National Multiple Sclerosis Society
National Health Care Reform Principles

Kim, diagnosed in 2000

National
Multiple Sclerosis
Society

America's health care crisis prevents many people with multiple sclerosis from living as powerfully as they could. In response, the National Multiple Sclerosis Society is relentlessly working to shape the health policies of tomorrow. The Society has adopted new National Health Care Reform Principles to help move us closer to change.

1. Accessible health care coverage
2. Affordable health care services and coverage
3. Standards for coverage of specific treatments
4. Elimination of disparities in care
5. Comprehensive, quality health care available to all
6. Increased value of health care
7. Access to high-quality, long-term supports and services

America spends more per capita on health care than any other country. Despite this, millions of Americans are either underinsured or have no insurance, so access to the highest level of health care is limited.

Health care reform is considered one of the most pressing domestic issues in America today. Nearly all national political candidates and elected officials agree that the status quo is not acceptable. Widely disparate views exist on how to fix the current system. In this context, significant discussions will be focused on how a new system should be developed and what the critical criteria should be in designing significant and meaningful reform. We can achieve considerable savings within the current model to help address the important issue of covering the costs for the expansion of access to quality health care in any reformed model.

Nearly 50 million Americans do not have any health insurance, and many millions more have inadequate coverage, leaving both their health and financial security highly vulnerable. As currently structured, the American health care system is all too often inaccessible, unaffordable, inefficient, wasteful, uncoordinated and administratively complex. The time is right for systemic change.

People living with multiple sclerosis and other chronic conditions or disabilities are particularly vulnerable in our current system. A chronic disease such as MS means extra reliance on health care services in order to maintain or cope with the effects of a deteriorating condition. Multiple sclerosis has no cure and must be managed with a spectrum of preventive, medical, rehabilitative, mental-health and long-term care services to help affected individuals and their families.

1

PRINCIPLE 1
HEALTH COVERAGE SHOULD BE ACCESSIBLE TO ALL.

The reasons for the high number of people without health insurance in America today are most often related to two factors: 1) the high cost of coverage, which places it out of reach for many employers and families, and 2) medical underwriting, or the process by which many people are legally denied coverage due to their health status. Additionally, complex rules and paperwork requirements make it difficult for many to get covered and stay covered when changes occur in their workplace, family, residence or income.

We believe ...

- Access to appropriate public or private health coverage should be assured regardless of health or disability, employment status, age, claims history or risk.
- Coverage should be guaranteed renewable and portable.
- Waiting periods, pre-existing condition exclusion periods and other measures designed to prevent consumers from participating in insurance should be eliminated, or at least minimized as much as possible. (Achieving full population coverage would reduce the need for these.)
- Documentation requirements for initial and continued enrollment in public insurance programs should be streamlined and kept to a minimum.
- Individuals should become eligible for Medicare immediately upon qualifying for Social Security Disability Insurance benefits.

Tiffany, diagnosed in 2004

2

PRINCIPLE 2

HEALTH CARE SERVICES AND COVERAGE SHOULD BE AFFORDABLE TO ALL.

People with chronic illness or disability are especially likely to be underinsured. That includes people with high deductible health plans, Medicare beneficiaries who cannot afford the Part D "donut hole" or a supplemental policy, and those who must pay 25% or more in co-insurance for essential drugs. In a 2007 random survey of people with MS, 21% reported spending less on food, heat and other necessities to pay for health care needs and 22% did not fill prescriptions or skipped doses of medicine despite having insurance coverage. Insurance premiums become more affordable when based on the broad dissemination of risk through community rating and re-insurance methods, and sliding scales to help those at lower incomes.

We believe ...

- Premiums should reflect a broad distribution of risk and not disadvantage people due to poor health status or claims experience.
- Out-of-pocket costs including deductibles, co-pays and co-insurance amounts should be limited through measures that prevent financial devastation to those most in need of care.
- Provisions to support those who are most financially needy should be in place, such as annual caps on medical expenses, stop-loss provisions, sliding scales and negotiated payments.
- Guidelines for reasonable medical loss ratios on health plans should be standardized and enforced.
- Arbitrary coverage limits (e.g., allowable number of visits per year) and lifetime caps on benefits should be eliminated as these discriminate against people with chronic care needs.

