Principles to Promote the Quality of Life of People with Multiple Sclerosis

multiple sclerosis
international federation

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Foreword

Photo: Richard Young

My mother was 35 when she was diagnosed with MS. At first life went on much as usual. Her one admission that she had the illness was very much in character: she read everything she could about it. But none of her pamphlets or booklets could tell her why she had the illness or how severely her life would be affected.
I would estimate that my mother saw a physiotherapist less than 10 times in the 10 years following her diagnosis. She lived in the country and couldn't drive; for a very brief period a physiotherapist came to visit her, but that somehow fell through, and the physiotherapist stopped coming. The same thing happened with the home help who was sent once Mum had given up work and was reduced to crawling upstairs instead of walking. There never seemed to be quite enough money to provide services for people with MS; the only option was to be hospitalised.

It was not only the rapid progression of the illness that affected my mother - and us, her family. It was the rapid deterioration of the quality of her life, her self-esteem, her independence.

Quality of life is something we must all fight for in every country around the world, and to fight we need tools that are appropriate to the battle ahead. That is why the Principles to Promote the Quality of Life of People with MS in this document are so important. They provide points of aspiration for all affected by MS, and their strategic application is an essential part of helping groups and individuals focus on what is best for their community. Beyond that, workshops and internet communication will allow a sharing of experiences and a building of best practice internationally. This document is only a beginning. The continuing impact of the Principles will come from your determination to apply them in your community and your nation. I wish you every success as you fight to improve the quality of life of people affected by MS around the world.

“Quality of life is something we must all fight for in every country around the world, and to fight we need tools that are appropriate to the battle ahead.”

J.K.Rowling

Preface

As early as 1947 the World Health Organization (WHO) described health as a "state of complete physical, mental and social well being, and not merely the absence of disease or infirmity." However, most health care services in the past focused on the treatment of a disease and its symptoms rather than paying attention to the whole person. Fortunately today, health care is shifting from a disease-oriented approach to one centred on the patient's experience and needs, with issues such as access to health care, independence and empowerment, employment, education and many other elements holding equal weight in assessing an individual's wellbeing.

With the aid of 15 collaborating centres around the world, WHO developed the WHOQOL-100 framework. In this, WHO defines Quality of Life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept, affected by the person's physical health, psychological state, level of independence, social relationships and to salient features of their environment.

The WHOQOL-100 framework was intended as a tool for general use in medical practice, research, audit and policy making. We are particularly pleased therefore to see that the Multiple Sclerosis International Federation (MSIF) has incorporated the WHOQOL domains into their Principles intended to affect policy, and to improve the lives of people affected by multiple sclerosis.

MSIF is one of the NGOs "in official relations with the World Health Organization", and I am in full support of the way MSIF has taken WHO's work another step forward. These Principles provide a comprehensive yet tangible focus for national MS Societies as they develop and implement plans to improve the quality of life of those affected by this life-long disease.

> **"These Principles provide a comprehensive yet tangible focus for national MS Societies as they develop and implement plans to improve the quality of life of those affected by this life-long disease."**

Benedetto Saraceno, MD
Director Department of Mental Health and Substance Abuse
World Health Organization

