Movement Disorders

KNOW YOUR RIGHTS

A resource for patients with Movement Disorders.

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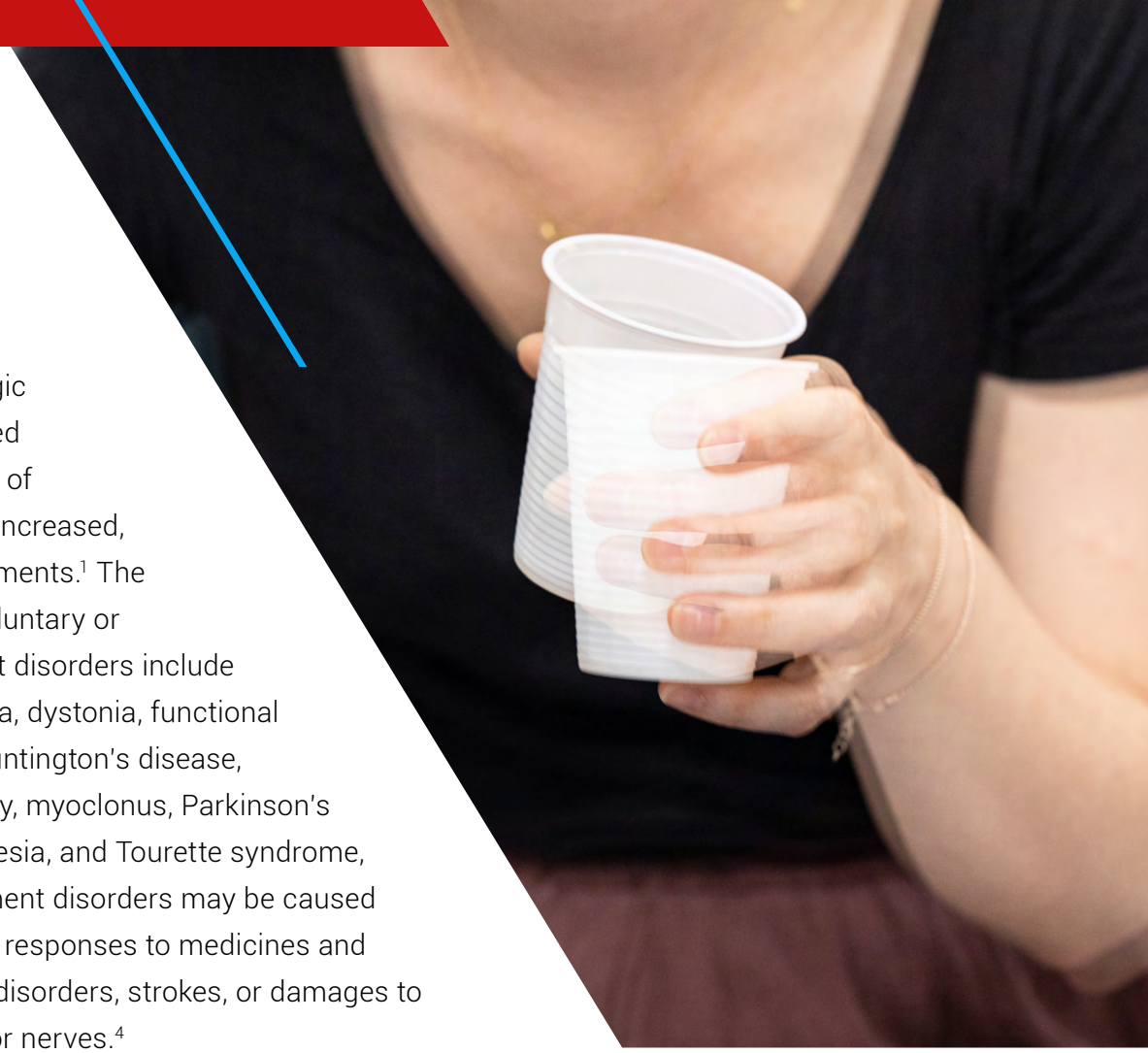