Michael, diagnosed in 2004

3

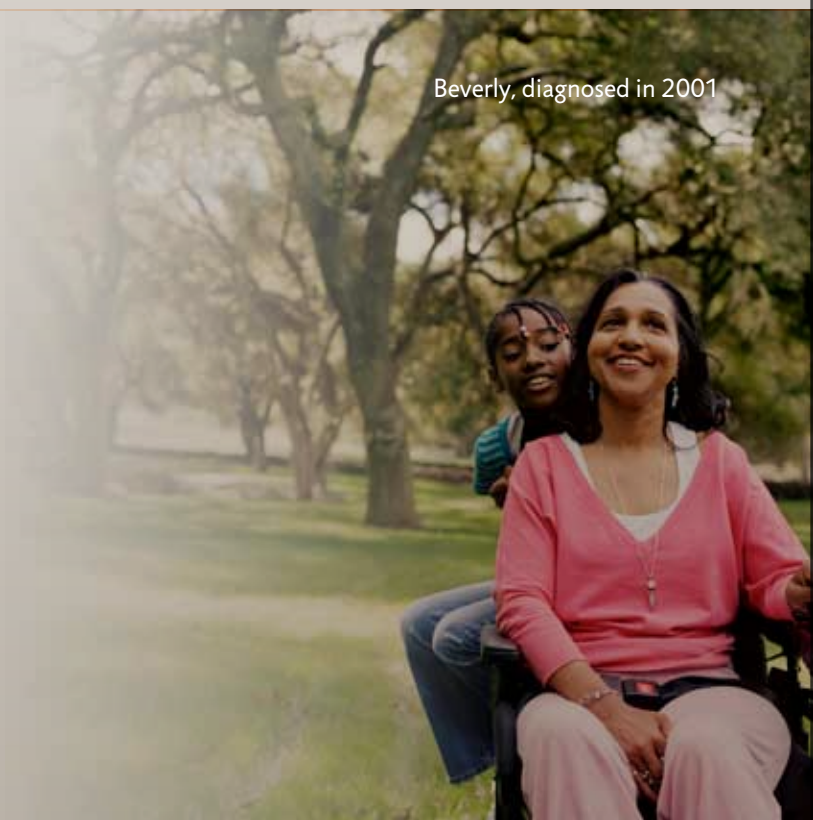
PRINCIPLE 3

STANDARDS FOR COVERAGE OF SPECIFIC TREATMENTS SHOULD REFLECT REASONABLE PROSPECTS FOR IMPROVEMENT AND/OR PREVENTION OF DETERIORATION.

Well-designed studies produce the scientific evidence necessary to continuously improve our understanding and promotion of quality MS care. Yet, when health plans condition coverage or reimbursement on overly strict standards of evidence, people with chronic and degenerative conditions are denied access to needed care. For example, much of the treatment for advanced MS, acute exacerbations and symptoms relies on patient access to new uses of proven therapies. Quality MS care demands a level of expertise and skill in the artful use of a wide range of clinical tools.

We believe ...

- Reimbursement authorization for "medically necessary" care should include therapies that help prevent physical and cognitive deterioration or maintain optimum functioning—even if "improvement" of the condition is not expected.
- All health plans should provide for timely and independent appeals including clear guidance to patients and providers on how to pursue them.
- Health plans should cover the patient-care costs of clinical trials and studies that increase knowledge of the comparative efficacy of existing therapies.
- Patient-centered care should enable health care providers to partner with their patients in clarifying treatment goals and methods and be supported in doing so with supportive payment methods.



Beverly, diagnosed in 2001

4

PRINCIPLE 4
DISPARITIES IN CARE SHOULD BE ELIMINATED.

Disparities in access to and outcomes of health services represent the failure to provide high quality care to all individuals. We deplore all disparities in care, whether based on ethnicity, economic status, geography, or disability. While health disparity is usually described as an issue of ethnicity or race, health disparities also exist in geographically underserved areas and for individuals with disabilities. It is difficult to access quality health care when providers or services do not have even basic accessible equipment, like accessible exam tables.

We believe...

- People with physical disabilities should have the same access to health care as others, accessible equipment and exam tables, assistive technology and appropriate assistance when needed should be available in all health care settings.
- Accessible transportation to needed providers and services, including appropriate specialist care, should be available.
- The same level of care and access to specialists should be available to all individuals seeking health care, regardless of whether the individual lives in an urban, rural or suburban setting.
- Telemedicine and other technologies should be used whenever appropriate to bridge the gaps in geographic disparities.

Tahirah, diagnosed in 2004

5

PRINCIPLE 5

COMPREHENSIVE, QUALITY HEALTH CARE SHOULD BE AVAILABLE FOR ALL INDIVIDUALS, AND THIS IS ESPECIALLY IMPORTANT FOR PEOPLE WITH CHRONIC DISEASES.

Continuity of care and timely access to appropriate medical providers help individuals with chronic diseases such as MS achieve and maintain optimal health and wellness. Models of care coordination (such as medical home, disease management and centers of excellence) that promote continuity of care and multi-disciplinary approaches to chronic care management improve care and reduce complications. Continuity of care is a key component to providing quality health care across the spectrum of complex conditions.

