



What is an Easy-Read?

Easy Read combines text with layout and imagery to simplify and explain information. Easy Read is a way to present information for people who are not familiar with English, or who have low literacy or learning disabilities.



What is this information about?

This information is for individuals who have been told by their health plan that it will not cover the cost of the medication their health care provider prescribed.

This information provides details on how you can challenge your health plan's denial of a medical service or treatment.

This information is for individuals with movement disorders and their caregivers.

ABOUT MOVEMENT DISORDERS



What are Movement Disorders?

A movement disorder can cause an individual to have trouble coordinating movements, and their movements may be faster or slower than typical movements.

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.1



What are the physical symptoms of **Movement Disorders?**

Common symptoms of a movement disorder include tremors, twitching, and muscle spasms.2

Other symptoms may include stiffness of limbs, loss of coordination, slow movement, inability to move, tightening of muscles, and difficulties swallowing and speaking.3



What are the mental symptoms of **Movement Disorders?**

Some individuals may experience mental health symptoms such as depression, anxiety, irritability, mood swings, delusions, and paranoia.4



How is a Movement Disorder diagnosed?

A movement disorder is diagnosed by your health care provider by asking questions about your health now and in the past (a medical history); performing a physical exam of your body; and ordering medical tests such as a blood test.⁵



Are there treatments for Movement Disorders?

Yes. Treatment options include physical and occupational therapy;⁶ injections;⁷ speech-language therapy;⁸ prescription drugs;⁹ and surgery.¹⁰



What if I wait to start treatment for my Movement Disorder?

Waiting to start treatment for movement disorders can result in your condition getting worse¹¹ or developing additional conditions¹²; such as depression,¹³ reduced life expectancy,¹⁴ and in some cases, death.¹⁵



What if I need my family to help me with daily activities because of my **Movement Disorder?**

For some individuals, progression of movement disorders can lead to a loss of physical independence resulting in an increased reliance on family, friends, or caregivers.16



Paid caregivers can be expensive; as a result, caregiving responsibilities can often to fall to an individual's family members.



If you are a caregiver looking for support and resources, the Department of Health and Human Services (HHS) has resources for caregivers that can be accessed here.

HEALTH PLAN INFORMATION



Why does my health plan not allow me to access the medication my health care provider ordered?

Health plans use a variety of practices that may limit access to your movement disorder treatment.

These policies are implemented to save the health plan money.

These policies are often called "benefit utilization" practices.



What is a step-therapy?

"Step therapy" or "fail first" requires individuals to try other treatments first and demonstrate that they do not work before the health plan will cover the originally prescribed treatment.

To "fail" on a treatment means the medication you tried did not make you feel better; and did not stop or improve your symptoms.

Some states have laws that limit what can be required in a step-therapy policy. For instance, some states have laws that only allow an individual to try and fail on a medication for 1 month (30 days).



What is non-medical switching?

Non-medical switching occurs when your health plan (not your health care professional or pharmacist) required you to take a different medication because the health plan will no longer pay for your current treatment.

Some individuals may also experience non-medical switching if their health plan increases the cost of the medication, and the individual can no longer afford it.

Switching to a generic

Being required to switch from your current treatment to a generic medication is not typically considered non-medical switching.17



Why is non-medical switching bad?

Nonmedical switching can cause symptoms to begin again.18



What is prior authorization?

Prior authorization is when your health plan requires you or your health care provider to get the plan's approval before the treatment is covered.

This often requires you or your health care provider to submit additional information that explains why you need this medication.



Why is prior authorization bad?

It can take several days, or even weeks, for your health plan to approve a prior authorization request.

Without proper treatment, you may continue to experience symptoms of your movement disorder.



What is cost-sharing?

Cost-sharing is what you have to pay before your health plan will cover 100% of your care.

Typically, you must pay a monthly copay for treatments before you meet your annual limit on cost-sharing. The 2023 maximum annual limit on cost sharing is \$9,100 for an individual and \$18,200 for a family.

Copays for a prescription drug can count towards an individual's annual limit on cost-sharing.

For example, if you have a \$100 copay for a prescription medication you must pay that copay at the pharmacy counter before being given your medication.