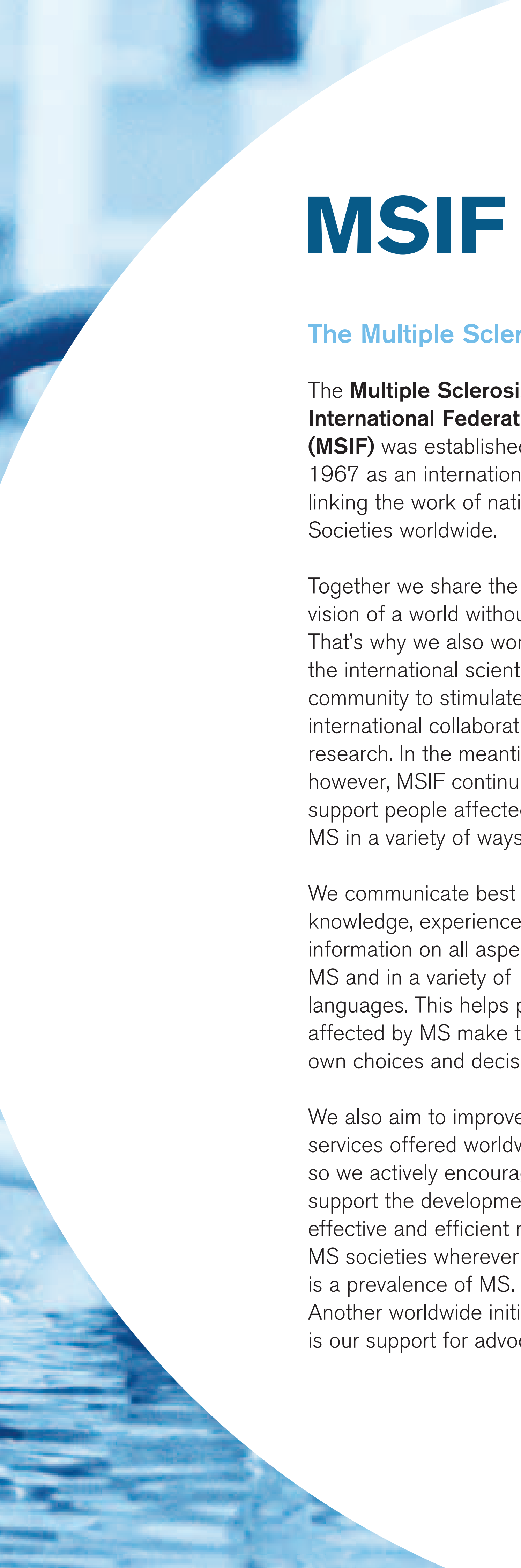

Photo: Eddie Safarik, MS Australia SWEAT AQUA Program, Australia

MSIF

The Multiple Sclerosis International Federation

The **Multiple Sclerosis International Federation (MSIF)** was established in 1967 as an international body linking the work of national MS Societies worldwide.

Together we share the global vision of a world without MS. That's why we also work with the international scientific community to stimulate international collaborative research. In the meantime however, MSIF continues to support people affected by MS in a variety of ways.

We communicate best practice knowledge, experience and information on all aspects of MS and in a variety of languages. This helps people affected by MS make their own choices and decisions.

We also aim to improve the services offered worldwide, so we actively encourage and support the development of effective and efficient national MS societies wherever there is a prevalence of MS. Another worldwide initiative is our support for advocacy campaigns to influence public policy in favor of people with MS.

Our various activities are underpinned by good governance and leadership, transparent financial and administrative structures, and a healthy fundraising capacity.

As a person with MS myself I have first-hand experience of the impact MS can have on quality of life, not only for the individual with MS but also for family and friends. By producing the Principles to Promote the Quality of Life of People with MS, MSIF leads the global MS movement, and I am honoured to be a part of it.

Sarah Phillips

Sarah Phillips
Chairman & President
Multiple Sclerosis International Federation

Introduction

Multiple sclerosis (MS) is a chronic, disabling disease affecting approximately 2.5 million people worldwide. Although the impact of the disease varies with the type of MS, with the individual, and often from day-to-day, common symptoms include fatigue, bladder and bowel disorders, vision problems, tremor, spasticity, abnormal speech, swallowing disorders, sexual dysfunction, difficulty performing basic everyday activities, (such as eating, bathing, dressing, and housekeeping,) cognitive impairment, mobility problems, pain and depression. As a result of these symptoms, MS can substantially and adversely affect an individual's quality of life (QOL). In addition, many people with MS leave the labour force and must depend on relatives or government programmes for financial and other support.

