



MIGRAINE PATIENT TOOLKIT: A GUIDE FOR YOUR CARE



ABOUT SWHR

The Society for Women's Health Research (SWHR®) is a nonprofit thought leader dedicated to promoting research on biological sex differences in disease and improving women's health through science, policy, and education. Founded in 1990 by a group of physicians, medical researchers, and health advocates, SWHR is correcting imbalances in health care for women by addressing unmet needs and research gaps in women's health. Thanks to SWHR's efforts, women are now routinely included in most major medical research studies and scientists are considering sex as a variable in their research. Visit www.swhr.org for more information.

ABOUT SWHR'S INTERDISCIPLINARY NETWORK ON MIGRAINE

SWHR's Interdisciplinary Science Networks identify knowledge gaps and opportunities to effect change for diseases and conditions that disproportionately, differently, or exclusively affect women. Launched in 2018, SWHR's Migraine Network is a diverse group of researchers, health care providers, patients, and health care opinion leaders working to educate and engage society about the burden of migraine.

NETWORK MEMBERS

Dawn Buse, PhD

Albert Einstein College of Medicine

Paul Fronstin, PhD

Employee Benefit Research Institute

Laurie Garner, PA-C, PhD

Woodford Family Physicians

Kelly Gavigan, MPH

Global Healthy Living Foundation

Brian Gifford, PhD

Integrated Benefits Institute

Toni M. Guglielmo

Patient

Matthew Harman, PharmD, MPH

Employers Health

Emily Kandel

Parent of patient

Lauren Neves, JD

Pharmaceutical Research and Manufacturers of America

Jelena Pavlovic, MD, PhD

Albert Einstein College of Medicine

Jaime Sanders

Patient

Donna Shaw

Patient

Karen T. Smith

Patient

Amaal Starling, MD

Mayo Clinic

Christine Utley, DNP, RN

University of Toledo

Sara van Geertruyden

Partnership to Improve Patient Care

William B. Young, MD

Thomas Jefferson University

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NOVARTIS



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Amy M. Miller, PhD

President and CEO

Rebecca Nebel, PhD

Former Director of Scientific Programs

Emily Ortman

Director of Communications

Sarah Wells Kocsis, MBA

Vice President of Public Policy

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MORE THAN JUST A HEADACHE



MIGRAINE DISEASE

A common and disabling neurological disease in which a person has had 5+ migraine attacks



MIGRAINE ATTACK

Severe head pain lasting 4–72 hours and often with symptoms such as nausea, vomiting, dizziness, and sensitivity to light and sound

MIGRAINE TYPES

CHRONIC

15+ headache days per month for at least 3 months in a row

EPISODIC

Fewer than 15 headache days per month

MENSTRUAL

Attacks occurring a few days before or during menstruation

WITH AURA

Attacks with sensory disturbances like flashing lights

DISEASE BURDEN AND BARRIERS TO CARE

#2

leading cause of global burden of disability

90%

of people mistake a migraine attack for a sinus headache

<50%

of people with migraine consult a health care provider



Society for
Women's Health Research

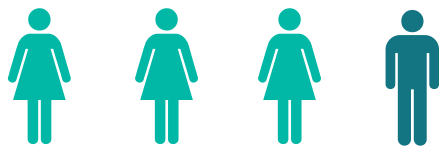
WHO DOES MIGRAINE AFFECT?



Families: If you have migraine disease, your child has a 50% risk of developing migraine too.

IMPACT ON WOMEN

Migraine affects women and men differently.



people with migraine are women



Because migraine is more prevalent in women, some perceive it as a feminized and less legitimate disease.

Migraine disease reaches peak prevalence in women during their 20s and 30s, when many women are balancing work, family, and social obligations.

Women are more likely to have:



Longer migraine attacks



Harder to treat attacks



More migraine-related symptoms



Higher levels of disability

TALKING WITH YOUR HEALTH CARE PROVIDER

HOW IS MIGRAINE DIAGNOSED?

