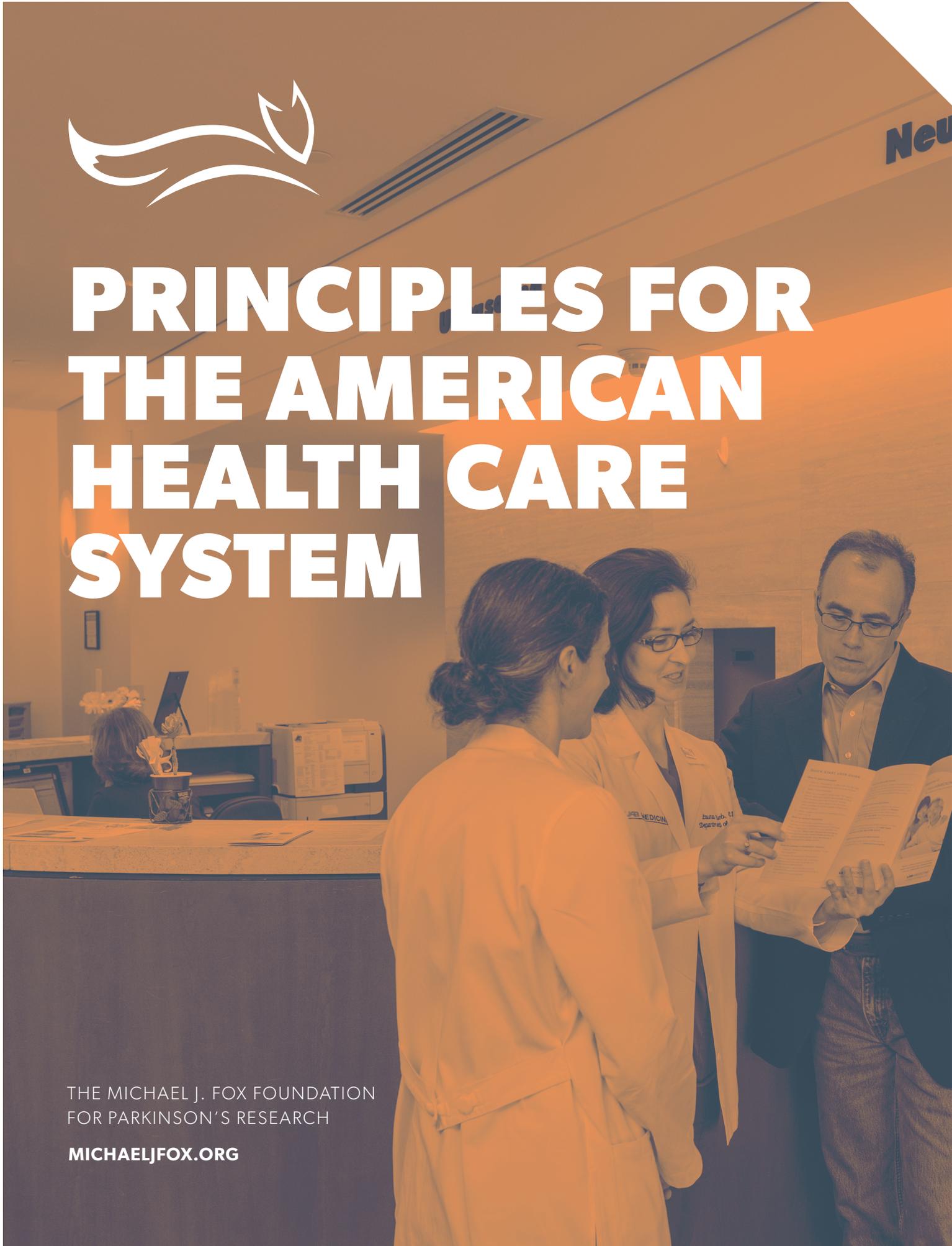




PRINCIPLES FOR THE AMERICAN HEALTH CARE SYSTEM

THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH

MICHAELFOX.ORG



Principle 1: Patient-centered care.