The \$100 you pay at the pharmacy counter should count towards your annual limits on cost-sharing.



What is copay assistance?

Some drug manufacturers provide copay assistance to help ensure individuals have stable access to their medication.

For example, your \$100 copay can be paid \$50 by you and \$50 by a drug manufacturer copay assistance program.

These programs were created to help ensure that an individual does not have to stop taking their medication because they are unable to afford the monthly cost.

Both the \$50 from you and the \$50 from the drug manufacturer copay assistance program should count towards your annual limit on cost-sharing.



What are Copay accumulators?

Your health plan can use a "copay accumulator" which will accept your \$50 and the copay assistance \$50, but only count your \$50 towards your annual limit on cost sharing.



Why is my health plan making me do a telehealth visit before I am allowed to go to my health care provider's office?

Some health plans require a telehealth visit before agreeing to cover the cost of an in-person visit.

If you do not feel comfortable having a telehealth visit ask your health plan for an exception.

Requiring a virtual visit before an in-person visit or imposing a higher copay for an in-person visit than a telehealth visit may also violate some state laws.



Why does my health plan make me pay the highest copay for my medication?

This is called "adverse tiering." Health plans often place newly approved or recently approved Food and Drug Administration (FDA) treatments on the highest tier.

This can violate certain state laws if done in a discriminatory manner.



What is a "benefit denial"?

A benefit denial is a health plans refusal to cover a service or treatment.

KNOW YOUR RIGHTS



What do I do if I want to take the medication my health care provider prescribed but my health plan denied coverage?

If your health plan refuses to cover your medication, you can try to change your health plans decision by:

- (1) Appealing the decision;
- (2) Requesting an external appeal; or
- (3) Filing a consumer complaint.

STEP 1:

FILE AN INTERNAL APPEAL



How do I file an appeal?

If your request for coverage (claim) is denied you have the legal right to appeal.

Your health plan should have sent you a letter explaining 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.

10



If you did not receive a letter from your health plan, call the health plan's customer service line to request this information.

The company website will list the toll-free telephone number to call.



Collect the determination letter and all other documents the insurance company sent you. Including:

- Your health plan 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).

If you do not have your health plan's medical necessity policy, call the health plan's customer service line to request this information.

The company website will list the toll-free telephone number to call.



If you are missing any health plan policies related to your appeal you can call the customer service number list on the company website.



You or your health care provider should submit the request as soon as possible.



How long will it take for the appeal to be reviewed?

It can take up to 30 days for your health plan to review and respond to the appeal.

If you paid for the treatment on your own and are waiting for the health plan to pay you back (i.e. get reimbursed) it can take up to 60 days to receive a response.



What if I haven't heard back after 30 or 60 days?

Follow up with your health plan until you hear back.

Take notes of every time you call including

- (1) who you spoke with;
- (2) the date and time you called; and
- (3) what you discussed.



Can someone help me file an appeal?

Yes. Your health care provider's office or clinic often has staff who can help you fill out forms to file an appeal.

Some offices may also provide a letter to be submitted with the appeal; or handle the appeal on your behalf.



What if my health plan denied the appeal?

If your appeal is denied, you can appeal 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.

STEP 2:

FILE AN EXTERNAL APPEAL



What is an external appeal?

An "external appeal" is a review conducted by an independent third party not related to the patient or the health plan.



How do I file an external appeal?

You must file a written request for an external appeal within four months of the date your received your internal appeal response.

Ex. Received internal appeal response on January 2. Must file external appeal by April 2.



How long does an external appeal take?

An external appeal should take no more than 60 days.

If it is an emergency external appeal then the appeal should be reviewed within four days.

To find out whom to contact in your state to request an external review, please go to www.CoverageRights.org.



Can someone help me file an external appeal?

Yes. Your health care provider's office or clinic often has staff who can help you fill out forms to file an appeal.

Some offices may also provide a letter to be submitted with the appeal; or handle the appeal on your behalf.



What if my external appeal is denied?

Your last option is to file a complaint with your state insurance commissioner or attorney general.

STEP 3:

FILE A CONSUMER COMPLAINT



Who do I contact about filing a consumer complaint?

Each state has a different agency responsible for reviewing consumer complaints.

