



Parkinson's Disease

Improving Treatment
While Working
Toward a Cure

By Mary Ann Chapman, PhD,
and David Charles, MD



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Introduction

More than 1 million people across the United States live with Parkinson's disease.

Parkinson's disease is a neurodegenerative condition characterized by tremor, rigidity, balance difficulties and slowness of movement.¹ These signs and symptoms stem from the loss of nerve cells that contain dopamine from motor control areas of the brain. As more of these nerve cells are lost over time, motor function worsens.

Research has shown that Parkinson's disease involves multiple areas of the brain and neural systems. This can result in non-motor symptoms, such as sleep difficulties, constipation, problems with smell, swallowing difficulties, speech difficulties, depression and anxiety, and cognitive problems.²

Although there is currently no cure for Parkinson's disease, researchers are working to find treatments to slow and eventually stop disease progression. In the meantime, many treatments are available to help control the symptoms, which can vary among patients and change over time.



Parkinson's disease is characterized by tremor, rigidity, balance difficulties and slow movement.

The Parkinson's Experience

Patients with Parkinson's experience the disease differently, based upon genetics, age of onset, disease stage and symptoms.



GENETICS

A minority of people have genetic variations that increase the likelihood of developing Parkinson's disease or, in rare cases, cause the disease.³ This genetic heterogeneity can affect the age of onset, how symptoms manifest and disease progression.³⁻⁵



AGE OF ONSET

Most people with Parkinson's disease begin to experience motor problems when they are in their 60s. Some people, however, experience problems much earlier.⁶ One notable example is actor-turned-Parkinson's-advocate Michael J. Fox, who was diagnosed with the disease when he was only 29 years old.⁷ Such cases are known as early onset or young onset Parkinson's disease. They are typically associated with a more difficult disease course and an increased likelihood of medication-related complications.⁶



DISEASE STAGE

Parkinson's disease typically begins with mild motor symptoms and progresses over the years to major, disabling motor symptoms. Over time, the medication most often used to control motor problems in Parkinson's disease, levodopa, becomes less effective. Patients then require higher doses. The dosage increase often causes motor problems of its own, particularly dyskinesias—uncontrollable, abnormal movements that can affect the face, hands, arms, legs, feet or torso.⁸ Patients may also experience new non-motor symptoms as the disease progresses, such as dementia, hallucinations and delusions.^{9,10}



SIGNS AND SYMPTOMS

The signs and symptoms of Parkinson's disease can vary markedly, even among people at the same disease stage. For instance, some people first notice a tremor in a hand, whereas others notice that their limbs are stiff and their movement is slower. Parkinson's disease has even been divided into different clinical categories based on variations in tremor, stiffness, balance, and non-motor symptoms such as cognition, sleep problems, hallucinations and delusions.¹¹ Parkinson's can also impact patients' mental health.



Treatment Options

Given the many different symptoms of Parkinson’s disease, as well as its progressive nature, different treatment options are needed to help optimize patients’ quality of life.

Current treatments may be grouped into:

- Exercise and rehabilitation
- Medications for motor symptoms
- Treatments for non-motor symptoms
- Deep brain stimulation
- Focused ultrasound



EXERCISE AND REHABILITATION

Exercise and rehabilitation approaches, such as physical, occupational and speech therapies, are recommended to treat Parkinson’s disease.¹²

Exercise improves balance, mobility and strength, and it helps alleviate both motor and non-motor symptoms.¹³ Physical rehabilitation provided by experienced, trained providers can reduce hip fractures, hospitalization and costs for people with Parkinson’s disease.¹⁴



MEDICATIONS FOR MOTOR SYMPTOMS

The primary medication for the motor symptoms of Parkinson’s disease is levodopa, a biochemical that the brain uses to make dopamine. The combination of levodopa and carbidopa (an enzyme inhibitor) dramatically improves motor symptoms of Parkinson’s disease. The combination has been the most common treatment for Parkinson’s since the 1960s.¹⁵

As Parkinson’s disease progresses, however, levodopa becomes less effective. Patients require higher and more frequent doses to prevent the return of symptoms, known as “off” time.⁸ This has led to the development of different levodopa formulations to prolong patients’ relief or to bridge the gap between regular doses.¹⁶ These include extended-release levodopa preparations that are taken orally, inhaled formulations of levodopa designed to act rapidly and continuously infused levodopa administered via an external pump.