Migraine is a common neurological disease in which a person has attacks of moderate to severe head pain lasting 4–72 hours that are often accompanied by symptoms such as nausea, vomiting, dizziness, and extreme sensitivity to light and sound.

Health care providers diagnose migraine by evaluating the history of your symptoms. Some tests (for example, blood work, imaging, head X-ray) may be performed to rule out other conditions, but there is no definitive test to show you have migraine.

That's why it is so important to prepare for your health care visit and be ready to articulate your personal experience. Your health care provider will need to know about your symptoms and their impact on your daily life and ability to function at work, school, and home. Clear communication assists your health care provider in accurately diagnosing you and designing a treatment plan tailored to you.

HOW TO PREPARE FOR YOUR HEALTH CARE PROVIDER VISIT

To help your health care provider understand your migraine experience, consider keeping a headache diary and bringing the information recorded to your visit.

Important items to track in your **headache diary** are:



Pain severity
and symptoms



Frequency and
duration of attacks



Medications or other
treatments used



Ability to function at
work, school, or home

You may also want to track possible personal triggers, or factors that may potentially set off a migraine attack. **Migraine triggers** do not cause attacks but may increase the risk of one occurring. Triggers are unique to each person and can be difficult to identify, but some common ones include sensitivities to light, sound, odor, and touch, certain foods and drinks, hormonal fluctuations (for women), weather changes, and stress.



QUESTIONS TO ASK YOUR HEALTH CARE PROVIDER

Prepare a list of questions to ask your health care provider during your visit. Questions may vary depending on whether you are being evaluated for the first time or receiving ongoing treatment. Some suggested questions to help get the conversation started are:

INITIAL EVALUATION

- 1 How do I know if what I am experiencing is migraine?
- 2 What factors might contribute to my migraine?
- 3 What treatment options are available to me?
- 4 What are the risks and benefits of these treatments?
- 5 How can I handle treatment side effects?
- 6 Could any of my current medications make a migraine attack worse?

ONGOING TREATMENT

- 1 How do I know if my migraine management plan is working?
- 2 What lifestyle and behavioral changes may help me control my migraine symptoms?
- 3 How often should I be seen and evaluated?
- 4 Where can I find resources to help educate myself, family, and friends about migraine?
- 5 What resources exist to help me understand financial options to pay for my treatment?

You can help foster clear communication with your doctor by asking direct, specific questions. Don't be afraid to restate what your health care provider has told you or to ask clarifying questions to ensure that you understand the answers.

HEADACHE DIARY

MONTH / YEAR :



ATTACK SEVERITY RATING

0	NONE
1-2	MINIMAL/ MILD
3-4	UNCOMFORTABLE
5-6	DISTRACTING/ DISTRESSING
7-8	INTENSE
9	UNMANAGEABLE
10	UNBEARABLE



FUNCTIONAL ABILITY RATING



RELIEF RATING



DAY	START	END	SEVERITY	FUNCTION	MEDICATIONS	TREATMENTS	RELIEF	MENSTRUATING
—	[TIME]	[TIME]	[0-10]	[0-10]	[NAME, DOSE]	[TYPE, WHEN]	[0-10]	[Y/N]
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Keeping a headache diary allows you to share a more complete picture of your migraine experience with your health care provider.

This monthly headache diary helps track when your attacks occur, their severity and effects on your ability to function, and your treatment actions and results. You may also want to make notes about your symptoms, triggers, and impact on your daily activities. With a better understanding of your migraine experience, your health care provider can design a treatment plan tailored to you.