To enhance the lives of people with MS, this report presents "principles" to improve their QOL. While these principles include health care, they reach far beyond medical care to a broad range of other domains. Moreover, these principles are not primarily focused on assessing or measuring QOL. Rather, they are designed to guide the development and evaluation of services and programmes that are provided by governments, for-profit and nonprofit health and social service providers, employers, and other organizations for people with MS.

These principles are also designed to be used by international organizations, national MS societies, people with MS and their families, governments, health and continuing care providers, researchers, businesses and others to evaluate existing and proposed services and programmes and to advocate for improvements.

The principles are problem-based. As such, they focus on the common issues that affect QOL for people with MS, for instance the distress and disability caused by the many symptoms of the disease, the inability in some cases to live at home, the loss of paid employment, the loss of mobility, and the lack of coordination between medical and social care. As a result, the principles are not linked to particular types or stages of MS.

It should always be kept in mind that the ultimate goal is a cure for MS. However, until a cure is found and can be broadly implemented, it is important to work to maintain or improve QOL for people with MS, utilizing a broad range of approaches such as those described in these principles.

The development of the principles was based on a series of interviews, a literature review, the clinical, programmatic, and research experience of the authors, and review by a Work Group and technical Oversight Group organized by the Multiple Sclerosis International Federation (MSIF).

The interviews were conducted with a range of international MS and QOL experts, MS clinical providers and people with MS; a list of people interviewed is presented in the Acknowledgements. The Oversight Group and Work group includes MS experts and people with MS representing a range of MSIF member countries; the members of the Oversight Group and Work Group are listed in the Acknowledgements.

The literature review included relevant journal articles, MS clinical textbooks, publications of national MS societies, and relevant web-based publications; a list is included in the References section. The References section also includes a level of evidence assigned to each publication.

The level of evidence definitions used in this literature review are as follows:

1a Meta-analysis of randomized controlled trials
1b Randomized controlled trial
2a Controlled study, without randomization
2b Quasi-experimental study
3 Non-experimental, descriptive study (e.g., comparative study, correlation study, case study)
4 Expert committee report, opinion and/or experience of respected authority

The principles are presented in a way that reflects the state of affairs when they have been fulfilled. This active voice is meant to empower people with MS and move away from passive formulations in which things are done “to” or “for” people with MS. Thus, the principles describe programmes and policies that work well and meet the needs of people with MS rather than being exhortations of what things “should be” done.

The principles are organized into the following ten themed sections:

- Independence and Empowerment
- Medical Care
- Continuing (Long-Term or Social) Care
- Health Promotion and Disease Prevention
- Support for Family Members
- Transportation
- Employment and Volunteer Activities
- Disability Benefits and Cash Assistance
- Education
- Housing and Accessibility of Buildings in the Community

Development of the principles was guided, in part, by the first five domains included in the World Health Organization's QOL framework, including physical health, psychological health, level of independence, social relations, and the environment. They were used as references to ensure that the scope of the principles would include all aspects of QOL relevant to people with MS. The WHOQOL domains addressed by each principle are indicated in a table in Annex 1.

Each section begins with a general statement supporting its theme and an introductory discussion of key issues. The principles are then presented in numbered paragraphs. Citations at the end of each principle indicate the references that provide supporting evidence. A summary of the number of supporting references for each principle by level of evidence is included in a table in Annex 2.

The Principles

1.0 Independence and Empowerment

People with MS are empowered as full participants in their communities and in decision-making about the management and treatment of the disease.

MS is a complicated disease that has a major impact on quality of life (QOL). It is important that programmes, policies and services enable people with MS to be as independent as possible and have control over their lives. The day-to-day uncertainty that many people with MS experience often causes a significant loss of QOL. To retain independence and empowerment, people with MS must be able to participate fully in their communities, in management and decision-making regarding their disease, and not be restricted in their treatments by financial liabilities. Governments should have legislation that protects their rights.