These novel medications can significantly improve the patient experience. For instance, patients who have difficulty swallowing can benefit from an inhaled medication.

Many other medications, some of which have different mechanisms of action, treat the motor symptoms of Parkinson's disease. They are often added to an existing levodopa /carbidopa regimen.²



TREATMENTS FOR NON-MOTOR SYMPTOMS

A variety of treatments are also available for Parkinson's non-motor symptoms.²

Neuropsychiatric symptoms, for example, are common in Parkinson's disease.⁹ Pimavanserin is a medication that is approved in the United States to treat hallucinations and delusions associated with Parkinson's disease. Constipation can be treated with fiber, stool softeners and laxatives. Low blood pressure, known as orthostatic hypotension, can be treated by increasing water and salt intake and wearing compression stockings. Although not specifically approved for Parkinson's disease, the medications modafinil and methylphenidate have been used for fatigue and daytime drowsiness, and antidepressant medications known as selective serotonin and norepinephrine reuptake inhibitors have been used for depression and anxiety.²



DEEP BRAIN STIMULATION

Another treatment option is deep brain stimulation, a surgical procedure in which tiny electrodes are implanted in a motor region of the brain. The electrodes are controlled by a pulse generator—a device similar to a heart pacemaker that's implanted under the skin in the upper chest. When turned

on, the device delivers electrical pulses that alter brain activity and help improve motor signs and symptoms.¹⁷ Although deep brain stimulation is typically used in patients with mid- and advanced-stage Parkinson's disease, it is being studied for use earlier in the disease with promising initial results.¹⁸



FOCUSED ULTRASOUND

In focused ultrasound, acoustic energy is delivered through the head to a precise location in the brain, without an incision. The acoustic energy creates a lesion in the brain tissue. When administered to the brain's thalamus, focused ultrasound reduces tremor associated with Parkinson's disease,¹⁹ and it is currently being studied for use in other brain areas and motor symptoms.²⁰

Given the heterogeneity of Parkinson's disease and the multitude of symptoms that patients experience, it is important that many different treatments are available. Indeed, patients with Parkinson's disease typically receive a combination of treatments that are designed to address their individual constellation of symptoms to help optimize their quality of life.