People with Parkinson's should be the primary focus of their health care, and the health care community should share the goal of improving quality of life for patients and their families.

Principle 2: Access to providers and health care services.

People with Parkinson's should have access to a network of knowledgeable providers and wide-ranging services in order to ensure they receive optimal treatment.

Principle 3: Comprehensive insurance coverage.

People with Parkinson's should have accessible, affordable and adequate coverage that meets their needs. They also are entitled to reasonable premiums and out-of-pocket costs.

Principle 4: Nondiscrimination.

People with Parkinson's should not be discriminated against due to their disease or other personal characteristics. These include — but are not limited to — age, gender, race, religion, ethnicity, cultural background, sexual orientation, gender identification, geographic location, level of disability or care setting. Patients should be treated with the utmost respect at all times.

Principle 5: Appropriate long-term care services and supports.

People with Parkinson's should have access to long-term care services and supports in a setting that suits their needs and does not create financial hardship.



Principle 1

PATIENT-CENTERED CARE

People with Parkinson's should be the primary focus of their health care, and the health care community should share the goal of improving quality of life for patients and their families. This occurs when:

- » Patients, caregivers and providers have meaningful interactions and participate in shared decision-making, resulting in a care plan that meets the patient's needs and provides relief from symptoms, pain, and physical and mental stress.
- » Providers educate patients and caregivers on the potential benefits and side effects of the appropriate treatment options.
- » Providers inform patients and caregivers about all aspects of disease management, including general wellness, exercise, medical and surgical treatments, complementary and alternative approaches, palliative and end-of-life care, and opportunities for clinical trial participation.
- » Patients and caregivers are provided with the educational resources necessary to make informed health care decisions and advocate for themselves; this includes non-pharmaceutical alternatives or adjunctive treatments, as well as attention to non-motor symptoms and other issues affecting quality of life.
- » Patients receive physical, occupational and speech therapy when necessary to treat symptoms, enhance quality of life and/or maintain function, even when therapy may not improve function.
- » Payers provide transparent and understandable information regarding the cost of treatments and health care services so patients can plan accordingly.
- » Patient privacy is respected under the assurance of Health Insurance Portability and Accountability Act (HIPAA) requirements.
- » Government regulators streamline the review and approval processes of new therapeutics while upholding rigorous standards that ensure efficacy and patient safety.

Principle 2

ACCESS TO PROVIDERS AND HEALTH CARE SERVICES

People with Parkinson's should have access to a network of knowledgeable providers and wide-ranging services in order to ensure they receive optimal treatment. This occurs when:

- » Patients are able to see, either in person or via telemedicine, providers who specialize in Parkinson's disease and its myriad of potential motor and non-motor symptoms. These include — but are not limited to — movement disorder specialists, allied health care practitioners (e.g., social workers, nurses, and physical, occupational and speech therapists) and other specialty providers (e.g., gastroenterologists, psychiatrists, etc.).
- » Care is coordinated by all providers involved in a patient's treatment plan, including those out-of-network when medically necessary and/or appropriate.
- » Providers have the latest information necessary to aid in diagnosis and management of Parkinson's disease.
- » Provider reimbursement reflects the expertise and time necessary to provide comprehensive Parkinson's care.
- » Telemedicine is used to the maximum extent possible, as this is a well-established, effective resource for delivering care.
- » Patients have access to prescribed medical and surgical treatments, durable medical equipment and other necessary health care services.
- » Cost sharing is not a barrier to care or treatment access, and medication 'tiers' do not discriminate against a patient based on their disease.*
- » Patients have access to emergency services, and emergency personnel are familiar with the symptoms and treatment of the disease.

*Cost sharing refers to out-of-pocket health costs patients must pay (e.g., co-pays, deductibles and co-insurance). Medication tiers are a means of categorizing drugs according to price, with medications in higher tiers costing more than those in lower tiers.



