



Why Medicare Matters for Movement Disorders



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Introduction

Forming the right words to say, holding a cup of coffee without spilling, or getting ready for work using a comb or razor—these are movements that most Americans repeat on a daily basis without a second thought. But for people living with movement disorders, an array of treatments, medications and therapies are required just to accomplish these everyday tasks.

Movement disorders are neurological conditions marked by abnormal body movements or slow, reduced movements. Spasms, tremors and lack of coordination are hallmark symptoms of movement disorders like Parkinson's, Huntington's and Tourette's syndrome. Lesser known but prevalent movement disorders like essential tremor and tardive dyskinesia are marked by uncontrolled trembling or twitching, respectively. Innovative medicine has raised hope for increased quality of life, though most

movement disorders have no cure and require lifelong medical intervention.

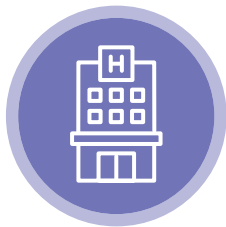
Medicare coverage is vital to address the spectrum of health care that these patients need. Seniors represent the majority of Americans living with movement disorders, though some people under the age of 65 with disabilities also qualify for Medicare because they rely on Social Security Disability Insurance. This may include people for whom the physical or mental health impact of movement disorders makes them unable to work.

Medicare must ensure treatment not only for the obvious physical symptoms but also related challenges. These include the serious mental health disorders that often accompany movement disorders and the financial challenges patients face in paying for treatment.

Medicare & Movement Disorders

A wide range of movement disorders exist. From Huntington's to dystonia, essential tremor to ataxia, movement disorders vary from patient to patient and have multiple symptoms that can proliferate over time. Options for treatment also run the gamut, ranging from physical and occupational therapy and speech-language therapy to oral medications, biologics, provider-injected medications and surgery in some instances.¹

Each part of Medicare addresses a different area of need.



Medicare Part A

Medicare Part A's coverage for hospitalization is essential, as many movement disorders progress over time. The longer a patient lives with a movement disorder, the more frequently he or she will experience episodes of dyskinesia, motor fluctuations, falls and cognitive impairment. The hospitalization rates of patients with Parkinson's, for example, are higher than that of their peers.²



Medicare Part B

Medicare Part B covers injected or infused drugs provided in a physician's office or inpatient setting. Part B is critical because botulinum neurotoxin injections can be used to both ease pain and relax overactive muscles in Huntington's or Parkinson's patients. They are also a first-line treatment for cervical dystonia.



Medicare Part D

Medicare Part D allows doctors to prescribe a wide range of medications to help patients manage the symptoms of movement disorders. Access is critical. For example, Parkinson's patients may be unable to work, travel, exercise, or maintain social connections to friends and family without medications to manage symptoms.

Medicare coverage must be comprehensive and flexible enough for patients and their health care providers to work together to tailor treatment plans, adjusting them over time.

In particular, policymakers must ensure that patients can access the Part D medications that are right for them—and that they can manage the out-of-pocket costs for treatment.



Comorbidity & Part D's Six Protected Classes

Medicare Part D provides important coverage for the treatment of both physical and mental aspects of movement disorders.

MOVEMENT DISORDERS & MENTAL HEALTH

In as many as 40% of cases, people with movement disorders experience mental health issues ranging from depression and anxiety to severe psychosis.

Abnormal movement symptoms and mental health symptoms may exacerbate one another, and a mental health condition can even result in a movement disorder. For example, some treatments for conditions like psychosis can result in tardive dyskinesia, a movement disorder characterized by repetitive, involuntary movements of the face and limbs.³

MAINTAINING ACCESS TO MEDICATION

Medicare prescription drug plans currently must cover all medications in six specific drug classes, which include antidepressants and antipsychotics. This is a life-saving protection for movement disorders patients, who already suffer

with physical symptoms and social difficulties as a result of their need for continuous care.

Nevertheless, this provision of Medicare Part D is a frequent target for cost-cutting reforms. Most recently, in 2019, policymakers looked to cut some of the six protected classes' protections, but public outcry managed to stop any changes from occurring. Proposals to reduce protections for the six drug classes also arose in 2018, 2015 and 2014.⁴ This trend suggests that the threat is far from over.

Ironically, cuts to the six protected classes may not even provide significant cost savings. A recent study showed that, in 90% of cases, patients select low-cost generic drugs from among the medications covered in the six protected classes.⁵

Variability in how movement disorders manifest makes it critical for doctors to tailor treatment to each individual patient. **By maintaining protections for the six classes, policymakers can continue to support personalized, patient-centered care for people with movement disorders.**

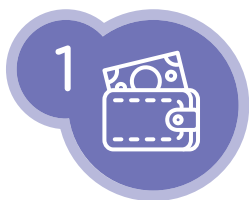


Keeping Patients' Costs Down

Seniors are hard hit financially by movement disorders because these conditions often present late in life and can worsen over time. The need for movement disorder medications and treatments can increase over time, though many seniors rely on a fixed income.

