# Rising medication costs for patients with neurologic disorders

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Costs for health care are rising in the United States, <sup>1</sup> and high drug prices are a large part of those costs. These prices, even for some drugs that have been available for a long time, are growing faster than other health care costs. In addition, the way patients pay for care has changed. In the last few years, high-deductible health insurance plans are more common. This means that patients are paying more out-of-pocket than they would have before. Rising costs of medical care, higher drug prices, and more out-of-pocket expenses means the topic of drug costs is important to patients.

## What did the authors study?

In their article "Out-of-pocket costs are on the rise for commonly prescribed neurologic medications," Dr. Callaghan and coauthors<sup>2</sup> studied how the cost of drugs used for neurologic diseases changed between 2004 and 2016. Many medicines used for the treatment of neurologic disorders are known to be expensive. Multiple sclerosis (MS) drug costs are especially high. However, it is less clear exactly how high these costs are, how they have changed, and how much patients are having to pay for medicine.

To answer these questions, the researchers used a large insurance company database with information from more than 73 million patients. From this information, they could look at what diagnoses patients had. They could also see which drugs they took, and what the costs of those drugs were. That cost also included out-of-pocket costs. The authors looked closely at medicine prescribed for 5 different neurologic conditions. These conditions included epilepsy, dementia, MS, Parkinson disease, and peripheral neuropathy.

### What did the authors find?

The authors found that as a group, the cost of drugs used to treat these conditions went up between 2004 and 2016. They noticed that out-of-pocket costs also went up very quickly. This was especially true for MS medicine, which grew more than 20 times across that period. This means those out-of-pocket drug costs went from \$15 per month in 2004 to more than \$300 per month by 2016.

While costs for individual MS drugs grew by about the same amount, costs of drugs for other conditions were different. For example, costs for some older drugs used to treat epilepsy or peripheral neuropathy were still low or went down. But some medicine in these groups (generally newer drugs) either stayed high or went up. Not including MS drugs, older medicines that had become available in generic form were cheaper.

### What do these findings mean for patients?

This study shows that patients with neurologic disorders are paying more out-of-pocket as drug costs go up. Also, higher costs of drugs will make it hard for many patients to get the drugs that they need.

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This research points to the need to find ways to lower drug costs. It also brings to light the need for better tools to make neurologists aware of the cost of drugs when they prescribe them. Except for MS drugs, which were always expensive, lower cost options were often available. Cost information is often not available when doctors are making those decisions.

Coverage for many drugs will be different depending on the patient's insurance plan. It can be difficult to decide which of 2 equal medicine choices might be less costly for the patient.

Insurance coverage will also need to change with increases in drug costs. High-deductible plans have been used as a tool so that patients have to shop for lower cost options. When all drug options are expensive, this means the patient will pay more out of pocket.

Having new drugs to treat neurologic disorders is wonderful news for patients. However, for patients to be able to get these medicines, better systems and tools are needed. This will allow patients to benefit from the treatments they need.

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# About medication costs

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In the United States, about 1 out of every 6 dollars is spent on health care. This totaled over \$3.5 trillion in 2017, the most recent year for which there is information.<sup>3</sup> These costs include payments to hospitals, doctors, other providers, insurance companies, device manufacturers, and drug makers. The cost of health care has grown faster than other parts of the economy and is a challenge.

Among the costs contributing to the cost of health care, medicine costs have grown quickly. This is a concern for patients with neurologic disorders, for many reasons. First, diseases of the nervous system are common. More than 1 in 6 people experience a neurologic disorder at some time in their lives. More than 1 in 3 people are affected either themselves or as a caregiver for a loved one. Also, many with these disorders need long-term treatments, including continued medication. Finally, many of the medicines used to treat these conditions are known as complex biologics—in other words, medicine that are difficult to make.

These and other factors have led to some surprising and often troubling trends in neurologic medicine prices. Rather than decreasing over time, some medicines have become more expensive even though newer drugs are available. For example, Copaxone has been available for the treatment of MS for many years. The cost for this drug went from just over \$3,000 per month in 2010 to more than \$5,600 per month in 2015. 4 This is despite competition from several newly approved MS drugs. Medicare is the federal insurance program for older or disabled patients. In 2013, Medicare spent more on one drug, Namenda, than it did on every payment to every neurologist in the country that year. Medicare paid \$1.5 billion for Namenda that year.

Some newer drugs for neurologic disorders represent remarkable advances in treatment but come at extraordinary costs. Nusinersen, a new treatment for a progressive childhood neuromuscular disorder known as spinal muscular atrophy, costs \$750,000 for the first year of treatment and \$375,000 annually thereafter. Many new medicines and cell-based therapies for neurologic disorders are coming, many of which will be expensive.

To manage costs of medicine and ensure patients with neurologic disorders have access to the treatments they need, our system's approach to drug costs will have to change. A number of policies have been proposed, summarized in a Position Statement from the American Academy of Neurology.7

Currently, Medicare is not allowed to negotiate with drug manufacturers. Allowing them to talk with drug makers for better prices could lower prices for patients. Medicare could be very powerful as it is the largest medicine coverage provider in the United States through its Part D program.

Permitting reimportation of medicine to the United States from countries where drug prices are much lower would lower costs to the system and to patients. Drug makers, insurance companies, and pharmaceutical benefits managers could work together to reduce waste and ensure that cost savings are passed on to patients in need.

New therapies are an exciting development for the specialty of neurology. Developing better solutions to manage drug costs will be necessary to ensure patients have access to the treatments they need.

### Additional resources

**Brain & Life** brainandlife.org/

### **Acknowledgment**

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