EXAMPLES OF SYMPTOMS

- Head and Neck Pain
- Nausea
- Vomiting
- Dizziness
- Aura
- Sensitivity to Light
- Sensitivity to Sound
- Vision Problems

EXAMPLES OF TRIGGERS

- Hormone Fluctuations (for women)
- Certain Foods and Drinks
- Dehydration
- Weather Changes
- Certain Odors and Scents
- Lights
- Sounds
- Stress

NOTES:

PREVENTING MIGRAINE ATTACKS

Preventive therapies are taken on a regular basis and aim to reduce the frequency of migraine attacks.

LIFESTYLE INTERVENTIONS

(To the best of your ability)

- Exercise regularly
- Get consistent, quality sleep
- Eat a healthy diet
- Stay hydrated
- Manage stress



MEDICATIONS

- ACE inhibitors
- Angiotensin II receptor blockers
- Antidepressants
- Antiepileptic drugs
- Beta blockers
- Anti-calcitonin gene-related peptide (CGRP) monoclonal antibodies (mAbs)
- OnabotulinumtoxinA (for chronic migraine only)

NONINVASIVE NEUROSTIMULATORS

- Single-pulse transcranial magnetic stimulation
- Transcutaneous supraorbital neurostimulation

BEHAVIORAL THERAPIES

- Biofeedback
- Cognitive behavioral therapy
- Relaxation training (e.g., meditation, guided visual imagery, progressive muscle relaxation)

NUTRACEUTICAL TREATMENTS

- Butterbur—pyrrolizidine alkaloids-free (petasites)
- Coenzyme Q10 (ubiquinone)
- Feverfew
- Magnesium
- Vitamin B2 (riboflavin)

TREATING MIGRAINE ATTACKS

Acute (or abortive) therapies aim to treat a migraine attack while it's occurring.

WHAT YOU CAN TRY ON YOUR OWN

Lifestyle Interventions

- Rest immediately
- Drink water
- Apply ice packs
- Sleep
- Consume ginger (e.g., candies, capsules, tea)
- Apply essential oils

Over-the-Counter Medications

- Nonsteroidal anti-inflammatory drugs (NSAIDs) with or without caffeine (e.g., aspirin, ibuprofen, naproxen)
- Acetaminophen with or without caffeine



WHAT YOUR HEALTH CARE PROVIDER CAN PRESCRIBE

- 1** Providers typically start by prescribing **first-line treatments**.



Medications

- Prescription-strength NSAIDs
- Triptans (oral and non-oral)
- Triptan/NSAID combination
- Ergot alkaloids
- Anti-nausea drugs
- Prescription-strength combination analgesics
- Steroids

Behavioral Treatments

- Biofeedback
- Relaxation therapy

Noninvasive Neurostimulators

- Single-pulse transcranial magnetic stimulation
- Transcutaneous supraorbital neurostimulation
- Vagus nerve stimulation

- 2** If first-line treatments provide incomplete relief, providers can prescribe backup therapies as **second-line treatments**.

Backup medications should be a different class of medication than those used initially to treat the attack.

- 3** If you are still in extreme pain after trying your first- and second-line interventions, **you may consider seeking treatment in an urgent care setting**.

TALKING WITH YOUR INSURANCE COMPANY

When you suffer from a chronic illness like migraine, you should work with your health care provider to ensure your care does not result in undue financial burden. Take advantage of resources that your health care provider offers and follow these tips on how to effectively talk with your insurance company.

KNOW THE DETAILS OF YOUR INSURANCE POLICY

Request a copy of your policy that explains:

- the health care services covered
- if and when you need a **referral** to see certain health care professionals
- if and when you need **prior authorization** to receive services or medications
- your policy expiration date

UNDERSTAND THE FINANCIAL ASPECTS OF YOUR POLICY

Most insurance plans require a **premium payment** to keep coverage active.

- Premium payments have a due date, plus a grace period.
- If a premium is not paid in full by the end of the grace period, the insurance company may suspend or cancel your coverage.
- Premiums for employer-sponsored plans are usually automatically deducted from your paycheck.

