

Seven principles to improve quality of life with MS

Based on the insights and experience of
people affected by MS and the
organisations and professions who serve
them



“ Quality of Life means individuals’ 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 in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment. ”* - World Health Organisation**

The MSIF movement's call to action on quality of life with multiple sclerosis

Through extensive consultation with people from over 30 countries we have learned about what influences quality of life for people affected by multiple sclerosis (MS). We have taken stock of advances in the understanding of MS, diagnostics, and disease modifying treatments (DMTs), as well as rapid advances in technology and the growing global challenge of inequality. This inequality is evident both between and within countries, especially in relation to access to treatments.

The set of 'principles' detailed in this document serves as the MSIF movement's call to action on quality of life, identifying the main areas in which every bit of progress can make a real difference to individuals. It recognises that quality of life is highly personal and changeable, with many interdependencies, and that it is for individuals to determine what matters to them. The principles are reinforced by many global treaties and consensus frameworks shared by other movements, and are intended to inspire and challenge us all.

We invite everyone to use the principles in their own way:

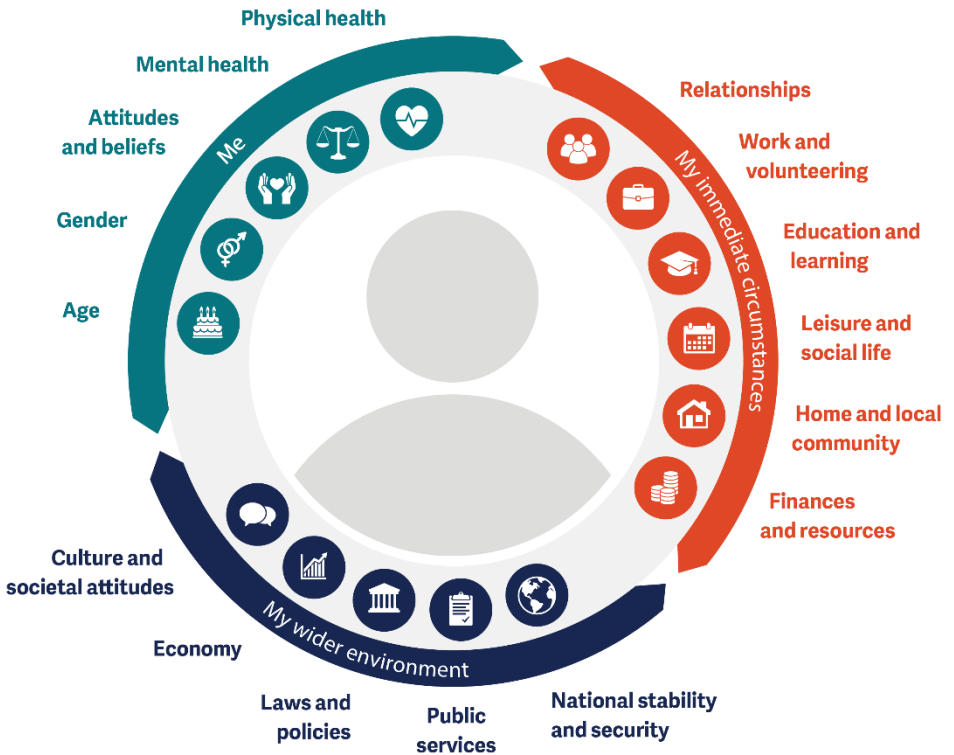
- **as individuals:** to think about our own quality of life and what we can do to enhance it, whether we have MS or know someone who does
- **as MS organisations:** in shaping and evaluating our strategies, programmes, advocacy and research

And we call on others to join us....

- **healthcare professionals and providers of services to people affected by MS:** to understand how what they do and how they do it affects quality of life
- **researchers and product developers:** to shape their investigations and the way they carry them out
- **Governments and health authorities:** to help shape laws, policies and actions.

What influences quality of life?

Many factors influence a person's quality of life, both inside and outside their direct control. These factors vary from person to person, from place to place and change over time. Multiple sclerosis (MS) can impact these factors at any time.



Seven principles to improve quality of life

The seven principles below are based on the insights and experience of people affected by MS and agreed by the MSIF movement. There is no priority amongst the principles – it is for individuals and organisations to decide what is most important to them at any time. No country can claim to have achieved them all. They are our call to action for continuous improvement in every country.