Principle 3

COMPREHENSIVE INSURANCE COVERAGE

People with Parkinson's should have accessible, affordable and adequate coverage that meets their needs. They also are entitled to reasonable premiums and out-of-pocket costs. This occurs when:

- » Insurance benefits recognize the continuum of Parkinson's care, including — but not limited to — outpatient, inpatient and mental health services; physical, occupational and speech therapy; medications and surgical procedures.
- » Food and Drug Administration (FDA)-approved diagnostics, drugs and devices for Parkinson's are available and affordable. Patients should have access to reasonably-priced branded drugs if the generic alternative is demonstrated to be less effective or tolerable in an individual.
- » Coverage includes exercise, wellness, nutrition, and complementary and alternative approaches that have been shown to be safe and efficacious.
- » Drug formularies (lists of prescription drugs covered by a specific health care plan) provide access to all available treatment options so health care professionals can choose the medication best suited for an individual patient.
- » Insurance premiums are not based on health status (i.e., people with pre-existing conditions, such as those with Parkinson's, cannot be charged higher premiums).
- » Payers make coverage decisions quickly, and standardized insurance appeals protocols are established.
- » Treatment continues uninterrupted during insurance coverage, plan design and/or provider network changes.
- » Neither annual nor lifetime caps on insurance coverage exist.
- » Reasonable annual individual and family out-of-pocket cost caps are established so that neither patients nor their families have to choose between medical care and other necessities.

- » Patients can make contributions to flexible savings accounts (FSA) and health savings accounts (HSA) that equal their maximum yearly out-of-pocket costs.*
- » Insurance plans are designed to cover a broad pool of individuals with varied health backgrounds, including people with and without chronic diseases. This allows premiums to be set at affordable rates for all members.

*FSAs and HSAs allow individuals to set aside pre-tax dollars to pay certain out-of-pocket health care costs.

Principle 4

NONDISCRIMINATION

People with Parkinson's should not be discriminated against due to their disease or other personal characteristics. These include — but are not limited to — age, gender, race, religion, ethnicity, cultural background, sexual orientation, gender identification, geographic location, level of disability or care setting. Patients should be treated with the utmost respect at all times. This occurs when:

- » Health care settings, including facilities, equipment, examination rooms and tables, are fully accessible, and assistive technology and/or services (e.g., interpreter) are provided at no additional expense.
- » Health care providers deliver culturally competent care that meets the needs of individuals from diverse backgrounds.
- » Mental health and substance abuse services are recognized as essential health benefits, and treatment and medication for these diseases are covered at a level equal to that of other medical illnesses.
- » Innovative tools and technologies (e.g., telemedicine) bridge geographic, linguistic, health literacy and disability gaps to enhance access, particularly for people with physical or cognitive limitations.
- » Those with pre-existing conditions (e.g., people with Parkinson's) cannot be discriminated against with a requirement of "continuous coverage."*

*Continuous coverage policies allow insurance companies to charge individuals higher costs if they have had a gap in health care coverage.



Principle 5

APPROPRIATE LONG-TERM CARE SERVICES AND SUPPORTS

People with Parkinson's should have access to long-term care services and supports in a setting that suits their needs and does not create financial hardship.* This occurs when:

- » Patients can choose from a range of appropriate and affordable options for home-, community- or facility-based long-term services that meet their needs, as well as those of their family and/or care partner.
- » Patients can maintain the highest level of independence possible with the assistance of durable medical equipment, ambulation aids, outpatient physical and occupational therapy, and home safety evaluations.
- » Caregivers have adequate resources, including training on how to support and care for a loved one with a chronic disease, respite care, counseling and financial management services.

*Long-term care refers to a range of medical and social services to assist with disease management and the completion of everyday tasks. This type of care can be provided in the home or community settings, or in assisted living or skilled nursing facilities.

For more information on these health care principles, please email policy@michaeljfox.org.

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