



**Myotonic
Dystrophy**
FOUNDATION

Health Insurance Considerations for People Living with Myotonic Dystrophy in the United States

The Myotonic Dystrophy Foundation (MDF) is the world's largest myotonic dystrophy-only patient advocacy organization. Our programs include funding critical research, providing comprehensive resources and support to affected individuals, advocating with government agencies to enhance the drug development pipeline, increase research funding, and improve patient services.

Disclaimer: This guide was created to educate and help you navigate insurance options. The information in this document is the opinion of the authors and should not be treated as legal advice. If you have legal questions, please consult the resources in the appendix.

A publication of the Myotonic Dystrophy Foundation (MDF)

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Understanding Health Insurance Coverage

Some of the most common questions received by the Myotonic Dystrophy Foundation (MDF) involve issues with health insurance coverage for people living with myotonic dystrophy (DM). People living with DM often struggle with securing coverage for costs associated with genetic testing, procedures, medications, durable medical equipment, and everything in between. It can often be difficult and frustrating to understand what a health insurance policy does and does not cover, and to obtain proper authorization for the appropriate, medically necessary level of care.

The problem obtaining proper authorization often stems from the unfamiliarity that healthcare providers and insurance companies have about the diagnoses, symptoms, and medical needs associated with DM. Myotonic dystrophy symptoms are similar to those of other chronic diseases, so misdiagnosis is common and insurance companies often fail to cover the costs associated with treating DM. For example, because it's difficult to obtain coverage for genetic testing, it can take over seven years for people with myotonic dystrophy type 1 (DM1) to be diagnosed and 11-14 years to confirm a myotonic dystrophy type 2 (DM2) diagnosis. Even after individuals are diagnosed, they often struggle to obtain coverage for durable medical equipment and medications to manage their symptoms.

To overcome barriers to insurance coverage, it's important to understand health insurance plans, the language of the health insurance industry, and where to go for help. This resource guide may help you navigate the process of making sure your medical treatments and medications are covered, as well as understand how to appeal your claim if it's denied. We hope that this guide will enable you to advocate for the delivery of healthcare services and treatments that enhance your health and well-being and that of all people living with DM.

Types of Insurance Plans

There are two main categories of health insurance - private and public.

- 1. Private Health Insurance:** There are various types of private health insurance. Private plans are often sponsored by an employer, private plans may be purchased directly from an insurance company, or private plans may also be purchased from insurance exchanges in participating states. There are two main types of managed care plans within private health insurance: **HMO** (Health Maintenance Organization) and **PPO** (Preferred Provider Organization).

HMO plans offer healthcare services through a network of healthcare providers. A "provider" may mean anything from doctor to physical therapists to hospitals to pharmacies, among other deliveries of healthcare services. Under an HMO plan, you must choose a primary care provider (PCP) within your network. The PCP is responsible for referring you to other specialists within your HMO network when needed. HMO plans only cover healthcare costs that are within the network. Since DM specialists are rare, it is unlikely that a person living with DM will have a specialist within their HMO network. Therefore, if you want to visit a DM specialist who is outside of your HMO network, you will need to get a referral to be seen out of network or pay for this visit out-of-pocket.

A **PPO** plan offers a more extensive network of healthcare providers to choose from. PPO plans generally offer more flexibility for seeing out-of-network specialists than HMO plans, but premiums tend to be higher. PPO plans typically require higher monthly payments in exchange for increased flexibility. In addition, with a PPO, you don't need to have a PCP. PPO plans often provide more freedom to visit DM specialists with a lower likelihood of having to pay out-of-pocket. If you have the option of choosing a PPO plan over an HMO plan and can afford the higher premium, it is recommended that you choose the PPO plan, because it will be more likely that services from out-of-network DM specialists will be covered.

Additional health insurance plans include an EPO (Exclusive Provider Organization), POS (Point of Service), and HDHP (High Deductible Health Plans), which are often used in conjunction with Health Savings Accounts (HAS), and Catastrophic Health Plans.

