid taking part in community life. This is especially frequent when the disease is accompanied by a motor disability that decreases the affected person's autonomy. Participating in sports or dance programs favours a kind of integration that counteracts social exclusion.

"Engaging in physical activity also represents a cherished social outing. People tell us how important they find that, and how much it raises their self-esteem. They are able to do more than they ever thought they could. For example, someone who was unable to walk for five minutes can now walk for as long as 25 minutes."

Jean-François Lamoureux Physical educator Centre d'activités physiques, Cégep de Drummondville "Physical activity first creates a feeling of well-being in a person with multiple sclerosis. Then, it helps them to carry out everyday activities such as holding a hair-dryer for ten minutes, moving from a wheelchair into bed or taking a shower standing up."

> Éric LeBouthillier Physical educator Centre de réadaptation Lucie-Bruneau

"The most wonderful thing is to see people smiling as they do their exercises."

Peter Boutin Physical educator Centre de réadaptation Lucie-Bruneau

# Fitness to fit every lifestyle!

As you can see, there are many ways for you to start enjoying physical activity:

indoor or outdoor physical fitness training, with the specific goal of improving your muscle strength and endurance, your general endurance and your specific endurance for certain tasks (walking or using a wheelchair, for example);

Strength and endurance;	tai chi and yoga;
weight training;	walking practice;
wheelchair exercise;	dance and body self-expression;
swimming and other exercises in the pool;	aerobics.

Whichever activities you choose, they will have to be perfectly adapted to your abilities and your pace. You could ask a physiotherapist, a fitness instructor, a kinesiologist, a physical therapist or any other professional with training in exercise physiology for their help.



# On your marks,get set,play.... Here are some examples of physical activities you could try:

Sports that can be played standing up	<ul> <li>individual sports: track and field, badminton, archery, etc.</li> <li>team sports: basketball, two-bounce volleyball, etc.</li> </ul>
Wheelchair sports	<ul> <li>individual sports: track and field (races, relays, throwing events)</li> <li>team sports: basketball, two-bounce volleyball, etc.</li> </ul>
Floor sports	<ul> <li>individual sports: floor judo, etc.</li> <li>team sports: most team sports can be played sitting or even lying on the floor.</li> </ul>
► Water sports	<ul> <li>swimming</li> <li>underwater diving</li> <li>waterSPolo: a variant of water polo invented at the Université de Sherbrooke. Players sit in different coloured inner tubes, which set the teams apart.</li> </ul>
Boating sports	<ul><li>sailing</li><li>kayaking</li><li>rowing, etc.</li></ul>
Snow sports	• there are special kinds of sleds that enable people with a motor disability to travel downhill or do slalom (see illustration on page 12).
Ice sports	• hockey: the people with a motor disability sit in chairs, while partners on skates push them.



# Fighting an invisible enemy

Fatigue, which is observed in the vast majority of cases, constitutes an unavoidable reality in MS. Specialists think that it is caused by the change in nerve impulses.

We now know that training in general endurance, cardiovascular health and general physical condition is the ideal weapon for combating 🛃 and a decrease in the time required fatigue. Thus, when people with MS exercise, their fatigue threshold is raised.

It is also essential to find the golden balance between rest and physical activity, since excessive rest increases deconditioning and, consequently, susceptibility to fatigue.

Thus, physical activity favours:

- $\Rightarrow$  a reduction in the energy required for each effort:
- $\rightarrow$  a higher fatigue threshold;
- for recovery.

Exercise is also said to reduce spasticity in certain people.

"Endurance is developed bit by bit. Gradually, people with MS become able to do more before they get tired."

Serge Faucher Kinesiologist, Collège de la région de l'Amiante (Thetford Mines)

"Often the first reaction of people who have multiple sclerosis is to say that they can't exercise because they're already tired when they start. The goals we work for are to avoid excessive fatigue and to ensure that the fatigue caused by exercise can be recovered from in just a few hours."

> Linda Parent Physical educator Centre de réadaptation Lucie-Bruneau

# The dangers of physical inactivity

Before taking a look at the many physical activities that may be adapted to the specific restrictions imposed by MS, let us examine the damaging effects of inactivity.

In fact, it has many, often harmful, consequences, not only for a person's motor skills and physical condition but also for their psychological state and social relationships.

Many specialists acknowledge that inactivity can result in a variety of medical complications, some of which could even have a significant impact on quality of life.

#### **Medical complications**

The main medical complications that may be associated with inactivity in people with MS are the following (note that they are not presented here in order of importance or frequency):

- impaired neuromuscular functions;
- infection of the upper respiratory tract (bronchitis and bronchial pneumonia);
- peripheral circulation disorder, e.g. thrombophlebitis;
- pressure ulcers;
- bowel and bladder problems;
- osteoporosis;
- contractures.