1.1. People with MS must be able to realize their full potential. They should have the opportunity to travel to places outside of the home, work at jobs, acquire an education, and do the other things that people without disabilities do. They should have the opportunity to participate in community life as much as is possible and desired. [1-31]

1.2. People with MS and their families must be involved in decisions about their medical treatment and other decisions that affect their lives. Even when there is cognitive impairment in the person with MS, the affected person and his or her family must be involved in the decision-making process to the fullest extent possible. They should collaborate closely with their physicians and other health care providers. 1,3,4,6,7,17,23,30,32-42

1.3. People with MS and their families have choices regarding their medical treatment and the other services they receive. Because each person is different, services must be tailored to the individual needs and choices of each person, and a broad range of services made available. 1,3,4,34,43-45

1.4. People with MS should have access to treatments, programmes, and services without regard to their ability to pay. 1,3,4,27,46-48

1.5. People with MS must be empowered to take control of the decisions affecting their lives and to self-manage the disease as much as possible. To encourage the highest possible degree of self-management, they should be able to access a broad range of information, advice, and education regarding the nature of MS, its treatment, and methods for improving QOL. Access to this information is to be made available through multiple sources, including books, pamphlets, websites, and health and social service professionals. Mutual or peer support opportunities should also be available to people with MS. 1,3-5,7,12,13,17,19,22,23,25-27,30, 32-35,37-40,42,45-47,49-65

1.6. Legislation must be enacted that protects the rights of people with MS and other people with disabilities against discrimination in all aspects of social and community life. Enforcement of these laws is to be consistent and effective. Among other things, these laws require governments, employers, building owners, transportation organizations, and others to make reasonable adjustments to improve accessibility for people with disabilities. These laws are to ensure that people with MS have access to all types of financial instruments, including current accounts and savings accounts, credit cards, insurance, loans, and all forms of financial assistance. [1,4,9,12,13,17,20,26-28,35,42,46,47,66,67]

2.0. Medical Care

People with MS have access to medical care, treatments and therapies appropriate to their needs.

MS is a serious condition, making access to medical care extremely important to the QOL of people with the disease. The wide range of symptoms and functional impairments that often accompany MS means that a broad array of services is needed. In addition, the twin facts that it is a long-term illness and that primary care providers may not treat many people with the disease result in a need for continuity of care by professionals who have specialized knowledge about treatment of MS. Because the time of initial diagnosis is particularly stressful, it deserves special attention from health care and other providers. Also because expert medical care is essential for people with MS, they must have access to necessary health care services including excellent diagnostic services, knowledgeable and skilled medical providers, up-to-date drugs and medical treatments and services that address their symptomatic needs.

2.1. Access to Health Care

2.1.1. All people with MS must have access to evidence-based, quality health care. [1,3,4,24,35,47,68]

2.1.2. Health care for people with MS includes medically-effective treatments, including symptom and disease modifying drugs, rehabilitation services, appropriate and affordable enabling technology that is tailored to the needs of people with MS, and continuing care services.

Medically-effective and culturally-appropriate treatments to manage the symptoms of MS must be made available. [2-4,6,7,11,16,17,19,24,32,35,37,42,44,45,47,53,56,57,59,61,69,71-128]

2.2. Initial Diagnosis

2.2.1. Physicians must be sensitive to the major psychological, social, financial, vocational and medical impact of telling a person that she or he has MS. Patients must have adequate time to ask questions of the physician. Newly diagnosed patients should be referred to the national MS Society and an MS nurse specialist or other health professional with MS treatment and counselling experience. [1,12,30,32,33,35,36,40,42,47,56,103,117,129-134]

2.2.2. At the time of the initial diagnosis, people with MS must have access to information about MS that is specific to newly diagnosed individuals, together with information on local and national medical, support, rehabilitation, and life-planning services. [1,30,35,36,42,54,56,63,103,106,114,133]

2.3 Physicians, Nurses, Hospitals and Other Medical Providers

2.3.1. Medical care is to be provided by clinicians who have expertise in MS, including neurologists. In order to ensure prompt and expert treatment of the wide range of symptoms and disabilities that people with MS may experience, both care and case management must be provided by multidisciplinary teams that specialize in MS. [1,3,4,6,16,17,27,35,42,61,65,68,103,115,119,122,124,125,128]