For more information about how these plans work, visit: <https://www.healthcare.gov/choose-a-plan/plan-types/>

Health Insurance Plan Costs

In addition to the monthly premium you pay for health insurance, there are other "out-of-pocket" costs that can impact your total spending on healthcare. When these other costs are factored in, they can sometimes be higher than the premium itself.

Deductible: How much you must spend for covered health services before your insurance company pays anything (except free preventive services).

Copayments and coinsurance: Payments you make each time you receive a medical service after reaching your deductible.

Out-of-pocket maximum: The most you may spend for covered services in a year. After you reach this amount, the insurance company pays 100% for covered services.

For more information about private health insurance costs, visit: <https://www.healthcare.gov/choose-a-plan/your-total-costs/>

- 2. Public Health Insurance:** Federal and State programs that offer insurance, most commonly Medicare and Medicaid, are forms of public health insurance. These programs are for people who qualify based on their age, income, employment status, and/or whether or not they live with a disability. Some people may be eligible for both Medicare and Medicaid. Medicare pays covered medical services first for dual eligible beneficiaries because Medicaid is generally the payer of last resort. To learn more about the difference between Medicare and Medicaid, visit: <https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/ProgramBasics.pdf>

Medicare is the federal health insurance program for people aged 65 and older who have paid into the Social Security system for a total of 10 years, people younger than 65 who are disabled, and people with ESRD (end-stage renal failure requiring dialysis or a kidney transplant). One important thing to know about Medicare is that unlike Medicaid, it does not pay for long-term care. For more information, watch this YouTube video about Medicare and long-term care: <https://www.youtube.com/watch?v=QK1CXN3DC3Q>

Medicare has four components, Parts A-D:

Part A (Hospital Insurance):

- Enrollment occurs automatically at age 65 with no premium charges. For individuals who did not pay into Medicare taxes while employed, Part A can be received by paying monthly premiums.
- Part A provides coverage for inpatient hospital care, critical access hospitals, skilled nursing facilities, and hospice care.

Part B (Medical Insurance):

- Part B covers physician and outpatient services, including the services of physical and occupational therapists and home healthcare. Part B also covers durable medical equipment and some preventive services.
- The standard Part B premium amount in 2020 is \$144.60 a month. If your income is high, you may have to pay more.

Part C (Medicare Advantage):

- Part C provides extra coverage such as vision, dental, and wellness coverage. This is a health plan run by a private company that contracts with Medicare to provide both Part A and Part B benefits.
- Out-of-pocket costs may be charged depending on which services are used.

Part D (Prescription Drug Coverage):

- Medicare Part D is also offered by private insurance companies approved by Medicare. Everyone with Medicare, regardless of income, health status, or prescription drug usage, has access to prescription drug coverage as of 2006. However, co-pays and costs vary by plan and medication. If you don't have Part D, many state government human service agencies and local health centers can refer you to local organizations or prescription assistance programs that can help.

If you are thinking about shopping for Medicare Part C or D, be sure to check out Medicare.gov: <https://www.medicare.gov/plan-compare/#/?lang=en>

Medicare Supplemental Insurance (Medigap) can pay most of the 20% costs Medicare doesn't cover. This supplemental insurance can help cover costs not covered under Medicare Part A and Part B. These types of policies are sold by private companies and can help cover the cost of copayments, coinsurance, and deductibles.

The Medicare glossary explains key terms in the Medicare program: <https://www.medicare.gov/glossary>. For more information about Medicare and how to enroll, visit <https://www.medicare.gov/>. You may also reach out to the State Health Insurance Assistance Program (SHIP) in your state: <https://www.shiptacenter.org/>

With 64 million people enrolled, **Medicaid** is the largest program providing medical health-related services and long-term care to low-income individuals and families. Medicaid was designed as a federal-state partnership to provide public funding for healthcare. States set income standards for adults without children. Parents of children are eligible for Medicaid if they meet income and asset standards. Medicaid provides benefits not typically covered (or covered to a lesser extent) by other insurers, including long-term services and supports. Medicaid also pays for Medicare premiums and cost sharing for more than 10 million people who are enrolled in both programs. In order to be eligible for Medicaid, your income must be below defined limits, usually set by the Federal Poverty Level (FPL): <https://www.healthcare.gov/glossary/federal-poverty-level-fpl/>