Insurance plans rarely cover 100% of the health care costs, leaving patients to pay the outstanding portion. The three primary types of patient **out-of-pocket costs** are:

- **a deductible** — a preset amount you must pay before insurance kicks in
- **coinsurance** — an amount (often a percentage) you must pay for services after a deductible has been reached
- **a copayment** — a preset, flat fee you must pay for services after a deductible has been reached

BE AWARE OF SPECIAL COVERAGE REQUIREMENTS

Some insurance companies have **prior authorization (PA) requirements** that must be met before they will cover a specific migraine treatment, medication, or procedure.

- Some plans may require a headache specialist to evaluate you before you can receive certain migraine medications.
- Some plans may require medications be prescribed in a specified order and with certain outcomes (e.g., **step therapy**).

Check your insurance company's website for PA requirements and forms or request this information by calling the member services number on the back of your insurance card.

- In most instances, your health care provider's office is responsible for submitting the PA, demonstrating the service or medication is **medically necessary**.
- Ensure PA forms are completed quickly and accurately with assistance from your health care provider's office.
- Inquire about "success stories" with other patients that may help guide your PA submission.

Stay on top of timing and key dates.

- Know when your PA information needs to be submitted and if any strict deadlines apply.
- Start the PA process early to avoid a potential delay in receiving medication or treatment.
- Find out how to expedite the PA process if your situation is urgent or time-sensitive.

Seek help if you are unable to manage your health insurance.

- Enlist the support of a case manager, a typically free resource provided by the insurance company, who can help you navigate the process.





BEFORE CALLING YOUR INSURANCE COMPANY

- Find your insurance card, which will have the following important information:

- insurance plan name

- member phone number(s)

- policy member number

- policy group number

- Make a list of your health care providers, their affiliations, and contact information.

- Locate relevant paperwork from your health provider(s) and insurance company, including Explanation of Benefits forms and bills.
- Create an organized file to keep all of your important documents in one place.
- Know your goal for the call and what you want to ask.



TIPS FOR TALKING TO YOUR INSURANCE COMPANY

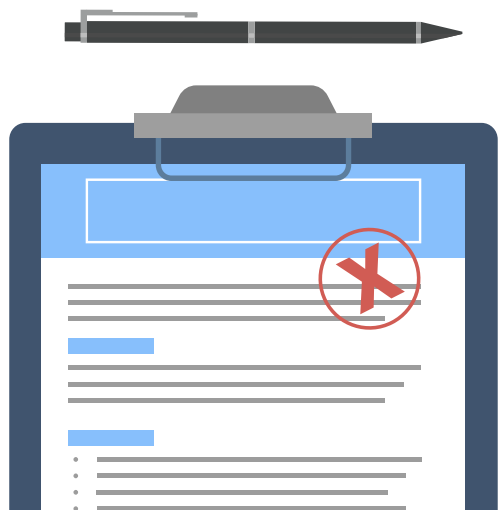
- Allocate plenty of time and be prepared for possibly long wait times.
- Speak clearly and calmly.
- Confirm you are speaking with right point of contact.
- Write down the date, time of your call, and the name of each person with whom you speak.
- Keep notes of key information obtained and agreed upon next steps.
- Be assertive. Continue to ask questions until they are answered.

WHAT TO DO IF YOUR HEALTH INSURER DENIES YOUR CLAIM

If your insurance company denied your claim for migraine-related care, would you know what to do? You have a legal right to appeal the decision. There are steps and **resources** available to help you, and you should coordinate with your health care provider in the appeals process.

REASONS YOUR CLAIM MIGHT BE DENIED

- the benefit isn't offered under your health plan
- the requested service or treatment is deemed “not **medically necessary**”
- the requested service or treatment is considered “experimental” or “investigative”
- your medical problem began before you joined the plan
- the health care provider from whom you received care isn't in your plan's approved network
- the requested treatment is not on your plan's **formulary**



YOU HAVE THE RIGHT TO APPEAL THE DECISION

Insurers are required to tell you how you can dispute their decisions and have them reviewed by a third party. If you decide to appeal, it's best to take action immediately. Read your insurance policy carefully to understand what it covers and outline your argument for why your insurer should honor your appeal.