"Because of the decline in motor and physical skills associated with multiple sclerosis, people with this disease generally engage in little or no physical activity. They avoid professions that require physical effort and they don't exercise. Inevitably, then, their motor efficiency and physical condition deteriorate."

Jacques Vanden-Abeele Associate Professor, Faculty of Medicine and Faculty of Engineering, Université de Sherbrooke

"Physical inactivity in people with multiple sclerosis is even more dangerous than physical inactivity in the average man or woman on the street."

> Marie-Claude Lavoie Viomax Coordinator Centre de réadaptation Lucie-Bruneau

# A dynamic approach to motor rehabilitation

The new focus in the rehabilitation of people with MS is based on the structured use of exercise. In this regard, the research carried out at the Université de Sherbrooke by Professor Jacques Vanden-Abeele and his team has allowed for the development of a dynamic rehabilitation approach. The major features are discussed below.

From the outset, it is important to clearly establish that so-called "adaptive" physical education, as well as games, sports and dance, are key elements of a reorganisation of the body and its motor skills. The physical activity programs, such as walking school, wheelchair school and sports and dance programs that have been designed for you, include the following elements:

- $\rightarrow$  basic dynamic rehabilitation;
- $\Rightarrow$  neuromotor training;
- training of your physical condition;
- prevention of osteoporosis.

# Preventing osteoporosis

Like paraplegic people, people with MS have an increased risk of osteoporosis.

It has been determined that physical activities that generate an impact, such as jumping or hopping, help prevent osteoporosis. Thus, it is recommended that you favour these kinds of activities (no matter how light the impact), as well as those that can strengthen muscles.

# The fundamental principles

Dynamic rehabilitation is the outcome of a series of principles; the main ones are presented below:

- YOU are the main agent in YOUR rehabilitation since you absolutely have to participate actively;
- the reorganisation can only take place through a self-assessment that will allow you to discover the optimal motor strategies based on your abilities;
- it is necessary to learn new motor skills: you need to learn and perform specific motor actions;
- > a spacious, dynamic environment is required;
- the motor actions must be meaningful to you;
- your training program must be customised;
- exercise for fun is more effective than exercise you are forced to do;
- work in small groups is enriching;
- unpredictability, spontaneity and creativity are essential factors for any good exercise session;
- reorganisation is a long-term process, full of unexpected events. Thus, rehabilitation must be prolonged beyond the stay in hospital, sometimes in a rehabilitation centre. It must even continue after you go home again.

# Start at the beginning

The starting point is not your disease but you yourself, with your own motor, physical, cognitive, psychological and social skills, as well as your own hopes and aspirations.

Basic dynamic rehabilitation is specifically designed to:

- improve motor efficiency by dynamic neuromotor training;
- gradually improve your physical condition;
- carry out an initial exploration of the kinds of games, sports and dance that you are able to do.



# The benefits

Regular exercise, sport and dance present many advantages as a rehabilitation method:

- these activities will improve your motor, physical and psychological capacities;
- they generally take place in sports facilities, which allows your rehabilitation to be "demedicalised";
- it has been proved that rehabilitation through sports reduces the duration and cost of rehabilitation;

- games, sports and dance are enjoyable, meaningful and dynamic and they take place in locations that are usually spacious;
- they favour and speed up social integration.

There's no doubt about it: they are focused on YOU !



# Dive into life

There are so many physical activities, and so many ways to perform them, that very few people with MS will not be able to find something they can do.

One particularly interesting possibility is engaging in physical activities in the water, that is, in "low-gravity" conditions. The effect of gravity is reduced by flotation and the water pressure makes it easier to keep your body upright.

These activities can be performed in a shallow pool or one whose depth can be adjusted due to a moveable floor. Specialised equipment makes it possible to transfer people who use a wheelchair.

"In the pool, we have developed flexion and extension exercises, as well as swimming exercises with inner tubes. The movements are really varied so it doesn't get monotonous."

Serge Faucher Kinesiologist, Collège de la région de l'Amiante (Thetford Mines)

## Shall we dance?

Brigitte Graff, dancer, choreographer and director of the Corps et Graff Company in Sherbrooke, has developed some strategies that allow people who have a motor disability to dance standing up, with or without a cane, crutch or walker, with or without help from another person, or even sitting in a wheelchair.

"We break every dance convention," she says enthusiastically. "We change the beat if necessary. A waltz in three-quarter time becomes a waltz in two-four time. The important thing is that a person with a disability is able to dance. The three favourite dances for people with motor problems are rock and roll dancing, tango and waltz. Any dance can be adapted."

### Wheeling better...

Approximately 25% of people with MS use a wheelchair. This situation demands not only good steering skills but also physical strength, especially in the upper limbs, when using a standard wheelchair.

Conversely, the frequent or constant use of a wheelchair entails that a person remains in the sitting position for long periods of time, which inevitably results in significant muscle weakening.