The following services must be provided for individuals who are enrolled in Medicaid:

- Inpatient and outpatient hospital services
- Physician services
- Early and periodic screening, diagnostic, and treatment services for individuals under 21
- Nursing facility services for individuals ages 21 years and older
- Home healthcare for people eligible for nursing home services
- Family planning services and supplies
- Rural and federally qualified health clinic services
- Laboratory and X-ray services
- Pediatric and family nurse practitioner services
- Nurse midwife services

Many states have expanded eligibility for Medicaid to include people with incomes up to 138 percent of the federal poverty line. The goal is to provide health insurance to more people who would otherwise be without it because their incomes are too high. To enroll in Medicaid, visit this link to find your local office: <https://www.medicaid.gov/medicaid/eligibility/index.html>

Children’s Health Insurance Program (CHIP)

If your income is too high for Medicaid, your child may still qualify for the CHIP. This program covers medical and dental care for uninsured children and teens up to age 19. CHIP qualifications are different in every state. In most cases, they depend on income. You can apply for CHIP through your state: <https://www.insurekidsnow.gov/coverage/index.html>

Other health insurance options include coverage under the **Veterans Administration (VA)** <https://www.va.gov/health-care/eligibility/> or **TRICARE** <https://www.tricare.mil/> and **Indian Health Services (IHS)** <https://www.ihs.gov/>, if eligible.

Common Services That Are Denied Coverage

People with DM are often denied coverage for medications and services that are not listed in their insurance formularies. Because DM is a rare disease, insurance companies are often not aware of the symptom management strategies that are medically necessary for people living with DM. Health insurers often deny claims because they think that certain services are not medically necessary, or because they view them as experimental or investigational for people with DM.

Below is a list of medical services that are commonly denied for DM care:

Medications:

- Modafinil (Provigil) and Armodafinil (Nuvigil): Treat excessive daytime sleepiness and sleep apnea.

Durable Medical Equipment:

- BiPap: Ventilator that helps with breathing and treating sleep apnea.
- Electric lifts (toilet seat lift, lift chair, lift for bathtub, etc.): Helps manage myotonia, atrophy, and/or myopathy.
- Braces (leg, knee, foot, etc.): Helps manage myotonia, atrophy, and/or myopathy.

Genetic Testing:

- People showing DM symptoms often have difficulty getting coverage for genetic testing to confirm diagnosis.
- Family members of people diagnosed with DM often struggle with getting coverage for genetic testing to determine whether they have DM as well. This can occur because their symptoms may not be as prominent as their family member who was diagnosed.

Specialists:

- Depending on the type of insurance an individual has, it can be difficult to get coverage for specialists, especially if that specialist is out-of-network.

In Vitro Fertilization:

- Many people living with DM experience fertility difficulties, but it is difficult to get in vitro fertilization covered by their insurance company.
- In vitro fertilization is helpful for individuals who want to have children but who may experience the reproductive-related symptoms of myotonic dystrophy, including low sperm count, higher risk for miscarriage and stillbirth, or problems with pregnancy.
- Preimplantation genetic diagnosis (PGD) may be part of the in vitro fertilization process, if there is family history of DM. This test examines embryos that were fertilized using IVF for genetic abnormalities before the embryo is transferred into a woman's uterus.

Filing a claim (pages 8-9) or an appeal (pages 10 to 11) with your insurance company can help to increase coverage.

The Claims Process

The first-line of decision making about a health plan's coverage is typically made by a utilization review manager/case manager. If your provider prescribes you a service for DM, this utilization review manager will conduct a utilization review before your insurance company can approve coverage. According to the American Physical Therapy Association (APTA), a utilization review is the evaluation of the medical necessity, appropriateness, and efficiency of the use of healthcare services, procedures, medications, and durable medical equipment under the provisions of your applicable health benefits plan.