CLAIM DENIAL NOTIFICATION

Your insurer must notify you in writing as to why it denied your claim and it must do so within specified timeframes based on the circumstance:

- For **prior authorization of a treatment**, your insurer must notify you within 15 days.
- For **medical services already received**, your insurer must notify you within 30 days.
- For **urgent care cases**, your insurer must notify you within 72 hours.

TO APPEAL, FOLLOW TWO STEPS... (SEE BACK)

STEP 1: FILE AN INTERNAL APPEAL

- Submit all forms required by your insurer and make copies for your records.
- Include any supplemental information that you want the insurer to consider, such as a letter from your health care provider.
- File within 180 days (6 months) of receiving notice of your claim denial.
- If the case is urgent, file sooner and ask your insurer to expedite the process.

Internal Appeal Documents

- **Explanation of Benefits** forms showing the denied services
- Internal appeal letter to your insurance company
- Letters from your doctor explaining medical necessity
- Notes from phone conversations with your insurer

WHAT TO EXPECT

Length of Process

If your appeal is for a service you have not yet received, your insurer must complete your appeal within 30 days. If your appeal is for a service you've already received, your insurer must complete your appeal within 60 days.

Written Notification

Your insurer must notify you in writing of its appeals decision. If the decision remains a denial, you can ask for an external review, and the insurance company's written notification must include guidance on how you can request one.

STEP 2: REQUEST AN EXTERNAL REVIEW

- Review the notice from your insurer and submit a written request within the required timeframe (generally 60 days from the date your insurer sent its final decision).
- You may appoint a representative who knows about your medical condition to file an external review on your behalf and who will need to complete an **authorized representative form**.

Types of Denials Subject to External Review

- Disagreements between you and your insurance company involving medical judgement
- Disagreements over whether treatments are “experimental” or “investigational”

WHAT TO EXPECT

Length of Process

Standard external reviews are completed no later than 60 days after the request was received.

Cost of an External Review

If your insurer has contracted with an independent review organization or uses a state external review process, you may be charged a fee. If so, the charge should not exceed \$25 per external review. If your insurance company uses the process administered by the Department of Health and Human Services (HHS), there is no charge.

ADDITIONAL RESOURCES

EMPLOYER

If you receive health insurance coverage through your employer, contact the human resources department. Ask whether your company has dedicated case managers who can assist with your appeal and whether you're eligible to participate in a state-run external review process.

STATE

If you need help filing an internal appeal or external review, contact your state's **Consumer Assistance Program**. Many states fund independent ombudsman offices or offer administrative help with difficult claims.

FEDERAL

For help understanding employer-sponsored benefits, contact **The Employee Benefits Security Administration** within the U.S. Department of Labor.