Meanwhile, people under age 65 who rely on Medicare because of disability may face even more dire financial challenges. In addition to cognitive or mental health challenges, they are more likely than older beneficiaries to live on a low annual income.⁶

To protect both groups of beneficiaries, policymakers can contain out-of-pocket costs, keeping expenses low and consistent. At least three important policy provisions could ease the financial burden on these patients.



First, policymakers can establish an **out-of-pocket cap** on spending for the Part D prescription drug plan.

Under most commercial and exchange health care plans, patients are protected from high costs by an out-of-pocket maximum. Medicare Part D, however, has no such caps on out-of-pocket spending.

This leaves people with movement disorders vulnerable. In 2020, the maximum Part D deductible is \$435, which beneficiaries must pay out of pocket before coverage under Part D starts. Coverage applies until a patient spends over \$4,000 for the year on medication, at which point they hit the “donut hole.” Here, only a portion of prescription drug costs are covered.

Patients who need expensive treatments can spend thousands in the donut hole before catastrophic coverage kicks in. Even then, they are saddled with 5% of costs during the catastrophic phase. This can mean thousands of dollars; one study showed 45% of beneficiaries spent over \$1,000 in one month, and nearly 20% spent \$2,500 in one month.⁷

Movement disorders can be expensive to treat. Patients have varied symptoms that can develop and change unpredictably over time, introducing the need for novel medications, biologics and even chemotherapies to manage their symptoms. A full 90% of Parkinson’s patients have periods where symptoms re-emerge even while on medication.⁸



Second, in addition to capping out-of-pocket costs, policymakers can make peoples’ expenses more predictable and manageable

through a measure called **out-of-pocket “smoothing.”**

This policy would apply a payment-plan approach, spreading beneficiaries’ prescription drug spending evenly across the year. Smoothing would protect Medicare beneficiaries from unmanageable bills at the pharmacy counter, especially early in the year before they’ve met their annual deductible.

Seniors demonstrate strong support for proposals that would make Medicare Part D more affordable. In fact, 75% of adults support

limiting what beneficiaries pay out of pocket in the Part D program.⁹

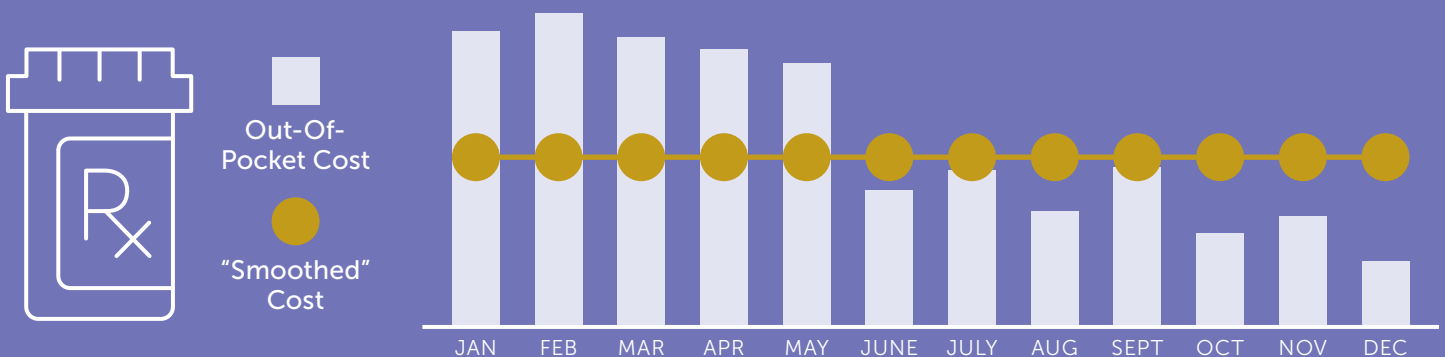


Third, policymakers could revisit existing restrictions on Medicare beneficiaries’ use of **co-pay cards** to reduce the out-of-pocket expense of their medication.

For patients on commercial health plans, co-pay cards can be obtained from their health care provider or online through the drug manufacturer’s website. When presented at the pharmacy counter, these cards help to pay down the co-pay required by the patients’ insurance company. Without these discounts, some patients would be unable to access their medication.

Medicare patients are prohibited from using co-pay cards, however, because the Office of the Inspector General interpreted them to violate federal anti-kickback laws. Revisiting policies on co-pay cards could significantly improve some patients’ ability to access their prescription medication and adhere to the regimen they’ve been prescribed.¹⁰

PRESCRIPTION DRUG OUT-OF-POCKET “SMOOTHING”



Conclusion

Medicare offers critical coverage for people with movement disorders. To continue providing for these patients' wide range of health care needs, policymakers must protect existing safeguards and ensure access to necessary drugs and treatments. That includes:

- Guarding the six protected classes policy
- Implementing out-of-pocket caps and smoothing measures
- Easing restrictions on Medicare beneficiaries' use of co-pay cards.

With thoughtful policies that protect the needs of Medicare patients for the long term, policymakers can ensure that patient-centered care and quality of life stay within reach for people with movement disorders.

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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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