Unfortunately, many individuals living with DM are often denied coverage for services because a utilization review manager will deem the services to be medically unnecessary. These decision makers may have no expertise in the complex, multi-systemic needs of a person living with DM. They are also likely to be unfamiliar with DM since it is a rare disease. Utilization review managers can reject claims outright or approve claims for part of the recommended diagnosis or symptom management plan. This is a common experience within the DM community.

Coverage denial can be especially frustrating because individuals with well-known diseases have a higher likelihood of coverage for services than someone with DM might have, even with the same insurance plan and the same symptoms. For example, one DM community member expressed their concern about a situation where their provider claimed they had narcolepsy instead of DM in order to get coverage for the drug Modafinil (Provigil), which helps individuals manage excessive daytime sleepiness. Since narcolepsy is an easily-diagnosed, well-known disorder, a utilization review manager found Modafinil to be a medically necessary service for managing narcolepsy symptoms. However, since DM is a rare disease, a utilization review manager may be hesitant to cover the Modafinil prescription because of their unfamiliarity with DM and its manifestations.

This DM community member, as well as many others, have expressed their concern that utilization review managers and insurance companies are often not aware of the symptom management strategies that are medically necessary for people living with DM. Adverse utilization management decisions may deny access to care that a healthcare provider determined to be medically necessary. For this reason, it's critical that utilization review managers are at least as qualified as the doctors and specialists prescribing the drugs or medical services to the DM consumer.

Read the following from the National Library of Medicine about the utilization review process: <https://www.ncbi.nlm.nih.gov/books/NBK234995/>

- **Pre-certification Review:** Conducted at the onset of a service or treatment. This review is performed before care is rendered in order to eliminate or reduce unnecessary services.
- **Concurrent Review:** Performed during the course of the diagnosis or symptom management process of care. Intervention occurs at various intervals and may encompass case management activities such as care coordination and care transitioning. Concurrent review may have the impact of curtailing an existing episode of care.
- **Retrospective Review:** Conducted after the service has been completed and assesses the appropriateness of the procedure, setting, and timing in accordance with specified criteria. Such reviews often relate to payment and result in denial of a claim. Financial risk for a retrospective denial is often, but not always, borne by the provider.
- If you are denied coverage after the utilization review process occurs, you are encouraged to appeal your insurance company's decision if you and your provider deem the rejected services to be medically necessary.

Appealing Your Health Insurance Company's Decision

If your health plan denies you coverage or refuses to pay a claim, you have the right to appeal that decision or have it reviewed by a third party. If your appeal is accepted, you can be reimbursed by your insurance company for the services that they failed to cover. There are two ways to appeal a health plan decision from an insurance company:

- 1. Internal Appeal:** A full and fair review that is conducted by the insurance company. An appeal needs to show that the medications or healthcare services that were denied should be covered by the plan based on its own rules and that the services are both appropriate and medically necessary. You can ask your insurance company to speed up this process if your case is urgent.
- 2. External Reviews:** Occurs when an independent third party reviews your case. Your insurance company does not have a final say over whether to pay a claim.

Learn more about the process for an internal appeal: <https://www.healthcare.gov/appeal-insurance-company-decision/internal-appeals/>

- 1. File a Claim:** A claim is a request for coverage. Either you or your healthcare provider will usually file a claim to be reimbursed for the costs of your treatment or services.
- 2. If Claim is Denied:** If your health plan denies your claim, they must notify you in writing and explain why it was denied:
 - a. Within 15 days if you're seeking prior authorization for a treatment
 - b. Within 30 days for medical services already received
 - c. Within 72 hours for urgent care cases
- 3. File an Internal Appeal:**
 - a. Complete all forms required by your health insurer. Or you can write to your insurance company with your name, claim number, and health insurance ID number.
 - b. Submit any additional information that you want your insurer to consider. This can include a letter from your provider.
- 4.** If you don't want to file the appeal yourself, the Consumer Assistance Program (CAP) in your state can file one for you. To find a CAP near you, visit <https://www.cms.gov/CCIIO/Resources/Consumer-Assistance-Grants/>

Your internal appeal must be filed within six months (180 days) after receiving notice that your claim has been denied. If your situation is urgent, you can ask for an external review at the same time as your internal appeal.