GLOSSARY

Medical

- **Abortive (or acute) therapy** — A treatment used to stop a migraine attack while it is occurring
- **ACE (angiotensin-converting enzyme) inhibitors** — Medications originally developed to lower blood pressure that may also reduce frequency or severity of migraine attacks
- **Acetaminophen** — An over-the-counter drug that treats fever, aches, and pains, and may be helpful in treating a migraine attack
- **Analgesics** — Drugs designed to reduce inflammation and pain that may also reduce the severity of a migraine attack
- **Angiotensin II receptor blockers** — Medications originally designed to lower blood pressure that may also reduce frequency or severity of migraine attacks
- **Antidepressants** — Medications originally developed to treat depression that may also reduce frequency or severity of migraine attacks
- **Antiepileptic drugs** — Medications originally designed to control seizures that may also reduce frequency or severity of migraine attacks
- **Aura** — Sensory disturbances (e.g., blind spots, vision changes, tingling in hands or face, trouble with speech and reading) that often occur before a headache
- **Behavioral therapy** — Treatment from a mental health care provider that may reduce the frequency or severity of migraine attacks (e.g., cognitive behavioral therapy, relaxation therapy)
- **Beta blockers** — Medications originally developed to treat chest pain (angina) and irregular heartbeats (arrhythmia) that may also reduce frequency or severity of migraine attacks
- **Biofeedback** — A technique used to bring awareness to the body's functions. Sensors help patients receive information about their body (e.g., muscle tension) that they can use to consciously make subtle changes (e.g., relaxing muscles).
- **Burden of disease** — The health, social, political, environmental and economic effects that a disease and its associated disability exert upon an individual and society
- **Butterbur (petasites)** — An extract made from the roots or rhizome of this plant may reduce the frequency of migraine attacks. Raw butterbur plant contains chemicals called pyrrolizidine alkaloids, which can cause liver damage and can result in serious illness, so only butterbur products that are certified as PA-free should be used.
- **Calcitonin gene-related peptide (CGRP)** — Protein that causes inflammation in the brain and a biological target for new migraine therapies
- **Chronic migraine** — Characterized by having more headache days than not (i.e., 15 or more headache days every month for at least three months)
- **Coenzyme Q10 (ubiquinone)** — A supplement that may reduce the frequency of migraine attacks
- **Cognitive behavioral therapy** — Strategies used to modify behavior and thinking that may reduce the frequency or severity of migraine attacks
- **Comorbid condition** — A health problem that exists simultaneously with another condition
- **Episodic migraine** — Characterized by having less than 15 headache days every month. High frequency: 9–14 headache days per month. Low frequency: 0–8 headache days per month
- **Ergot alkaloids** — Medications that may reduce the severity of a migraine attack (e.g., dihydroergotamine, ergotamine)
- **Feverfew** — A plant-derived therapy that may reduce the frequency of migraine attacks
- **First-line treatment** — A medication or treatment that should be taken at the onset of symptoms to reduce the severity of a migraine attack
- **Menstrual migraine** — Migraine attacks (without aura) that occur within two days before or after the start of a woman's period. Menstrually-related migraine can occur at other times of the menstrual cycle.

- **Migraine attack** — Characterized by moderate to severe head pain, lasting 4–72 hours (if left untreated), and often accompanied by symptoms such as nausea, vomiting, dizziness, aura, sensitivity to light and sound, and pain in the face and neck
- **Migraine disease** — A chronic neurological disease in which a person has had at least five migraine attacks
- **Migraine trigger** — Some change, event, lifestyle factor, or environmental influence that precedes a migraine attack
- **Monoclonal antibodies (mAbs)** — A new class of drugs that target the calcitonin gene-related peptide and the CGRP receptor to prevent migraine attacks
- **Neurostimulators** — Devices that use electrical stimulation to alter nerve activity in order to reduce neurological symptoms
- **Nonsteroidal anti-inflammatory drugs (NSAIDs)** — Medications that may be effective at treating migraine attacks (e.g., aspirin, ibuprofen, naproxen)
- **Nutraceutical treatment** — Use of nutritional supplements to prevent migraine attacks (e.g., herbs, vitamins)
- **OnabotulinumtoxinA (botulinum toxin)** — An injected medication that may prevent migraine attacks
- **Preventive therapy** — A treatment that when used on a regular basis may prevent migraine attacks
- **Relaxation therapy** — Learning how to achieve a state of increased calmness within a few minutes by slowing down the sympathetic nervous system, which is responsible for producing the stress response
- **Second-line treatment** — A medication or treatment that can be used as a backup option if the first-line treatment fails to provide relief from a migraine attack
- **Single-pulse transcranial magnetic stimulation** — A self-administered device that produces magnetic pulses at the back of the head, which may reduce the frequency or severity of migraine attacks
- **Steroids** — Medications that may reduce the severity of migraine attacks
- **Stigma** — A socially and culturally embedded process through which individuals (such as people who have migraine) experience stereotyping, devaluation, and discrimination. Stigma potentially impacts quality of life, behavior, and life chances.