- Empowerment, independence and a central role for people affected by MS in decisions that affect their lives
- Access to comprehensive and effective treatments and care for the changing physical and mental health needs of life with MS
- Support for the network of family, friends, loved ones and unpaid caregivers
- Work, volunteering, education and leisure opportunities that are accessible and flexible
- Accessible public and private spaces, technology and transport
- Financial resources to meet the changing needs and costs of living with MS
- Supportive attitudes, policies and practices that promote equality and challenge stigma and discrimination

Empowerment, independence and a central role for people affected by MS in decisions that affect their lives

Why is this important?

This principle affects every aspect of quality of life. It includes freedom of thought; personal beliefs and values; the rights of every individual to self-determination. Its influence is broad, including social, professional and intimate relationships and opportunities to participate in society. It draws on insights from numerous health, welfare and political settings showing that quality of life is enhanced when people can participate fully in decisions that affect their lives and take responsibility for themselves. This means having the right information, skills, opportunities and a supportive context that recognises diversity in all its forms. Whilst independence and empowerment can mean different things to different people, they are often the first thing a person affected by MS talks about when considering quality of life.

Some key features:

- People affected by MS realise their full potential in all the aspects of life that are important to them
- People affected by MS participate in decisions about their treatment, care and lifestyle in line with their personal beliefs and values
- Services take into account the needs and priorities of the individual and are designed to be user-friendly
- Information about MS is trustworthy, up to date and directly accessible by people affected by MS
- People affected by MS shape and fulfil their roles and responsibilities within the family, community and wider world
- People affected by MS have leadership roles throughout the MS movement
- Personal wellbeing (including diet, exercise, sleep) and resilience-building are directed by the person affected by MS
- Spiritual support is accessible in line with individuals' beliefs and practices

Access to comprehensive and effective treatments and care for changing physical and mental health needs of life with MS

Why is this important?

MS has complex and numerous direct on physical and mental health. These impacts can be visible and invisible, and they can in turn affect other aspects of quality of life. The impacts and symptoms of MS vary from person to person both in nature and in severity, and they change over time. They can interact with a person's other health conditions. Treatments themselves can have side effects. For many people affected by MS, the mental and emotional health impacts are as important as the physical impacts.

Some key features:

- Early diagnosis, monitoring and review
- Multidisciplinary, integrated care planning with services provided close to where people live
- Age-appropriate and gender-sensitive information about MS, including the specific needs associated with MS in childhood and adolescence
- Choice of effective, accessible and affordable treatments to meet the varying needs, preferences and priorities of individuals with MS
- Service providers who listen to individuals' needs and respect the expertise that comes from lived experience
- Research for more effective treatments with fewer side effects and easier use as well as research to find ways to prevent, slow, stop or reverse the accumulation of damage and disability associated with MS
- Research on the barriers and facilitators to access including financial, cultural, administrative, and geographic barriers
- Accessible general healthcare, screening and preventive services including mental, sexual and reproductive health
- Psychological and emotional support as required including around diagnosis and decisions about the future
- Rehabilitation and palliative care services appropriate to the stage of life
- Individuals' privacy, confidentiality and sensitivities are respected

Support for the network of family, friends, loved ones and unpaid caregivers

Why is this important?

This principle recognises that the quality of life of a person with MS is closely linked to that of their families and other loved ones. When one is affected, so is the other. People affected by MS – spouses, partners, family members, close friends and unpaid caregivers – experience health, emotional, social and financial impacts of their own, which are usually under-recognised and poorly addressed in public policy and services. People with MS and people affected by MS can both become vulnerable to abuse, exploitation, discrimination and stigma. The principle also acknowledges that people with MS often have caregiving roles themselves.

Some key features:

- Family members are recognised as individuals with their own quality of life needs
- People have access to support with personal and sexual relationships and their changing dynamics
- The care-giving role is understood, acknowledged, valued and financially supported
- Child and adolescent caregivers get special attention to protect their education, health, social and personal development
- Care and respite services are designed in ways that respect the personal time of family members
- Individuals' personal privacy, confidentiality and sensitivities are respected
- Funding is available for professional assistance with personal care
- People with MS and people affected by MS each have opportunities to expand their own social networks
- Health policy research addresses the composition of the support network and strategies to enhance it

Work, volunteering, education and leisure opportunities that are accessible and flexible

Why is this important?