OVERVIEW

Movement disorders are a group of neurologic conditions characterized by altered coordination of movements, including increased, slow, or reduced movements.[1] The movements may be voluntary or involuntary.[2] Movement disorders include ataxia, cervical dystonia, dystonia, functional movement disorder, Huntington's disease, multiple system atrophy, myoclonus, Parkinson's disease, tardive dyskinesia, and Tourette syndrome, among others.[3] Movement disorders may be caused by genetics, infections, responses to medicines and treatments, metabolic disorders, strokes, or damages to the brain, spinal cord, or nerves.[4]

SYMPTOMS OF MOVEMENT DISORDERS

Common symptoms of a movement disorder include tremors, twitching, and muscle spasms.[5] Other symptoms may include stiffness of limbs, loss of coordination, slow movement, inability to move, tightening of muscles, and difficulties swallowing and speaking.[6] Some individuals may also experience psychiatric symptoms such as depression, anxiety, irritability, mood swings, delusions, and paranoia.[7]

Individuals living with movement disorders may also experience cognitive symptoms including depression, anxiety, sleep disturbances, confusion, and dementia.[8] For instance, the Parkinson's Foundation estimates that as many as 40 percent of people with Parkinson's disease will experience anxiety and at least 50 percent will experience some form of depression.[9]

DIAGNOSIS OF MOVEMENT DISORDERS

To diagnose a movement disorder, your health care provider will often take a detailed medical history, perform a physical exam, and order imaging and diagnostic tests (e.g., blood tests, electrocardiograms, muscle biopsies).[10] Although some movement disorders may be detected via telehealth appointments, some health care professionals may recommend an in-person visit to assess the individual for any involuntary movements that the individual may be unaware of, and are not visible during a telehealth visit.

As explained below, it is important that patients promptly start treatment after receiving a diagnosis. However, racial and socioeconomic disparities may impact an individual's ability to access treatment for movement disorders.[11] For example, one study found that Black patients were four times less likely to be started on treatment for Parkinson's disease compared to white patients.[12]

TREATMENT OPTIONS

There are several treatments that can help relieve pain and minimize movement disorder symptoms.[13] Options for treatment include physical and occupational therapy;[14] injections;[15] speech-language therapy;[16] prescription drugs such as blood pressure medications, antiseizure medications, antianxiety medications, anticholinergic agents;[17] and, in more advanced cases, surgery.[18]

Once a movement disorder diagnosis is received, it is important that patients are able to promptly start treatment. Delaying treatment for movement disorders can result in individuals experiencing disease progression[19] and developing additional conditions such as cognitive impairments,[20] depression,[21] reduced life expectancy,[22] and in some cases, death.[23]

Treating and managing movement disorders can have significant financial implications for individuals and their families. One study found that people diagnosed with tardive dyskinesia can accumulate health care costs of nearly $55,000 a year.[24] Similarly, another study reported that some Huntington's patients had annual health care costs of nearly $40,000 annually.[25]

CAREGIVER IMPACT

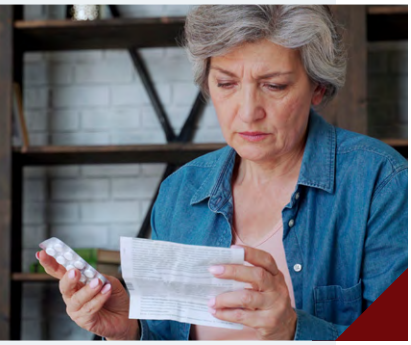
Progression of movement disorders can lead to a loss of functional independence. For some individuals, this will mean an increased reliance on family, friends, or caregivers.[26] Paid caregivers can be expensive; as a result, caregiving responsibilities can often to fall to family members. Collectively, family caregivers across the U.S. provide an estimated 36 billion hours of unpaid care annually at an estimated value of $600 billion.[27] Without proper support, such as respite care, caregiving responsibilities can result in emotional fatigue. For instance, one study found that as many as 70 percent of family caregivers exhibit clinically significant symptoms of depression, and 11 percent report a decline in their physical health.[28] Fortunately, the Department of Health and Human Services (HHS) has resources for caregivers that can be accessed **here**.

Health insurers use a variety of practices that may delay or deny access to your movement disorder treatment. To find out whether your insurer may have improperly delayed or denied access to your treatment, ask yourself the following questions:

STEP THERAPY

Did my insurer make me try a different treatment before covering the movement disorder treatment or therapy that my care team originally prescribed?