We believe...

- Health care services for individuals with chronic illnesses should include access to the full spectrum of health care needed throughout the person's life.
- Any coverage plan should include a set of comprehensive benefits to address the most common areas affecting people with chronic conditions, including but not limited to: medical care, prescription drugs, dental care, rehabilitation services, preventive care, hospital in-patient care, mental health, durable medical equipment and hospice care.
- Unfettered access to appropriate medical providers, including specialists, should be assured as it is essential to providing the best possible care at the earliest possible time for people with chronic illnesses.
- Provider reimbursement rates should be increased to reflect the complex care required to treat those with chronic illnesses, helping to ensure an adequate number of providers is available.

Chris, diagnosed in 1993

6

PRINCIPLE 6

THE VALUE OF HEALTH CARE SHOULD BE INCREASED THROUGH THE UNIVERSAL USE OF INTEROPERABLE ELECTRONIC MEDICAL RECORDS AND INCREASED EMPHASIS ON PREVENTION.

Enhancements to the coordination of care, particularly for those with complex chronic conditions, can produce improvement in quality care and increased efficiencies. This is possible through the adoption of proven standards, tracking progress and treatments across treatment settings, identifying and eliminating redundant services, avoiding contradictory treatments, and reducing medical errors. That will all be more feasible when we have universal utilization of interoperable electronic medical records. Further improvements to individual health can be realized through an increased focus on prevention and the recognition that we all have a stake in securing optimal health through individual and societal choices.

We believe...

- Interoperable electronic medical records should be standard system-wide. They should include rigorously enforced privacy standards and safeguards, and patients should be allowed to access their own records.
- Systems and reforms to reduce unnecessary or redundant procedures and treatments should be implemented, while maintaining the individual's rights and protections.
- Through more coordinated use of technology, current expenditures that put an unnecessary burden on the health care system through waste, fraud and abuse should be targeted and systematically reduced.
- Excessive administrative expenses should be limited to ensure that health care expenditures focus primarily on providing direct patient care, care management and education.
- People should have increased access to information, education, resources and environmental supports that help them to make healthier choices, understand and manage their own health care to the degree possible, and live healthier lives.

PRINCIPLE 7

PEOPLE SHOULD HAVE ACCESS TO HIGH-QUALITY, LONG-TERM SUPPORTS AND SERVICES (INCLUDING ASSISTIVE TECHNOLOGY) IN SETTINGS THAT BEST MEET THEIR NEEDS.

For people with chronic illness and disabilities, the need for long-term supports and services is a significant issue. Any health care reform that does not address the need to improve the provision of long-term care in America creates a false dichotomy between health care and long-term care. People living with chronic, disabling conditions understand fully that access to quality long-term supports and services is integral to maintaining optimal health. That is basic to the concept of ensuring a continuum of care throughout all the stages of life.

We believe...

- Reform should adhere to the Olmstead principles, which provide the basis for accessible home and community-based care support and services to allow people to be as independent as possible in the most appropriate integrated setting. Care coverage should include home modifications and equipment, which enable individuals to live at home as independently as possible.

- The importance of the role of the caregiver should be included in the design of adequate financial, emotional and practical supports including appropriate assessments, care management, counseling, training and respite care.

- The quality and quantity of home care and services should be improved through enhanced standards of quality home care and service and the elimination of barriers to a sufficient home health and services workforce, with a particular focus on wages.

- Broad-based mechanisms (including long-term care coverage and tax incentives) for averting personal financial devastation in the face of the enormous costs of long-term services should be developed and implemented.

- Access to assistive technology that allows individuals to maintain the highest level of functioning should be considered an essential part of a comprehensive health care plan.

- Skilled nursing home care, for those who most need this level of care, should be affordable and safe, with access to appropriate medical supervision, social support, and ombudsman protections. Reimbursement rates for these facilities should reflect the increased cost of providing care to people with disabilities.

Kim, diagnosed in 1986

The National Multiple Sclerosis Society's National Health Care Reform Principles were developed in collaboration by volunteers, chapter members, staff, health care professionals, and people living with MS who serve on the Society's Federal Activism Council. Our National Board of Directors approved these Principles on May 8, 2008.

Multiple sclerosis stops people from moving. The National MS Society exists to make sure it doesn't. We relentlessly advocate every day for community, state, and federal policies and programs that benefit the lives of people with MS.

To learn more about the National MS Society's positions on health care issues, visit www.nationalMSsociety.org/advocacy.

National Multiple Sclerosis Society

Chris, diagnosed in 1993