

March 19, '08: **Principles to Promote Quality of Life of People with Multiple Sclerosis**

Category: ADDITIONAL MS Resource Sites

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What Does "Human Rights" Have to Do with MS?

Usually, the term "human rights" conjures up violations and atrocities, such as prisoners being tortured or genocide taking place in a far-away country. However, human rights have a broader purpose than simply protecting people from the worst things that can happen. To put it simply, human rights are about dignity and what needs to happen (or not happen) so that each person can live with the dignity that they deserve, simply because they are human.

What does that have to do with multiple sclerosis (MS)? Plenty. We did not become less valuable as humans when our immune systems started attacking our myelin and we became less steady on our feet, or slower to find our keys. However, in order for us to live our lives to the fullest and contribute the most we can to society, sometimes we need a little help.

We may need special medical care. We may need our workplaces adapted so that we can do our jobs. We may need transportation and public buildings to be made accessible so that we can get where we need to go and function once we get there.

We are not asking for special treatment. We are asking to let us be humans and do the things that humans do. It is in this spirit that the Principles to Promote Quality of Life of People with Multiple Sclerosis were developed by the Multiple Sclerosis International Federation.

Why Were the Principles Developed?

The introduction to the Principles states: "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 quality of life for people with MS..." In this context, the term "quality of life" is defined by the World Health Organization 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."

Basically, the Principles were developed so that we, people with MS, and those who work to make life better for us (doctors, MS organizations, researchers, and governments) have a set of common goals to strive for. This document captures these ideals in one place.

How Were the Principles Developed?

The Principles were developed by the authors, then reviewed by a group of experts convened by the MSIF. The authors conducted a series of interviews (with people with MS and doctors) and an extensive literature review, which included journal articles, MS clinical textbooks and web-based publications.

The Principles

1) 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.

2) Medical Care

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

3) 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.

4)Health Promotion and Disease Prevention

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

5)Support for Family Members

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

6)Transportation

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

7)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.

8)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.

9)Education

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

10)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.

Sources:

Principles to Promote Quality of Life of People with Multiple Sclerosis. Multiple Sclerosis International Federation.

The WHOQOL Group (1994) Development of the WHOQOL: Rationale and current status. *Int. J. Mental Health.* 23(3), 24-56.

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