This practice is called "step therapy" or "fail first" because it requires patients to try other treatments first and demonstrate that they do not work or are intolerable before the health plan will cover the originally prescribed treatment. Your insurer may require you to try and fail on multiple different treatments before covering the one prescribed by your care team.[29] This can lead to delays in access to medically necessary treatment, which in turn can result in disease progression. Step therapy policies may violate federal or state laws if your insurer treats you and others with similar diagnoses differently because of your health condition. In addition, some states have passed legislation to limit the type of step therapy protocols that can be used. For instance, some state laws prohibit trying and failing on more than one treatment, failing on a treatment you have already tried and found ineffective, or failing on an off-label treatment. Additionally, you may also be entitled to an exception from the step therapy process.



NONMEDICAL SWITCHING

Is my insurer forcing me to take a different medication, even though my current treatment is working, by refusing to cover it any longer or increasing my copay?

This practice is referred to as "nonmedical switching." It occurs when your insurer (not your health care professional or pharmacist) forces you to switch from your current treatment to a different (but not a generic equivalent) treatment by either refusing to cover your drug therapy any longer or increasing the out-of-pocket cost of your treatment.[30] Nonmedical switching can result in relapse and disease progression. One study found that when patients were nonmedically switched, over 75 percent of them experienced side effects as a result of the switch.[31] In addition, nonmedical switching may violate certain states' consumer protection laws.[32]

PRIOR AUTHORIZATION

Did my insurer's require me to get their approval before I was allowed to begin or continue my prescribed movement disorder treatment or therapy?

This practice is called "prior authorization." It happens when your insurer requires you or your doctor to get your insurer's approval before the treatment or therapy is covered. Approval is based on the insurer's standards, which may be inconsistent with medical standards of care and harmful to patients. These policies can also violate state and federal laws if applied in a certain manner.

ADVERSE TIERING

Did my insurer require me to pay a high copay for certain medications that treat my condition?

This practice is called "adverse tiering." It can be used by insurers to shift much of the cost for newer or innovative therapies to patients by placing expensive drugs on what are called "specialty tiers." Certain tiering policies may also violate certain federal and state laws if used in a discriminatory way.[33]

COPAYMENT ACCUMULATORS

If I receive coupons or discounts to help pay for my medication copays, does my insurer prohibit those coupons or discounts from counting toward my annual deductible?

This policy is known as a "copayment accumulator." Copayment accumulators force patients to pay more out of pocket when copayment assistance runs out and the insurance deductible has not been met. These policies are frequently buried in the fine print of insurance contracts and may violate state consumer protection laws.[34] As of June 2023, at least 18 states have passed laws that prohibit health plans from implementing copayment accumulators.

"EXPERIMENTAL TREATMENTS"

Is my insurer denying coverage for my treatment because it is "experimental", despite the treatment being recently approved by the FDA?

In general, an insurer may deem a treatment experimental if it determines that the treatment is not the standard of care for a particular condition. Experimental treatments may include non-FDA-approved treatments, those that lack substantial evidence to support their medical effectiveness, and off-label treatments.

TELEHEALTH VISITS

Does my insurer require me to complete a virtual visit before being able to have an in-person visit? Does my insurer require me to pay a higher copay for an in-person visit compared to a telehealth visit?

The decision as to whether an in-person visit is necessary should be between you and your health care provider. Imposing pre-requisites of an in-person or telehealth visit first before the preferred type of visit may operate as a barrier for some and result in patients not seeking care at all. If you feel you are not able to communicate comfortably with your health care provider via a telehealth appointment, contact your plan and request an exception to have an in-person visit instead.

My insurer refuses to cover a movement disorder treatment or therapy that my health care professional prescribed to me. **What can I do?**

If your insurer refuses to cover your treatment, here are three steps you can take to try to change your insurer's decision:

- Appeal the decision;
- Request an external review; or
- File a consumer complaint.

How do I appeal the decision?

If your insurer denies your claim, you have the legal right to an internal appeal.[37] This means you can ask your insurer to conduct a full and fair review of its decision. To appeal the denial, you should do the following:

Review the determination letter. Your insurer should have sent you a determination letter to tell you that it would not cover your claim. Review this document so you can understand why your insurer denied your claim and how you can appeal the denial.