To determine whom to contact and how to submit the complaint, please go to www.CoverageRights.org.



What is included in a consumer complaint?

Typically, 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 I submit a 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.

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.



Who should I call to help me file a complaint?

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

REFERENCES

- National Library of Medicine, Movement Disorders, https://medlineplus.gov/movementdisorders. html#:~:text=Movement%20disorders%20are%20 neurologic%20conditions,Decreased%20or%20slow%20 voluntary%20movement
- 2. Life Span, Warning Signs for Movement Disorders, https://www.lifespan.org/centers-services/movement-disorders-program-rhode-island-hospital/warning-signs-movement-disorders
- Mayo Clinic, Movement Disorders, https://www.mayoclinic. org/diseases-conditions/movement-disorders/symptomscauses/syc-20363893; Life Span, Warning Signs for Movement Disorders, https://www.lifespan.org/centersservices/movement-disorders-program-rhode-islandhospital/warning-signs-movement-disorders
- Gemma Cummins, Michael Zandi, & Roger A. Barker, Movement disorders and psychiatry, https://www.ncbi. nlm.nih.gov/pmc/articles/PMC5764446/#:~:text=The%20 spectrum%20of%20psychiatric%20symptoms, disorder%2C%20delusions%2C%20and%20paranoia.
- 5. Cleveland Clinic, Movement Disorders, v https://my.cleveland clinic.org/health/diseases/24847-movement-disorders.
- University of Michigan, Movement Disorders, https:// www.uofmhealth.org/conditions-treatments/brainneurological-conditions/movement-disorders
- University of Michigan, Movement Disorders, https:// www.uofmhealth.org/conditions-treatments/brainneurological-conditions/movement-disorders
- St. Joseph's, Speech Therapy for Movement Disorders, https://www.sjchs.org/a-z-services-list/institute-forneurosciences/comprehensive-services/movementdisorders-program/speech-therapy-for-movementdisorders
- Ananya Mandal, Treatment of Movement Disorders, https://www.news-medical.net/health/Treatment-ofmovement-disorders.aspx; https://nyulangone.org/ conditions/movement-disorders/treatments/medicationfor-movement-disorders

- NYU Langone Health, Medication for Movement Disorders, https://www.news-medical.net/health/Treatment-of-movement-disorders.aspx
- 11. Ananya Mandal, Parkinson's Disease Prognosis, https://www.news-medical.net/health/Parkinsons-Disease-Prognosis.aspx#:~:text=Untreated%20prognosis,treated%20patients%20of%20Parkinson's%20disease
- Szabolcs Szatmari, Ben Min-Woo Illigens, Timo Siepmann, Alexandra Pinter, Annamaria Takatas & Daniel Bereczki, Neuropsychiatric symptoms in untreated Parkinson's disease, https://www.ncbi.nlm.nih.gov/pmc/articles/ PMC5360401/
- Szabolcs Szatmari, Ben Min-Woo Illigens, Timo Siepmann, Alexandra Pinter, Annamaria Takatas & Daniel Bereczki, Neuropsychiatric symptoms in untreated Parkinson's disease, https://www.ncbi.nlm.nih.gov/pmc/articles/ PMC5360401/
- 14. Ananya Mandal, Parkinson's Disease Prognosis, https://www.news-medical.net/health/Parkinsons-Disease-Prognosis.aspx#:~:text=Untreated%20 prognosis,treated%20patients%20of%20Parkinson's%20 disease
- American Association of Neurological Surgeons, Movement Disorders, https://www.aans.org/en/Patients/ Neurosurgical-Conditions-and-Treatments/Movement-Disorders
- 16. Michael J Fox Foundation, Care Partners, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7840426/
- 17. Aimed Alliance, Non-Medical Switching, https://aimedalliance.org/nonmedical-switching/.
- 18. Patients Rising Now, Fighting Nonmedical Switching, https://patientsrisingnow.org/fighting-nonmedical-switching/; Endocrine News, The Year in Endocrinology, https://endocrinenews.endocrine.org/wp-content/uploads/EN1217_INT-web.pdf.



1455 Pennsylvania Avenue NW, Suite 400 • Washington, DC 20004 202-349-4089 • AimedAlliance.org