

# CHARTER OF THE RIGHTS

of Persons with Multiple Sclerosis  
and Related Disorders, their Families,  
and Carers

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# CHARTER OF THE RIGHTS

## of Persons with Multiple Sclerosis and Related Disorders, their Families, and Carers

### 1 Health

All individuals with MS and related disorders, their families, and carers, have the right to the highest level of health. This includes complete physical, mental, and social well-being in every phase of the disease and within all aspects of life. They have the right to be at the center of decisions that concern them and to receive care that is based on extensively integrated pathways and personalized individual projects.

### 2 Research

All individuals with MS and related disorders, their families, and carers, have the right to rigorous, excellent, and innovative scientific research. This research should be directed, promoted, and financed in a co-responsible manner by all stakeholders who share this mission towards personalized care. The right to research also implies scientific citizenship, meant as widespread knowledge about research and involvement in it for all citizens alongside affected individuals. This ensures full participation and the translation of research into concrete solutions for individuals and society.

### 3 Self-Determination

All individuals with MS and related disorders, their families, and carers, have the right to self-determination. This includes the ability to build and realize their own personal life projects with full autonomy. This right implies receiving support, enablement, and empowerment, including from their patient association, in accessing all available resources.

### 4 Inclusion

All individuals with MS and related disorders, their families, and carers, have the right to full and effective inclusion. This includes the ability to participate in intelligent and sustainable communities designed according to the principles of universal accessibility. They should have access to necessary and appropriate measures, support, and reasonable accommodations, while being protected against any form of discrimination, including multiple discriminations.

### 5 Employment

All individuals with MS and related disorders, their families, and carers, have the right and duty to contribute to the progress of society through dignified, freely chosen and maintained, inclusive, secure, and flexible work. They should be able to reconcile their life and health needs with work commitments and have full access to any appropriate and necessary reasonable accommodation.

### 6 Education and Training

All individuals with MS and related disorders, their families, and carers, have the right to receive inclusive and equitable education and training, including guidance on opportunities to acquire skills for volunteer and civilian service in the community. They should be able to reconcile their life and health needs with educational and training paths through full access to all appropriate accommodations.

### 7 Simplification

All individuals with MS and related disorders, their families, and carers, have the right to simple and prompt processes and services. This includes access to inclusive digital environments that enable them to exploit available opportunities. They have the right to access benefits and services they are entitled to through rational procedures, allowing them to comply with all relevant obligations in a streamlined way and free of charge.

### 8 Innovation

All individuals with MS and related disorders, their families, and carers, have the right to innovation in contexts and domains relevant to their full inclusion and quality of life. Innovation should occur within a framework of sustainable development, equality, and ethical use of technology. It should also promote and enhance partnership models between the public and private sectors, ensuring immediate and direct returns to individuals by generating social impact.

### 9 Information and Communication

All individuals with MS and related disorders, their families, and carers, have the right to access correct, clear, timely and enabling information. This information should be built and disseminated in response to the needs and expectations of the stakeholders. They have the right to participate in the construction and dissemination of information that focuses on the disease, responses provided by services, research, rights and policies, and the role of MS Society. They should be protected from misinformation and have access to respectful and truthful communication about the disease and its impact on individuals and the community.

### 10 Active Participation

All individuals with MS and related disorders, their families, and carers, have the right and duty to actively participate in decision-making and the implementation of policies relevant to them as either individuals or groups, also through their representative Society. They should assume and maintain the role of the protagonist and ambassador of the rights outlined in this Charter and of the Multiple Sclerosis and Related Disorders Agenda, sharing the responsibility with all stakeholders.