2.3.2. 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. [1-,6,11,16,17,24,35-37,42,44,45,47,53,56,59,61,65,68,71-74,76-78,81,86,90,94-104,106,109,111-119,121-128,135-138]

2.3.3. Medical facilities, such as hospitals, must take into account and make reasonable modifications of physical facilities and equipment to accommodate the physical disabilities of people with MS, including difficulty walking, bathing, and getting on and off examining tables. [3,35,135]

2.3.4. Treatment for MS must be co-ordinated with treatment for other acute and chronic medical conditions and with continuing care needs. Protocols for referrals and transferring responsibility among different providers and health care organizations should be agreed upon by all relevant parties. Services are seamless from the patient's perspective. [3,27,30,35,42,124,125,128]

2.3.5. People with MS must have continuity of care with their clinical providers over an extended period of time. The focal point for continuity is a provider with sufficient time and motivation to learn about each patient's individual experience with MS, to listen to the patient's questions and concerns, and to explore the full range of symptoms. This provider could be an MS nurse specialist, a physician knowledgeable about MS, or another health professional who specializes in MS care. [1,3,4,7,12,30,33,35,54,57,65,103,137]

2.3.6. All neurologists, primary care physicians, nurses, and other health professionals who work with people with MS must have the goal of promoting QOL, and not just clinical management of the disease. 1,3,4,6,12,18,19,27,30,40,45,48,49,56,65,70-72,74, 76,94-97,99-102,138,139

2.4. Symptom Management

2.4.1. Medically-effective and culturally-appropriate treatments must be available to address the symptoms of MS, including (but not limited to) fatigue, depression, cognitive impairment, impaired sexual function, pain, bladder and bowel dysfunction, limited mobility, vision problems, and others. Health professionals must consider in a systematic way whether a person with MS has additional, sometimes "hidden" symptoms or problems that can affect QOL. 2-4,6,7,11,16,17,19,20,35-37,40,42,44,45,47,48, 53,56,57,59,61,65,68-70,72,76-78,82,90,95-99, 101-103,105,106,109,110,112,113,115-119,121, 122,124-128,135-137,140-152

3.0 Continuing (Long-Term or Social) Care

People with MS have access to a wide range of age-appropriate care services that enable them to function as independently as possible.

Continuing care refers to nursing home care, respite care, home health care, personal care, adult day care, and other services designed to address functional impairments, such as the inability to eat, bathe, or dress oneself. Continuing care services allow people with MS who have disabilities to function more independently. QOL for people with MS is greatly enhanced when principles for home and community based care, residential care, and adequate financial remuneration for care-givers are supported.

3.1. People with MS must have access to a wide range of home, community based and respite care services that help individuals reside in their homes as long as possible. [4,8,10,20,35,42,47,81,86,103,115,153,154]

3.2. Institutional or residential services, such as nursing homes, should be used only if home and community based care is no longer appropriate. Services in these institutional facilities must be designed to take account of the interests and needs of people with MS, who are typically younger than other residents. [35,42,47,103,155-157]

3.3. Paid professional continuing care providers must receive adequate training in the specific features of MS, and adequate pay, fringe benefits, and supervision.

4.0. Health Promotion and Disease Prevention

People with MS have the information and services they need to maintain positive health practices and a healthy lifestyle.

Medical care often dominates the services provided to people with MS yet there are a number of other activities and services that promote wellness and prevent other diseases. Health promotion activities include relaxation techniques, stress management, energy conservation techniques, cooling therapy, aerobic, mobility, and balance exercises, and other wellness practices.

Disease prevention includes immunizations (e.g., influenza) and other routine medical services (e.g., pap smears). People with disabilities have been found to have less access to preventive care services, due to a variety of physical and other types of barriers.