This principle focuses on some of the links between aspects of the external environment and elements of quality of life that contribute to a person's sense of self-worth, independence and belonging. Rights to education, work and leisure are recognised human rights. Participating in these activities as equals empowers and enables people with MS to contribute as valued members of the family and wider society. Participation also enhances visibility and public understanding of MS, which in turn contributes to removing stigma and discrimination.

Some key features:

- Rights to work and study are protected
- Educated and informed employers; accessible workplaces and flexible working practices
- Access to career advice, training and professional development opportunities
- Educational institutions are accessible and have flexible approaches to learning and assessment processes
- Leisure, sport and social facilities are accessible and welcoming (encouraging, promoting participation)

Accessible public and private spaces, technology and transport

Why is this important?

This principle enables participating in many of the other principles – getting around easily at home and outside is important for participating in society, relationships, education, work and leisure activities. Physical barriers or complex systems for accessing buildings and transport are common, even in health facilities, and having to rely on other people for assistance compromises independence. Online or virtual public spaces are increasingly important and require similar attention to accessibility.

Some key features:

- Rights to choose where to live and to decide when to move to accessible accommodation
- Housing that is designed or adapted and equipped to suit changing needs and preferences
- Transport that is accessible for a range of needs – not just for wheelchairs: seating, support rails, trained operators
- Public buildings – civic, commercial, healthcare, leisure, places of worship - that are designed or adapted and managed to be accessible for a range of needs – not just for wheelchairs: toilets, rest spaces, door design, trained staff
- Welcoming and non-discriminatory attitudes
- Digital and mobile technology and services that provide increased opportunities for people affected by MS, and are accessible and usable by people with a range of impairments

Financial resources to meet the changing needs and costs of living with MS

Why is this important?

This principle is relevant to almost every aspect of quality of life. People affected by MS experience substantial financial costs – for medicines, care, adaptations (such as walking aids, assistive computer software, adaptations around the home) and transport. Many household budgets cannot cope with these impacts and other expenditure suffers. In many countries, households that rely on government benefits often remain on the poverty line. These financial strains can impact on family relationships and increase isolation.

Some key features:

- The full financial impact of MS is researched and understood, including underlying factors and implications for policy and practice
- People with MS can earn their own living and manage their own finances
- Financial services (banking, investment planning and borrowing advice) are available for people affected by MS
- Government assistance and insurance programmes are designed to meet the variable financial needs of those with and affected by MS
- MS is recognised as a qualifying condition for government assistance and other relevant benefits such as subsidised public transport

Positive, supportive attitudes, policies and practices that promote equality and challenge stigma and discrimination

Why is this important?

This principle focuses on the role of the external environment in affecting quality of life, emphasising the importance of explicit attention to equality issues. MS is relatively uncommon, poorly understood by policy makers and service providers and often has invisible symptoms, increasing the likelihood that needs will be overlooked. Many countries lack even basic data on MS prevalence. Lack of societal understanding of MS increases vulnerability especially for people already facing risk related to gender, sexuality, poverty, race or social status.

Some key features:

- Health professionals, support workers, employers, educators and the general public are aware of MS and understand their role in promoting the Principles
- Legislation and policy that promotes dignity for all
- Investment of public resources in reducing inequalities associated with MS
- Inclusion on electoral registers and accessible voting systems
- Inclusive approaches to innovation in communications, infrastructure and other technology development
- Attention to vulnerability and exclusion issues in research and policy-making

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MSIF Quality of Life Principles Work Group

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Read more about the insights behind this work and the many people who contributed to it by visiting:

www.msif.org/seven-principles-to-improve-quality-of-life/.

About the MS International Federation (MSIF)

The MSIF movement is a unique global network of MS organisations, people affected by MS, volunteers and staff from around the world.

Multiple sclerosis (MS) is a condition of the central nervous system (the brain and spinal cord) with no known cause or cure. Around 2.3 million people worldwide are living with MS and many of these people have little access to the support they need.

Our vision is a world without MS

Our mission is to inspire, mobilise and bring the world together to improve the quality of life of everybody affected by MS and to end MS forever

Find out more about our strategy, 'Together we're stronger than MS', here: www.msif.org/about-ms/our-strategy/.

Our members