You may also request an expedited appeal process, and **request that your next reviewer for medical services be a specialist in neuromuscular disorders**, if possible.

Your insurance company may not grant this request, but it at least makes clear that a non-specialist may not fully understand the clinical factors involved in determining what is appropriate and medically necessary care in your case.

If your utilization reviewer fails to explicitly state why you were denied coverage and only cites that services are “not meeting criteria for medical necessity,” you should call your insurance company and **ask for the specific criteria they used in making their decision**. The telephone number for your insurance provider should be listed on the back of your insurance card. You have the right to request a copy of the medical necessity criteria being used to make the determination. If you are directed to a website from your insurance company, ask them to guide you to the correct page over the phone because it may be difficult to find online. You can request to speak with a supervisor if you aren't getting the help you need from the employee that answers the phone. If your insurance company still denies your claim, you can file for an external review.

For details about the process of an external review, visit: <https://www.healthcare.gov/appeal-insurance-company-decision/external-review/>

- 1. File for an External Review:** You must file a written request for an external review within four months from the date you receive a notice or final determination from your insurer that your claim has been denied. You may appoint a representative, e.g. your doctor or another, to file an external review on your behalf.
- 2. External Reviewer Issues a Final Decision:** An external review either upholds your insurer's decision or decides in your favor. Your insurer is required by law to accept the external reviewer's decision.

There are multiple types of denials that can go to external review:

- Any denial that involves medical judgment where you or your provider may disagree with the health insurance plan.
- Any denial that involves a determination that a treatment is experimental or investigational.
- Cancellation of coverage based on your insurer's claim that you gave false or incomplete information when you applied for coverage.

In addition to requesting an expedited appeals process, you can also request that your next reviewer for medical services be a specialist in neuromuscular disorders. Your insurance company may not grant this request, but it will make clear to them that a non-specialist may not fully understand the clinical factors involved in determining what is appropriate for your care as a person with DM.

For any additional questions about insurance coverage and how to start the appeal process, contact MDF at **1-86-MYOTONIC**, or email us at info@myotonic.org

A Successful Appeal Case Study

The following information was captured from the 2017 *Los Angeles Times* article “How to fight back when an insurer denies your healthcare claim” by David Lazarus. Use this link to view the article: <https://www.latimes.com/business/lazarus/la-fi-lazarus-winning-insurance-appeals-20170117-story.html>.

This case was chosen due to the similarities in the denied coverage of medication types prescribed to individuals living with postural orthostatic tachycardia syndrome (POTS) and individuals living with myotonic dystrophy.

California resident Bill Waxman has appealed denied insurance claims, on behalf of his 24-year-old daughter Alison, countless times. Alison is diagnosed with postural orthostatic tachycardia syndrome (POTS). Alison’s cardiologists prescribed her the heart medication Corlanor to help with symptom management. However, the Waxman’s insurance plan denied Alison coverage for the medication, claiming that its intended use was for a different heart disorder. Waxman filed a claim requesting for coverage for his daughter, but he was denied. See pages 8-9 for information about the claims process.

Similar to Alison’s challenges, many medications prescribed to individuals living with myotonic dystrophy were also originally intended to help with symptom management of other diseases. For example, modafinil (brand name: Provigil) is usually prescribed to help individuals diagnosed with narcolepsy manage their symptoms. However, individuals with myotonic dystrophy who experience sleep apnea are often prescribed modafinil by their providers as well. Because the drug was not originally intended for people who experience myotonic

dystrophy, they are sometimes denied coverage by their insurance providers with the claim that the medication is not ‘medically necessary.’ In this case, filing an appeal like the Waxmans did would be beneficial for seeking coverage.

Waxman’s internal appeal process began with interpreting his daughter’s denied claim letter (see page 10 for information about filing an internal appeal). Denied claim letters often use medical jargon and terminology that’s difficult to understand. After deciphering the claims denial letter, Waxman met with his daughter’s cardiologist and his pharmacy benefit manager to discuss appealing the denial; however, there was still no change. Pharmacy benefit managers are companies that manage prescription drug benefits on behalf of health insurance companies.