4.1. People with MS must be offered quality information and training for a wide range of health promotion practices, depending on patient preferences and their effectiveness in enhancing QOL for the individual.

1,3,5,7,17,24,25,31,35,36,45,47,51,53,55,56,59-61,
104,124,126-128,142,148-150,158-165

4.2. Good nutrition and physical fitness must be encouraged for people with MS by their clinical providers and counsellors.

1,3,6,16,17,24,35,36,45,47,51,53,56,59,61,76,104,
112,122,124,126-

4.3. Physicians should not over-emphasize MS care at the expense of health promotion and disease prevention. People with MS must be provided with routine preventive medical care.

1,3,6,7,36,42,56,160,168

5.0 Support for Family Members

Family members and caregivers receive information and support to mitigate the effects of MS.

Most MS-related services are provided to the person with MS by family members and other informal carers, who are also profoundly affected by having a relative or friend with MS. These family and friends benefit from services designed to help them cope with the stress and other impacts associated with the disease.

Children can be affected by having a parent with MS and may not fully understand the reasons for a parent's health problems, think they have somehow caused them or feel neglected as a member of the family. The effort required to maintain an effective parenting role despite the symptoms and disabilities of MS can be a major source of stress for people with MS. Conversely, maintaining a meaningful role as a parent can be a source of enhanced QOL. These principles acknowledge and address the special needs of care-givers to help maintain their quality of life when a person has MS.

5.1. Services and training must be available to family members and other informal carers affected by MS as well as to the person with MS. They must also be provided with information about available community services that may provide support. [1,3,7,8,10,15,17,20,35,42,47,53,58,64,109,114,117,130,169-185]

5.2. Respite care must be available to relieve the burden on family members and other informal carers. It should be available either in the home or in institutions providing continuing care. 1,3,15,35,47,103,126,130,180,183-185

5.3. Family members and other informal caregivers must be routinely evaluated regarding their caregiving-related physical and emotional stress and other personal needs. 1,3,15,35,42,47,103,117,127,130,136,169-182,184,185

5.4. People with MS and their families must have access to family and relationship counselling. 1,3,6,15,17,23,25,35,37,42,47,53,55,57,58,106,109,113,130,152,169-182,184,185

5.5. Services must be available to people with MS to aid them in their parenting responsibilities. Children are to be protected from taking on inappropriate roles as caregivers for parents with MS. 1,3,6,25,31,35,37,47,126,130,152,174

5.6. Services must be available to prevent physical, financial, and psychological abuse of people with MS by family members and other informal caregivers. 1,3,117,130,184

6.0 Transportation

People with MS have access to their communities through accessible public transportation and assistive technology for personal automobiles.

Mobility for people with MS can be greatly enhanced when they continue to drive or when alternative transportation is available. People with MS may have difficulty with transportation because of their functional disabilities, cognitive impairment and use of mobility aids, yet public transportation, often their only available resource, is sometimes not available or difficult to use. Lack of transportation can mean that people with MS remain inside their homes, inhibiting their ability to participate in life in the community.

6.1. Services should be available to enable people with MS to continue driving their own cars as long as possible, if desired. [3,6,15,17,30,47,124,165]

6.2. For people with MS who cannot or do not drive, accessible transportation services must be available and affordable. [3,6,35,47]

7.0 Employment and Volunteer Activities

Support systems and services are available to enable people with MS to continue employment as long as they are productive and desire to work.

Many people with MS leave the labour force because of the symptoms of the disease, such as fatigue, functional disability, and cognitive impairment. Leaving the workforce can have a major effect on family income as well as an individual's self-esteem. Some people with MS could continue to work if employers provide assistance and restructure their work.

A wide range of accommodations or adaptations are possible, including part-time work, additional breaks in the work day, working only mornings, reducing the room temperature, changing work tasks, telecommuting, reducing travel, providing ramps, providing offices near restrooms, and others. Governments and social service providers can contribute by providing vocational rehabilitation and training programmes.

