

Project goal

To provide and disseminate an up-to-date global framework (based on evidence from people affected by MS, MSIF member organisations' experience, an updated literature review and input from medical and other professionals or experts) that supports local, national and international actions to improve the quality of life of people with and affected by MS.

Background

The Principles (produced in 2005) outline the gold standard of what people affected by MS need in order to have quality of life.

By examining available evidence from across the world, the Principles identify ten key factors that could help enhance the lives of people affected by MS.

Ten years on, the Principles are still being used by MSIF's member organisations to inform strategic plans and advocacy campaigns, and to prioritise the care and support services they provide. They are a highly valued and flexible international framework for national action.



Ten years on

The world has changed a lot since the Principles were first produced, as has the situation for people affected by MS. Now is the time to revisit and refresh the Principles to:

- bring renewed global attention to the ways life can be improved for people affected by MS **right now**
- incorporate recent developments such as the Convention on the Rights of Persons with Disabilities, new treatments for relapsing-remitting MS, use of social media etc.
- be more representative of gender, different regions, culture and contexts
- reflect the evolution of the way quality of life is understood and present new evidence on the topic

Who are the Principles for?

The Principles will be used by:

National MS organisations

For advocacy initiatives on a national level, strategic planning and to plan the development of their service and support programs.

People affected by MS

To evaluate and advocate for the services and support they need.

MSIF

For advocacy initiatives on an international level and to input into our strategy development, support WMSD and to enable us to speak out globally on behalf of people with MS and MSIF Member Societies by campaigning for improved services and support for people with MS.

Project plan

PHASE 1	PHASE 2	PHASE 3	PHASE 4
Initiation (complete)	Evidence review and global consultation to inform recommendations	Agree revised Principles, prepare publication and toolkit, seek endorsements and launch	Post launch support, promotion, monitoring and learning
December 2015 to January 2016	February 2016 to September 2016	September 2016 to May 2017	May 2017 onwards

The current 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 Benefits and Cash Entitlements

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.

Get involved

We want to hear your views on the current Principles. Are they still relevant? Are there any you think are missing?

Please get in touch and share your thoughts with Doreen McIntyre or Lynne Elliott
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For more general information about this project, please contact Ceri Angood
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Together we can make this already useful resource even more relevant, effective and impactful.