As a next step, Waxman then gathered a list of academic papers, using [Google](#) and [PubMed](#), in order to find studies that used the drug Corlanor to help treat POTS. After doing his research, Waxman wrote a document with his findings and sent it to his pharmacy benefits company as part of his internal appeal. Soon after he was informed that his daughter’s prescription for Corlanor had been approved for coverage for one year.

Waxman claims that filing for appeals often takes him weeks of effort; however, most often he prevails.

(The process for approval of an appeal can take less time than this case took. We encourage you to be optimistic and have hope that you can successfully appeal your case. If you need help with navigating the appeal process, please contact MDF at info@myotonic.org).

Sample Appeal Letter A: Denial of Coverage for Specific Medication

[Date]

[Name]

[Insurance Company Name]

[Address]

[City, State ZIP]

Re: [Patient's Name]

[Type of Coverage]

[Group number/Policy number]

Dear [Name of contact person at insurance company],

Please accept this letter as [patient's name] appeal to [insurance company name] decision to deny coverage for [state the name of the specific procedure denied]. It is my understanding based on your letter of denial dated [insert date] that this procedure has been denied because: [quote the specific reason for the denial stated in denial letter]

As you know, [patient's name] was diagnosed with [disease] on [date]. Currently Dr. [name] believes that [patient's name] will significantly benefit from [state procedure name]. Please see the enclosed letter from Dr. [name] that discusses [patient's name] medical history in more detail.

[Patient's name] believes that you did not have all the necessary information at the time of your initial review. [Patient's name] has also included with this letter, a letter from Dr. [name] from [name of treating facility]. Dr. [name] is a specialist in [name of specialty]. [His/Her] letter discusses the procedure in more detail. Also included are medical records, and several journal articles explaining the procedure and the results.

Based on this information, [patient's name] is asking that you reconsider your previous decision and allow coverage for the procedure Dr. [name] outlines in his letter. The treatment is scheduled to begin on [date]. Should you require additional information, please do not hesitate to contact [patient's name] at [phone number]. [patient's name] will look forward to hearing from you in the near future.

Sincerely,

[Your name]

Sample Appeal Letter B: Denial of Coverage for a Necessary Procedure

[Date]

[Name]

[Insurance Company Name]

[Address]

[City, State ZIP]

Re: [Patient's Name]

[Type of Coverage]

[Group number/Policy number]

Dear [Name of contact person at insurance company],

Please accept this letter as my appeal to [insurance company name] decision to deny coverage for [state the name of the specific procedure denied]. It is my understanding based on your letter of denial dated [insert date] that this procedure has been denied because: [quote the specific reason for the denial stated in denial letter]

I have been a member of your [state name of PPO, HMO, etc.] since [date]. During that time I have participated within the network of physicians listed by the plan. However, my primary care physician, Dr. [name] believes that the best care for me at this time would be [state procedure name]. At this time there is not a physician within the network who has extensive knowledge of this procedure. Dr. [name of primary care physician], a plan provider, has recommended that I have the procedure done outside the network by Dr. [name of specialist] at [name of treating facility].

I have enclosed a letter from Dr. [name of primary care physician] explaining why he recommends [name of procedure]. I have also enclosed a letter from Dr. [name of specialist] explaining the procedure in detail, his qualifications and experience, and several articles that discuss the procedure.

Based on this information, I am asking that you reconsider your previous decision and allow me to go out of network to Dr. [name] for [name of specific procedure]. The procedure is scheduled to begin on [date]. Should you require additional information, please do not hesitate to contact me at [phone number]. I look forward to hearing from you in the near future.

Sincerely,

[Your name]

Key Insurance Terms

These terms have been taken from HealthCare.gov's glossary. To view a full list of their terms, visit: <https://www.healthcare.gov/glossary/>

A

Affordable Care Act (ACA): This healthcare reform policy was signed into law by President Barack Obama and is otherwise known as Obamacare. The ACA has many components, but overall, it has expanded Medicaid eligibility; prevents insurance companies from denying coverage based on pre-existing conditions; created the Health Insurance Marketplace which allows people to shop for and enroll in affordable health insurance; and it has allowed persons under 26-years-old to remain on their parents' health insurance plans.