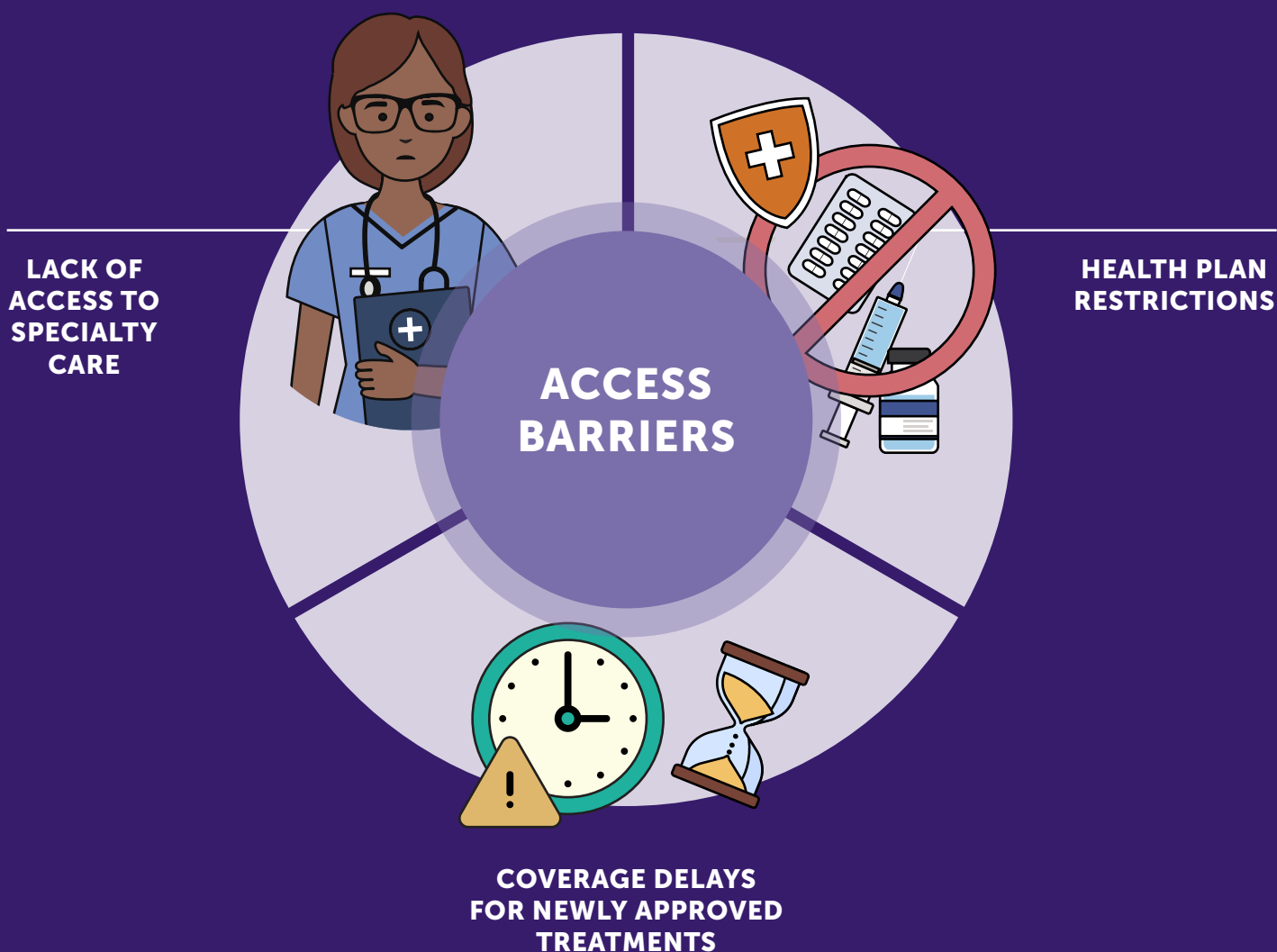
All treatments have the potential for side effects. Some, such as sore muscles after exercise, are mild. Others can be major or even life threatening.

Physicians prescribe medications for patients because they believe the benefits outweigh the side effects. It is important for patients and physicians to discuss the advantages and disadvantages before beginning any treatment.

Access Barriers and Patient Care

Although there are many effective treatments for Parkinson's disease, they are useful only if patients can access them.

Barriers faced by patients with Parkinson's disease include lack of access to specialty care, health plan restrictions, and the lag between when a treatment is approved and when it is first covered by insurance.





LACK OF ACCESS TO SPECIALTY CARE

Parkinson's disease is a difficult condition to manage because of its complexity, including its different motor and non-motor symptoms and its progressive nature. Given this complexity, Parkinson's disease patients who are treated by neurologists and movement disorder specialists have the best outcomes and live the longest.²¹ But only about 50% of Parkinson's patients receive treatment from general neurologists, and an additional 9% receive treatment from movement disorder specialists.²² Furthermore, only 20% of Parkinson's disease patients receive physical therapy, and fewer than 10% receive occupational and speech therapy.⁹

These alarming numbers suggest that many Parkinson's disease patients in the United States don't receive optimal care. Moreover, several treatments for advanced Parkinson's disease, such as deep brain stimulation and focused ultrasound, are typically available only from movement disorder specialists at large medical centers.