- **Transcutaneous supraorbital neurostimulation** — A self-administered device that uses electrodes on the forehead to stimulate supraorbital nerves, which may reduce the frequency or severity of migraine attacks
- **Triptans** — Medications that can treat acute migraine attacks
- **Vagus nerve stimulation** — A self-administered device that delivers electrical stimulation to the vagus nerve, which may reduce the severity of migraine attacks

Non-Medical

- **Appeal** — A patient request that the decision to partially or fully deny a benefit or payment be reviewed by their health insurer
- **Claim** — A patient or health care provider request that a benefit or reimbursement be given by the health insurer for a covered health care service or item
- **Case manager** — A health care professional who is responsible for evaluating a patient's needs and identifying the most effective, efficient, and feasible ways of helping them based on the available resources. This role may vary in different settings.

Example: A health insurance case manager may focus on anticipating a patient's future needs and proactively addressing them.
- **Coinsurance** — The percent of payment for a covered service that the patient pays after the deductible is met each benefit period. Copays may also still apply.

Example: Your health insurer will pay 75% of your medical bill. The remaining 25% must be paid by you. This 25% is considered your coinsurance.
- **Copayment (copay)** — The fixed amount that a patient pays to their health care provider when they receive a service. The amount may vary based on the type of service received and on the insurance plan.

Example: You visit your primary care provider for a routine check-up. Your insurance plan requires a \$15 copay for this service, which you pay up front to your health care provider.

- **Deductible** — The amount that the patient pays during the coverage period (usually one year) before the health insurer will pay for all health care services

Example: Your plan requires an annual \$1,000 deductible. You will be expected to pay for the first \$1,000 of costs toward your health care services. After you reach \$1,000, your health insurer will pay for the rest of your health care services that year.

- **Experimental or investigational** — A class of medical procedures, treatments, drugs, and devices that are not currently the standard of care and/or are not approved by the FDA, but may benefit patients
- **Explanation of benefits** — A statement sent from a health insurer to a patient that explains what portion of expenses are the insurer's responsibility and what portion of expenses are the patient's responsibility for a certain claim
- **Formulary** — A list of prescription drugs covered by a prescription drug plan or another insurance plan
- **Health insurance** — A type of insurance coverage that pays for medical expenses incurred by the insured person. Health insurance can either reimburse the insured person for expenses or pay the health care provider directly.
- **Maximum out-of-pocket (MOOP) limit** — The maximum amount set by the federal government that an individual or family may be required to pay during the plan year for all in-network and covered health care services

- **Medically necessary** — Health care services, procedures, equipment, or supplies that meet the standards of medicine and are required for the prevention, diagnosis, or treatment of a patient's health issue

Example: An MRI needed to diagnose a shoulder injury is a medically necessary procedure and is the standard of care.

- **Out-of-pocket (OPP) cost** — The cost that the patient is required to pay, which may differ by plan but is restricted by a set maximum out-of-pocket (MOOP) cost
- **Preauthorization** — Also known as precertification, prior approval, or prior authorization, this is a non-binding distinction of medically necessary services, equipment, treatments, or drugs by the health insurer. Depending on the insurance plan, preauthorization may be required before certain health care services are received, except in the case of an emergency.
- **Premium** — Payments made by the patient to a health insurer to ensure that their plan maintains coverage of health care expenses
- **Referral** — A written order from a primary care provider that some health insurance plans may require before a patient can receive care from a specialist
- **Step therapy** — An approach in managed medical care intended to control the costs and risks posed by prescription drugs. The practice begins medication for a medical condition with the most cost-effective drug therapy and progresses to other more costly or risky therapies only if necessary.

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