For those people with MS who do leave the labour force, substitute activities are important to sustain a sense of purpose in life. Examples include voluntary activities, creative arts, serving as MS peer counsellors, assisting with MS Society or MS centre administration or advocacy efforts, pursuing further education, and others.

7.1. Services must be available to allow people with MS to continue employment as long as they are productive and desire to work. [3,6,9,12,13,15,17,19,20,25-28,30,35,42,46-48,56,59,65-67,124,152,165,186-189]

7.2. Employers must provide job modifications and other adaptations or accommodations to enable people with MS to continue working. Employers must be educated about the nature and symptoms of MS, and how job modifications can often enable people with MS to remain productive employees for many years. [3,9,12,13,15,17,19,20,26-28,35,37,38,42,46,47,56,65-67,124,152,165,186-189]

7.3. Employers should provide time off for family members and other informal care-givers to accommodate the unexpected needs of people with MS. Employers should be educated about the roles of family members in treating and managing acute exacerbations and symptoms of MS. [3,13,15,19,28,37,47,189]

7.4. Vocational rehabilitation and training services must be available to help people with MS return or stay in the labour force, if desired. [3,6,12,13,26-28,35,42,46,47,65-67,124,152,186,187]

7.5. When people with MS do retire from paid employment, they must be provided counselling and encouragement to develop alternative, voluntary activities that can fill the void often left by the loss of work. The transition out of paid employment is to be planned well in advance to ensure people with MS receive all of the services to which they are entitled, to prepare for alternate occupations or activities, and to avoid the stress that may accompany abrupt, unplanned transitions from work to retirement. [3,8,20,21,25,37,42,189]

8.0 Disability Entitlements and Cash Assistance

Disability entitlements and services are available to those in need, provide an adequate standard of living, and have flexibility to allow for the disease variability that is characteristic of multiple sclerosis.

Many people with MS who leave the labour force are dependent on disability entitlements and means-tested cash assistance for their income. Thus, the eligibility standards, payment levels and administration of these entitlements have a direct impact on the QOL of people with MS. These principles address the importance of this type of financial assistance, including the application process, level of support and flexibility in administration that can greatly affect the well-being of people with MS.

8.1. Eligibility criteria and application procedures for public and private disability entitlements and means-tested cash assistance must be fair and not unduly burdensome nor restrictive. [27,28,46,67]

8.2. Cash payment levels for public and private disability benefits and means-tested cash assistance must be high enough for people with MS to have an adequate standard of living. [8,15,28,46,48,67,190]

8.3. Disability entitlements must be flexible, allowing for partial disability, to enable people with MS to take time off when needed or to continue working part-time, if desired. [9,28,47,66,67]

9.0. Education

MS does not inhibit the education of people with MS, their families or careers.

In a modern economy, education is critical to obtain good jobs. In addition, participating in the education of one's children is a central role of being a parent. In order to participate in these activities, people with MS need educational institutions to accept their disabilities and accommodate their special needs. For example, they can allow people with MS to take classes in the morning when fatigue is less, reduce classroom temperature, allow tape recording or note takers for people with cognitive disabilities and provide distance learning opportunities.

9.1. Schools, colleges and other educational institutions must provide assistance for people with MS when needed, to enable them to pursue education to the extent of their abilities. [15,19]

9.2. Schools, colleges and other educational institutions must be physically accessible to people with disabilities, including people with MS.

9.3. Schools must provide assistance to parents with MS when needed so that they can participate in their children's student programmes, in school volunteer activities, and in parent-teacher conferences.

10.0 Housing and Accessibility of Buildings in the Community

Accessibility, both of public buildings and in the availability of accessible homes and apartments, is essential to independence for people with MS.

Because many people with MS have disabilities that limit their mobility and require use of ambulatory aids, scooters and/or wheelchairs, a great deal of housing and buildings in the community are not accessible or easy to use.

For example, buildings and homes that require going up and down stairs often mean that substantial parts of the house or building cannot be used by a person in a wheelchair. A basic need for people with MS is for housing and buildings that address their special concerns and provide access to services they need and activities they desire.