HEALTH PLAN RESTRICTIONS

Another barrier faced by patients with Parkinson's disease is access to newer medications that have advantages over their older counterparts but typically cost more. One example is pimavanserin, a medication approved by the Food and Drug Administration to treat hallucinations and delusions related to Parkinson's disease.²³

Through the use of prior authorization and specialty medication tiers, health plans restrict access to pimavanserin.²⁴ They instead steer patients toward lower-cost antipsychotic medications that lack proven efficacy,²⁵ have adverse cognitive effects²⁶ or require frequent monitoring for a life-threatening blood condition.²⁷

Another example is the medication amantadine. It is available in several different formulations, including

an immediate-release medication that is typically taken several times per day and an extended-release formulation that is taken once at night. The extended-release formulation improves control of motor symptoms,²⁸ and does not produce the adverse side effects observed with high doses of the immediate-release formulation.²⁹ However, because the older, immediate-release formulation is cheaper for insurers, they typically limit access to the innovative extended release medication through utilization management tools, limiting access to patients who could benefit from treatment. This type of utilization management is common for innovative Parkinson's treatments.



COVERAGE DELAYS FOR NEWLY APPROVED TREATMENTS

Once new treatments for Parkinson's disease are approved by regulatory authorities, there can be a substantial delay before they are available to patients. An example of this is patient access to newly approved infusion therapies. As Parkinson's disease progresses, patients typically require treatment options beyond oral levodopa to help minimize dramatic motor fluctuations that swing between extremely slow movements and uncontrollable dyskinetic movements. One method that helps reduce these swings is to deliver levodopa continuously into the intestine through a small external infusion pump. Additional medications for Parkinson's disease are also being developed for delivery via an infusion pump.

But a new rule from the Centers for Medicare and Medicaid Services jeopardizes patient access to pump therapies.³⁰ As a consequence, patients with Parkinson's disease may experience substantial delays in obtaining pump therapies that are currently in development or planned for the future. Delays of up to one year may be expected because of the time that passes between when the FDA approves new pump therapies and when major insurers begin covering it. Other times, commercial health insurers utilize tools like new-to-market exclusions to delay access to newly FDA-approved therapies. Such long delays are unacceptable.



Policy Solutions



DEVELOP A MULTI-PART STRATEGY FOR BETTER ACCESS TO SPECIALTY CARE

The lack of access to specialty care requires a multi-part strategy. This could include improved access to telehealth for under-served patients, incentives for young physicians to specialize in neurology and movement disorders, and expansion of programs such as Project Echo that pair local physicians with specialists.³¹

Insurers should minimize practices that limit access to new medicines and instead prioritize optimal and patient-centered health care. Meanwhile, state and federal policymakers must pass restrictions on these types of health plan tactics in order to ensure patients can access—and afford—their treatments.



ACCELERATE ACCESS TO NEW PARKINSON'S MEDICATIONS

New medications are on the horizon, both in early- and late-stage development for Parkinson's disease, and it is critical that patients can access these as soon as they are FDA approved. Meanwhile, insurers must prioritize quicker coverage decisions that allow FDA-approved therapies to benefit patients.



RESTRAIN UTILIZATION MANAGEMENT PRACTICES

Health plans' utilization management tools like prior authorization, step therapy and specialty medication tiers make it difficult for patients to access new medications that could dramatically improve their lives.

Conclusion

Parkinson's disease is a heterogeneous condition, characterized by differences in genetics, age of onset and symptoms that change over the course of disease. Numerous treatments are available for both motor and non-motor signs and symptoms, and a variety of new treatments are in development.

Given that new treatments often have important advantages, patients need access to them in a timely manner. Addressing barriers such as insurance restrictions and lack of access to movement disorder physicians will help optimize care for people with Parkinson's disease, who already face daunting challenges in their daily lives.



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About the Authors

Mary Ann Chapman, PhD, is a scientific writer based in Mead, Washington.

David Charles, MD, is a practicing neurologist and chief medical officer of the Alliance for Patient Access.



The **Movement Disorders Policy Coalition** brings together advocacy groups, health care providers, patients and other stakeholders to inform policy impacting patient-centered care for people living with movement disorders.



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