Collect information. Collect the determination letter and all other documents the insurance company sent you. This includes your insurance policy and your insurer's medical necessity criteria. "Medical necessity criteria" refers to your insurer's policy for determining whether a treatment or service is necessary for your condition.[38]

Request documents. If you did not receive the determination letter or do not have your policy information, the medical necessity criteria, or the instructions and forms for filing an appeal, call the insurer's customer service representative and ask for these documents. The company website will list the toll-free telephone number to call.

Submit the appeal request. It is important for you or your health care professional's office to submit the appeal request as soon as possible along with the letter from the health care professional and all additional information the insurer requested.

Once you file an appeal request, expect to wait up to 30 days to hear back from the insurance company regarding a treatment you hope to receive. It can take up to 60 days for a response if you received the treatment and are waiting for reimbursement.

Follow up. Follow up with your insurer regularly until you hear back. Be sure to keep a record of the name of any representative you speak with about the appeal, the date and time you spoke with that person, a confirmation number for the call, and a summary of your discussion.

Call your health care professional's office. The health care professional's office or clinic has people on staff to help with the external appeal process. They will tell you how to fill out the forms to request an appeal, write an appeal letter on your behalf, or handle the appeal request for you.

How do I tell my insurer the treatment my health care provider prescribed is not experimental?

You should ask your insurer for a written statement of the exact reasons for the denial (i.e., why the treatment is considered experimental), if that information has not already been provided. Review your plan documents carefully to see how the plan defines "experimental" (or "investigational" or "unproven") treatment. These terms can vary from plan to plan.

The FDA will only approve a treatment if there is evidence that the treatment is safe and effective. Therefore, if your treatment has recently been approved by the FDA and is indicated for your condition, then you may be able to appeal the denial on the basis that it is no longer "experimental." If you are being prescribed an FDA-approved treatment off label (i.e., it is not indicated for your condition), review your plan documents closely. Some plans have exceptions for coverage of FDA-approved off-label treatments for certain disorders if specific conditions are met.[39]

What if my insurer denies my appeal?

If your appeal is denied, you are entitled to take your appeal to an independent third party for an "external review," which means the insurance company no longer gets the final say over whether to approve a treatment or pay a claim. The situation applies if the insurer denies your appeal or if your medical situation is urgent and waiting would jeopardize your life or ability to function.

How do I request an external review?

To trigger an external review, you must file a written request for an external review within four months after the date you receive a notice or final determination from your insurer that your claim has been denied.[40] The process should take no more than 60 days. However, in urgent situations requiring an expedited review, the process should take no longer than four business days. To find out whom to contact in your state to request an external review, please go to www.CoverageRights.org.

How do I file a complaint?

If your insurer denies your coverage after the external review process, you can file a complaint with the insurance commissioner or attorney general in your state. To determine whom to contact and how to submit the complaint, please go to www.CoverageRights.org.

Your complaint should include the following information:

- The name, address, email address, and telephone number of the person filing the complaint ("Complainant");
- The name of the insured individual, if different from the Complainant;
- The names of any other parties involved in the claim (for example, the plan administrator or pharmacy benefit manager);
- The name of the insurance company and the type of insurance;
- The state where the insurance plan was purchased;
- Claim information, including the policy number, certificate number, claim number, dates of denial, and amount in dispute;
- The reason for and details of the complaint; and
- What you consider to be a fair resolution.

You should also submit the following supporting documents with your complaint:

- A copy of your insurance card;
- Copies of coverage denials or adverse benefit determinations from your insurer;
- Copies of any determinations made by internal and external reviewers;
- Any materials submitted with prior appeals and complaints;
- Supporting documentation from your health care professional;
- A copy of your insurance policy; and
- All responses from your insurer.

What happens after the state insurance commissioner or attorney general receives my complaint?

The insurance commissioner or attorney general will assign someone to research, investigate, and resolve your complaint. That person will examine your account, records, documents, and transactions. He or she may question witnesses, request additional documents from other parties, and hold a hearing. If the insurance commissioner or attorney general determines that the insurer violated laws or regulations, he or she may order the insurer to give you the requested coverage or compensate you.

Whom should I call if I have any questions about filing a complaint?

To determine whom to call in your state, please visit CoverageRights.org.

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