That is why it is important for people who use a wheelchair to stay physically fit, thanks to regular exercise. To do this, specialists have designed a whole panoply of exercises to do in the wheelchair, in a chair, on the floor (sitting or lying down) or in the pool.

# ...and having fun!

Wheelchair sports are the ideal option for any person whose range of movement is limited physically and for whom traditional sports in the standing position are inappropriate or simply impossible. This kind of activity also makes it possible to improve your steering...

Which sports are accessible to people in wheelchairs?



# Expert advice

The physical conditioning and training specialists we consulted while preparing this document have some excellent advice for you that will help you to take full advantage of the joys of physical activity. Here are some tips:

- The most important thing is to go gradually. Rome wasn't built in a day...
- Choose activities that motivate you.
- Take regular breaks.
- Don't hesitate to ask for advice.
- Respect your own pace.
- Don't exercise during MS attacks.
- > Opt for exercise that develops endurance more than physical strength.
- Start with sessions that last 10 minutes per day (four or five times a week). Remember that regularity is more important than length of time.
- Choose the time of day when you feel best to do your exercises. During the summer, it's usually coolest in the morning.
- Set realistic goals.
- Start to exercise as soon as possible after receiving your diagnosis of MS.

"People with multiple sclerosis shouldn't be afraid that physical activity will make their condition worse. The opposite is true: it will improve with exercise, just as it does for everyone else."

> Jean-François Lamoureux Physical educator Centre d'activités physiques, Cégep de Drummondville

"Everything is possible. When we have quadriplegic people who can dance or do tai chi, I see no reason why people with multiple sclerosis shouldn't do as much. We adapt to their abilities and modify the exercises accordingly."

> Jean Laroche Exercise specialist, Université de Sherbrooke

"Physical inactivity has negative impacts on multiple sclerosis itself and increases the risk factors, as well."

> Éric LeBouthillier Physical educator Centre de réadaptation Lucie-Bruneau, Montreal

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Handout for the presentation given at the Montérégie Chapter of the Multiple Sclerosis Society of Canada's second conference, Saint-Jean-sur-Richelieu, Saturday, December 1, 2001.

 L'école du fauteuil roulant. (Wheelchair school.)

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 S'entraîner en s'amusant. (Have fun exercising.)

Newsletter of the Association de la sclérose en plaques de l'Estrie. December 2000.

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- La SP... ça marche !!! (MS... moving right along!) Handout for the presentation at the Espoir Famille Conference organized by the Quebec Division of the Multiple Sclerosis Society of Canada, Sherbrooke, October 16, 1999.
- Le sport en fauteuil roulant... pour une vie active. (Wheelchair sports... for an active lifestyle.)

Quebec Wheelchair Sports Association. June 1998.

 L'utilité et la nécessité des activités physiques pour les personnes ayant la sclérose en plaques. (The usefulness and necessity of physical activities for people with multiple sclerosis.)
 Handout for the presentation at the Quebec Division of the Multiple Sclerosis Society of Canada's Symposium, Oka, May 30, 1998.

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Au mieux de sa forme... tout en douceur ! Exercise video for people with multiple sclerosis, adapted from the American version called Gentle Fitness, and produced in cooperation with Marie-Claude Lavoie and Linda Parent, 2003.

#### MULTIPLE SCLEROSIS SOCIETY OF CANADA

Everybody Stretch: A Physical Activity Workbook for People with Various Levels of Multiple Sclerosis, Janine Fowler, B.Phys.Ed., 2003, 45 pages.

- TAOIST TAI CHI SOCIETY OF CANADA Taoist Tai Chi for Special Needs bilingual edition, 1994, 136 pages.
- Yoquatics: Hatha Yoga practiced in Water, videotape produced by TEI Agency Ltd, 2000.
- Sit and be Fit (specialty exercise, videotape for MS with Mary Ann Wilson, R.N.), 1993.
- Stretching with a Helper for People with MS: An Illustrated Manual, National MS Society, 2002.

Organisations and associations that are involved in the field of physical activity and/or rehabilitation

- Irish Wheelchair Association Tel: 01 8186 400 Web: www.iwa.ie
- National Rehabilitation Hospital Tel.: +353 1 2355000 www.nrh.ie
- Irish Society of Chartered Physiotherapists (ISCP)
   Tel: 01 402 2148
   www.iscp.ie
- National Council for Exercise and Fitness (NCEF)
   Tel: 061 202 8298
   www.ncefinfo.com
- ▶ Yoga Federation of Ireland Tel: 01 235 2120 www.yfi.ie
- Irish Yoga Association www.iya.ie
- ► The Irish Association of Physical Therapists www.iapt.ie
- Irish Sports Council Tel: +353 1 860 8800 www.irishsportscouncil.ie

Check out their local sports partnerships programme, available in most counties in Ireland. Multiple Sclerosis Ireland is the national organisation providing information and support to the MS community. Our services and resources are provided nation wide and are available to anyone affected by MS. This includes the person with MS, family members, carers, employers, health professionals and anyone interested in the work of MS Ireland.