Appeal: A request for your health insurance company to review a decision that denies a benefit or payment.

C

Children's Health Insurance Program (CHIP): If your children need health coverage, they may be eligible for the Children's Health Insurance Program (CHIP). CHIP provides low-cost health coverage to children and families that earn too much money to qualify for Medicaid. In some states, CHIP covers pregnant women. Each state offers CHIP coverage and works closely with its state Medicaid program.

Claim: A request for payment that you or your healthcare provider submits to your health insurer when you get items or services you think are covered.

Coinsurance: The percentage of costs of a covered healthcare service you pay (20%, for example) after you've paid your deductible. Let's say your health insurance plan's allowed amount for an office visit is \$100 and your coinsurance is 20%. If you've already paid your deductible, you will pay 20% of the \$100 visit so you will only pay \$20 and your insurance company will pay the rest. However, if you have not met your deductible you will have to pay the full \$100.

Copayment: A fixed amount (\$20 for example) you pay for a covered healthcare service after you've paid your deductible.

D

Deductible: The amount you pay for covered healthcare services before your insurance plan starts to pay. With a \$2,000 deductible for example, you pay the first \$2,000 of covered services yourself. Once you exceed \$2,000, your insurance company will pay for additional medical costs.

E

Emergency services: Evaluation of an illness, injury, symptom, or condition so serious that a reasonable person would seek care right away and treatment to keep the condition from getting worse.

Exclusive Provider Organization (EPO): A managed care plan where services are covered only if you use doctors, specialists, or hospitals in the plan's network (except in an emergency).

Excluded services: Healthcare services that your health coverage or plan doesn't pay for.

Explanation of Benefits (EOB): A summary of healthcare changes that your insurance company sends you after you see a provider or get services. It is not a bill. It is a record of the healthcare you or individuals covered on your policy got and how much your provider is charging your insurance company.

F

Formulary: A list of prescription drugs covered by a prescription drug plan or another insurance plan offering prescription drug benefits. Also called a drug list.

H

Health Maintenance Organization (HMO): A type of health insurance plan that usually limits coverage to care from doctors who work for or contract with the HMO. It generally won't cover out-of-network care except in an emergency.

Hospital outpatient care: Care in a hospital that usually doesn't require an overnight stay.

I

In vitro fertilization (IVF): IVF is a medical procedure in which mature eggs are retrieved from ovaries and are fertilized outside of the uterus (usually in a lab). Fertilized eggs are then transferred back into the uterus for the remainder of gestation.

M

Medicaid: A state public health insurance program that provides free or low-cost health coverage to some low-income people, families, and children, pregnant women, the elderly, and people living with disabilities.

Medicare: A federal public health insurance program for people 65 and older and certain younger people with qualifying disabilities. It also covers people End-Stage Renal Disease (ESRD).

N

Network: The facilities, providers, and suppliers your health insurer or plan has contracted with to provide healthcare services.

Network plan: A health plan that contracts with doctors, hospitals, and other healthcare providers to provide members of the plan with services and supplies at a discounted price.

O

Out-of-network copayment: A fixed amount (for example, \$30) you pay for covered healthcare services from providers who don't contract with your health insurance or plan. Out-of-network copayments usually are more than in-network copayments.

Out-of-pocket costs: Your expenses for medical care that aren't reimbursed by insurance. Out-of-pocket costs include deductibles, coinsurance, and copayments for covered services plus all costs for services that aren't covered.

Out-of-pocket maximum/limit: The most you must pay for covered services in a plan year. After you spend this amount on deductibles, copayments, and coinsurance, your health plan pays 100% of the costs of covered benefits.

P

Point of Service (POS): A type of plan where you pay less if you use healthcare providers that belong to the plan's network.

Preferred Provider Organization (PPO): A type of health plan where you pay less if you use providers in the plan's network. You can use doctors, hospitals, and providers outside the network without a referral for an additional cost.

Preimplantation genetic diagnosis (PGD): A form of genetic testing that analyzes and examines embryos during in vitro fertilization (IVF) before fertilized eggs are transferred back to the uterus in order to determine if the embryo has certain genetic conditions.

