



**BETH  
DIAGNOSED IN 2009**

**ACCESS  
TO HIGH  
QUALITY **MS**  
HEALTHCARE  
PRINCIPLES**



National  
Multiple Sclerosis  
Society



**JOE  
DIAGNOSED IN 2010**

Access to affordable, high quality healthcare is essential for people with multiple sclerosis (MS) to live their best lives. MS activists have been at the forefront of efforts to ensure people get the healthcare they need.

The rapid evolution of the healthcare system in the United States, inspired in part by MS activists, has led to significant progress in the care and treatment of people with MS. Individuals can no longer be denied enrollment into a health plan due to a pre-existing condition nor can they be charged more or be given fewer benefits due to having MS. Lifetime limits on the amount of insurance benefits a person may receive have been eliminated and there are caps on annual out-of-pocket healthcare costs that previously caused financial hardship.

Yet, much vital work remains to be done. MS medications are increasingly expensive and insurance coverage for the medications has become restrictive for some. Finding an MS specialist covered by one's insurance plan is becoming more challenging, as is locating sufficient coverage for maintaining physical function through services like rehabilitation and wellness coaching. There are also numerous disparities in care such as those related to race and ethnicity that prevent people from both routine and specialized care.

**The National MS Society and MS activists must continue to ensure that the voices of people affected by MS are heard and drive change wherever it's needed. To guide our work in achieving access to affordable, high quality care for all people with MS, the National MS Society's Access to High Quality MS Healthcare Task Force developed the following set of principles.** The experiences, concerns and hopes of people with MS are reflected within the principles, as extensive outreach was a core part of their development. These principles are the foundation of our actions and moving forward, the Society's advocacy, communication, programmatic and research strategies will reflect these firm beliefs.

Our ultimate goal of affordable, high quality healthcare may seem elusive, but it is within grasp if everyone affected by MS—including people accessing healthcare services, healthcare providers, patient advocacy groups, family members, pharmaceutical companies, insurance companies and health policy officials—commits to improving the system through a focused, collaborative effort. Together, our relentless resolve can help people with MS live their best lives.



**LEXI  
DIAGNOSED IN 2009**

NATIONAL MULTIPLE SCLEROSIS SOCIETY | **ACCESS TO HIGH QUALITY MS HEALTHCARE PRINCIPLES**

# 1

## **PRINCIPLE 1**

### **People with MS are at the center of their healthcare decision-making.**

**This principle is realized when:**

- People with MS have the information and resources they need to make informed decisions and advocate for their healthcare needs.
- People with MS and their healthcare providers have meaningful discussions to understand individual goals, needs and preferences and determine optimal treatments and strategies including wellness.
- The cost of healthcare services and treatment and what insurance plans cover are transparent, understandable and publicly available.
- People with MS are able to access information that describes the transactions and relationships amongst the organizations delivering healthcare.
- The effectiveness of healthcare services and treatments is known and understandable.



**CARLOS  
DIAGNOSED IN 2001**

# 2

## **PRINCIPLE 2**

### **People with MS have access to a comprehensive network of providers and healthcare services focused on producing the best outcomes at affordable costs.**

**This principle is realized when:**

- Benefits are comprehensive and include appropriate services, medicines, treatments, equipment, supplies and assistive technology.
- Rehabilitation and wellness services, including complementary and alternative approaches, are available to maintain optimal health and improve quality of life.
- A diverse range of healthcare providers with the experience and expertise to treat and manage the symptoms and complexities of MS, including out-of-network providers when medically appropriate, are available.
- Price and increases in prices are not barriers to accessing the optimal MS treatment for individual needs.
- Care is coordinated amongst all healthcare providers treating the person with MS.



**RONA  
DIAGNOSED IN 1986**

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# 3

## **PRINCIPLE 3**

### **People with MS have access to comprehensive health insurance plans with affordable premiums, deductibles and other out-of-pocket costs.**

**This principle is realized when:**

- A full range of FDA -approved MS disease-modifying therapies is covered including expenses associated with monitoring and delivery.
- Treatments that are effective for managing symptoms are covered whether they are FDA-approved for MS or used as an off-label treatment for MS.
- Insurance coverage is available for wellness-focused strategies including complementary and alternative approaches that have demonstrated benefit.
- Insurance appeals processes are standardized, easily navigated, and resolved in a timely manner with explained rationale.
- Care and treatment are continuous and uninterrupted during changes in insurance coverage, plan design and health provider networks.



**CARLOS  
DIAGNOSED IN 2001**

# 4

## PRINCIPLE 4

### **Healthcare providers have greater awareness, resources and tools to enable the timely diagnosis, treatment and symptom management of MS.**

This principle is realized when:

- Healthcare providers have information to aid in early symptom recognition, diagnosis and treatment, in consultation with MS specialists when necessary.
- Healthcare providers caring for people with MS have the most up-to-date information to competently manage the complexity of MS.
- Healthcare providers meaningfully discuss wellness interventions including complementary and alternative approaches with their patients.
- Reimbursements for healthcare providers reflect the expertise and time necessary to meet the complex needs of people with MS.



**WILLIAM  
DIAGNOSED IN 2002**

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# 5

## PRINCIPLE 5

**People with MS have access to and receive high quality ms care regardless of disparities including but not limited to disease progression, level of disability, geographic location, socioeconomic status, gender, sexual orientation, race/ethnicity, cultural background, age and care setting (home- and community-based or residential).**

This principle is realized when:

- Innovative tools and technology bridge geographic, linguistic and health literacy gaps and enhance access for people with severe physical and cognitive limitations.
- People with physical disabilities obtain care in healthcare settings with accessible equipment, exam tables, assistive technology and other necessary assistance at no additional cost and with the support of their insurer when needed.
- Healthcare services and providers deliver culturally competent care and meet the linguistic needs of individuals from diverse backgrounds.



**DAVID  
DIAGNOSED IN 1986**

# 6

## **PRINCIPLE 6**

**People with MS have access to high-quality long-term supports and services (including assistive technology) in settings that best meet their needs and prevent financial hardship for the individual and family.**

This principle is realized when:

- People with MS can choose from the full range of age appropriate and affordable home-based, community-based and facility-based health and social service options to meet individual needs and preferences.
- Family caregivers have adequate financial, emotional and practical supports including care management, counseling, training and respite care.
- People with MS access the medical equipment and assistive technology that maintains each person's highest level of functioning and independence.
- People with MS and their families can access a wide range of financial options and strategies to plan for the potential challenges of a long-term and costly chronic illness.



**SUSAN**  
**DIAGNOSED IN 1988**

The National MS Society's National Board of Directors adopted the Access to High Quality MS Healthcare Principles on November 7, 2014. The principles were developed by the Society's Access to High Quality MS Healthcare Task Force—a 13-member body consisting of people with MS, health policy and system experts, healthcare and service providers and Society staff. The experiences, concerns and hopes of people with multiple sclerosis were considered by the Task Force throughout the process and are reflected in the principles.

The National MS Society and MS activists must continue to ensure that the voices of people affected by MS are heard and drive change wherever it's needed. To learn more about this work and how you can be part of the solution, visit [www.nationalMSSociety.org/accesstocare](http://www.nationalMSSociety.org/accesstocare).



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