Our Core services Include:

#### Individual or family support

Through our case work service our teams of professional Regional Community Workers support the person with MS through the transitional changes that MS, as a disease, presents. Support is also available to the family members in dealing with the challenges they may face as a family unit.

#### Living with MS programmes

A range of living with MS programmes, workshops and activities are organised throughout the country that are targeted at various groups such as those newly diagnosed, carers, children of parents with MS and health professionals.

#### ◆ MS Helpline 1850 233 233

Our confidential helpline provides immediate information and support to those affected by MS. The helpline is opened from Monday to Friday 10am – 5pm and Tuesday and Thursday evenings from 6.30pm – 9.30 pm.

#### ◆ The MS Care Centre

The centre offers short-term respite care for people with MS and also provides an opportunity for residents to access a multidisciplinary team assessment. The Occupational Therapist, the Physiotherapist and the MS nurses can explore issues relating to symptoms, treatments etc and provide guidance on appropriate management at home and in the community.

#### Voluntary Branches

Our voluntary Branches are a support network for people and families living with MS in local communities. Run by people affected by MS for people affected by MS, our Branches provide a range of services such as a welfare service, fundraising and social gatherings.

#### Information

Our information tools include a variety of booklets and information sheets, our website www.ms-society.ie, our MSnews magazine, national conferences and seminars and the valuable knowledge and experience of our staff.

#### Research

MS research is the most beneficial way to improve understanding of the disease, leading to better treatments, interventions, management and ultimately a cure for MS. Our dedicated research fund annually finances a number of medical and social research projects.

#### Representation

MS Ireland advocates on an individual and collective platform for the improvement in service, resources and policies that will assist all people affected by MS to live the life of their choosing.

The MS community is a strong, vibrant gathering of different people and groups affected by or interested in MS. Some of our members are actively involved in the Society and attend programmes, volunteer and speak publicity about their MS. Others prefer to maintain their privacy and wish only to receive information. However much or little you want to get involved, become a member today to keep in informed. Call 1850 650 950 or sign-up online at www.ms-society.ie

#### **Contact Details**

#### National:

Multiple Sclerosis Ireland, 80 Northumberland Road, Dublin 4. Tel: 01 6781600 Fax: 01 6781601 Email: info@ms-society.ie MS Helpline: 1850 233 233 mshelpline@ms-society.ie Fundraising Hotline: 1850 650 950

#### **MS Care Centre**

65 Bushy Park Road Rathgar, Dublin 6 Tel: 01 490 6234 Email: mscare@ms-society.ie

#### Regional

#### **East Coast Dublin and Wicklow**

MS Ireland East Coast Area Unit 10a, The Egan Centre, Dargle Road, Bray, Co Wicklow Tel: 01 2866800 Email: eca@ms-society.ie

#### North County Dublin and City

MS Ireland Northern Area, 65 Bushy Park Road, Rathgar, Dublin 6 Tel: 01 4905933 Email: na@ms-society.ie

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MS Ireland South West Area 65 Bushy Park Rd Rathgar, Dublin 6 Tel: 01 01-4905933 Email: swa@ms-society.ie

#### Southern Region (Cork)

MS Ireland, Southern Regional Office North Quay House, Pope's Quay, Cork Tel: 021 4300001 Email: southern@ms-society.ie

#### Southern Region (Kerry)

Ms Ireland Southern Region Office, The Courtyard House, Fairhill, Killarney, Co Kerry. Tel: 064 663 0851 Email: siobhanl@ms-society.ie

#### North East Region

MS Ireland North Regional East Office 1 Church Street, Carrickmacross, Co Monaghan Tel: 042 96 64410 Email: northeast@ms-society.ie

#### Western Region

MS Ireland Western Regional Office Roxboro House, Raliegh Row Galway Tel: 091 862478 Email: western@ms-society.ie

#### South Eastern Region

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#### **Midlands Region**

MS Ireland Midlands Regional Office Newtown Terrace Athlone, Co. Westmeath Tel: 090 64 76353 Email: midlands@ms-society.ie

#### North West Region

MS Ireland North West Regional Office Unit 6 Rossview Business Park Port Rd, Letterkenny Co. Donegal Tel: 074 91 25017 Email: northwest@ms-society

#### **Mid-West Region**

MS Ireland Mid-West Regional Office 'Tara' Resource Centre, St. Nessans Road, Ballykeefe, Limerick Tel: 061 335 565 Email: midwest@ms-society.ie

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#### Our Mission

To enable and empower people affected by MS to live the life of their choice to their fullest potential

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