Premium: The amount you pay for your health insurance every month. In addition to your premium, you often must pay other costs for your healthcare, including a deductible, copayments, and coinsurance.

R

Referral: A written order from your primary care provider for you to see a specialist or get certain medical services. In many HMOs you need a referral before you can receive medical care from anyone except your primary care provider.

S

Specialist: Providers who have completed advanced clinical education and training in a specific area of medicine (e.g., neurologists).

Additional Resources:

American Physical Therapy Association - What is Utilization Management? <https://www.apta.org/WhatsUM/>

Centers for Medicare & Medicaid Services - From Coverage to Care, A Roadmap to Better Care and a Healthier You: <https://marketplace.cms.gov/technical-assistance-resources/c2c-roadmap.pdf>

Global Genes - Navigating Health Insurance: https://globalgenes.org/wp-content/uploads/2018/11/Navigating-Health-Insurance_DIGITAL_spread_op.pdf

HealthCare.gov - 3 Steps in the Internal Appeals Process: <https://www.healthcare.gov/appeal-insurance-company-decision/internal-appeals/>

HealthCare.gov - 2 Steps in the External Review Process: <https://www.healthcare.gov/appeal-insurance-company-decision/external-review/>

HealthCare.gov - Health Insurance Plan & Network Types: HMOs, PPOs, and More: <https://www.healthcare.gov/choose-a-plan/plan-types/>

HealthCare.gov - How to Appeal a Marketplace Decision: <https://www.healthcare.gov/marketplace-appeals/>

HealthCare.gov's Glossary of Health-related Words: <https://www.healthcare.gov/glossary/>

LA Times- How to fight back when an insurer denies your healthcare claim: <https://www.latimes.com/business/lazarus/la-fi-lazarus-winning-insurance-appeals-20170117-story.html>

National Association for Rare Disorders - Financial Assistance Resources: <https://rarediseases.org/for-patients-and-families/help-access-medications/financial-assistance/>

National Association of Insurance Commissioners (NAIC) state map and contacts: https://content.naic.org/state_web_map.htm

National Eating Disorders Association (NEDA) - The NEDA Parent Toolkit: <https://www.nationaleatingdisorders.org/parent-toolkit>

National Library of Medicine - Utilization Management: Introduction and Definitions: <https://www.ncbi.nlm.nih.gov/books/NBK234995>

NIH Genetic & Rare Diseases Information Center - Tips for Finding Financial Aid: <https://rarediseases.info.nih.gov/guides/pages/149/tips-for-finding-financial-aid>

NIH Genetic & Rare Diseases Information Center (GARD): <https://rarediseases.info.nih.gov/diseases/10419/myotonic-dystrophy>

Patient Advocate Foundation - A Patient's Guide to Navigating the Insurance Appeals Process: <https://www.patientadvocate.org/wp-content/uploads/NavigatingInsuranceAppeals.pdf>

Patient Advocate Foundation - PAF Co-Pay Relief Program: <https://www.patientadvocate.org/connect-with-services/copay-relief/>

Patient Advocate Foundation's National Financial Resource Directory: <https://www.patientadvocate.org/explore-our-resources/national-financial-resource-directory/>

Providence Health and Services: Oregon and Southwest Washington: <https://oregon.providence.org/about-us/billing-center/sample-insurance-denial-appeal-letters/>

Social Security Administration- Extra Help with Medicare Prescription Drug Plan Costs: <https://www.ssa.gov/benefits/medicare/prescriptionhelp/>

State Health Insurance Assistance Programs (SHIP) - Local Medicare Help: <https://www.shiptacenter.org/>

U.S. Department of Health & Human Services - What is the difference between Medicare and Medicaid? <https://www.hhs.gov/answers/medicare-and-medicaid/what-is-the-difference-between-medicare-medicaid/index.html>

The mission of the Myotonic Dystrophy Foundation is to enhance the quality of life of people living with myotonic dystrophy and accelerate research focused on treatments and a cure.



**Myotonic
Dystrophy**
FOUNDATION

My Cause. My Cure.

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