10.1. Housing

10.1.1. People with MS must have access to basic adaptations of their homes, to enable them to reside in the community as long as possible. [3,8,38,42,47,124,165,191]

10.1.2. People with MS must not be restricted from loans, grants, or other forms of financial assistance for making home adaptations because of their disease. [3,8,38]

10.1.3. A significant proportion of all new housing must be accessible from initial design and construction and not require adaptations to achieve accessibility for people with MS. [3,8,38,191]

10.2. Accessibility of Buildings in the Community

10.2.1. Buildings in the community, especially government offices and educational settings, must be accessible to people with MS. [8,47,57]

10.2.2. New public buildings must be designed and built for accessibility to people with MS and other disabilities. [3,8,57]

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Annex 1. WHO QOL Domains Matrix

	Physical Health	Psychological Health	Level of Independence	Social Relations	Environment
1.1			✓	✓	✓
1.2			✓		✓
1.3			✓		✓
1.4			✓		✓
1.5	✓	✓	✓	✓	✓
1.6					✓
2.1.1	✓	✓			✓
2.1.2	✓	✓			✓
2.2.1		✓			✓
2.2.2	✓	✓	✓		✓
2.3.1	✓	✓			✓
2.3.2	✓	✓			✓
2.3.3			✓		✓
2.3.4	✓	✓			✓
2.3.5	✓	✓			✓
2.3.6	✓	✓	✓	✓	
2.4.1	✓	✓			✓
3.1			✓		✓
3.2			✓		✓
3.3					✓
4.1	✓	✓			✓
4.2	✓	✓			
4.3	✓	✓			✓
5.1		✓			✓
5.2		✓			✓
5.3	✓	✓			✓
5.4		✓			✓
5.5		✓			✓
5.6	✓	✓			✓
6.1			✓		✓
6.2			✓		✓
7.1			✓	✓	✓
7.2			✓	✓	✓
7.3			✓		✓
7.4			✓	✓	✓
7.5			✓	✓	✓
8.1			✓		✓
8.2			✓		✓
8.3			✓		✓
9.1			✓		✓
9.2			✓		✓
9.3			✓		✓
10.1.1			✓		✓
10.1.2			✓		✓
10.1.3			✓		✓
10.2.1			✓		✓
10.2.2			✓		✓

Annex 2. Number of supporting references by level of evidence

	Levels of Evidence					
Principle	1a	1b	2a	2b	3	4
1.1					22	9
1.2				1	8	10
1.3					3	4
1.4					6	1
1.5		3		2	24	15
1.6					9	7
2.1.1					5	2
2.1.2	1	9	2	9	17	43
2.2.1				4	6	9
2.2.2					4	8
2.3.1					4	15
2.3.2		7	2	5	11	41
2.3.3				1	1	1
2.3.4					3	5
2.3.5					7	6
2.3.6		3	2	4	11	10
2.4.1		6	1	8	18	43
3.1		1			6	6
3.2					3	4
3.3						
4.1		6		3	11	16
4.2		5		1	8	21
4.3					4	5
5.1				1	24	10
5.2				1	7	4
5.3				1	18	8
5.4				1	23	12
5.5				1	5	6
5.6				1	2	2
6.1					4	4
6.2					2	2
7.1					17	14
7.2					16	12
7.3					6	2
7.4					9	9
7.5					6	2
8.1					2	2
8.2					5	2
8.3					3	2
9.1					2	
9.2						
9.3						
10.1.1					5	3
10.1.2					3	
10.1.3					4	
10.2.1					3	
10.2.2					3	

Levels of Evidence

1a	Meta-analysis of randomized controlled trials
1b	Randomized controlled trial
2a	Controlled study, without randomization
2b	Quasi-experimental study
3	Non-experimental, descriptive study (e.g., comparative study, correlation study, case study)
4	Expert committee eport, opinion and/or experience of respected authority

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