



Resources for

**GOUT
PATIENTS**

 ALLIANCE FOR
Gout Awareness

 @GoutAlliance

 Alliance for Gout Awareness



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The Alliance for Gout Awareness works to reduce stigma and empower patients by improving public understanding of gout.

Inside this packet you'll find resources from our member organizations on living with and managing gout. We hope you'll find these materials helpful in your journey with gout.

About Gout

Gout is a type of inflammatory arthritis (sometimes called gouty arthritis) that develops in people who have high levels of uric acid in their body. Uric acid is produced naturally by the body and from eating foods that have purines. Purines are substances in animal and plant foods that the body converts to uric acid. Normally, the kidneys remove this acid from the blood and it leaves the body through the urine. With gout, excess uric acid builds up in the joints and forms needle-like crystals that cause extreme pain.

A gout attack can also be caused by joint injury, infection, kidney problems, medications or diet habits (e.g., a purine-rich, sugary diet, drinking too much alcohol or not enough water). Being overweight, having a family history of gout or having untreated high blood pressure, diabetes or metabolic syndrome also increases the risk of developing gout.

FAST FACTS

- **Gout is the most common type of inflammatory arthritis.**
- **It affects about 8.3 million individuals age 20 or older, at least three-fourths of whom are men.**
- **The buildup of uric acid in the blood stream is called hyperuricemia.**
- **In women, gout tends to occur after menopause.**
- **Heart disease is common in people with gout.**



Information and support at your fingertips.

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Words to Know

Anti-rejection medicine:

Medicine taken to keep the body from rejecting a newly transplanted organ.

Arthritis:

An inflammation of the joints that usually causes pain.

Diabetes:

A disorder in which the body either cannot make insulin or cannot use it properly. Insulin is a hormone that controls how much sugar is in your blood.

Dialysis:

A process that filters (cleans) your blood when your kidneys no longer do this well. It is one of the basic forms of treatment for kidney failure.

Diuretics:

A type of medicine that helps your body get rid of unneeded water and salt.

Gout:

A form of arthritis that causes pain and swelling.

High blood pressure:

The force of blood against the wall of your blood vessels. High blood pressure means the force is consistently higher than what is healthy.

Hyperuricemia:

An excess of uric acid in the blood.

Infection:

The presence of an organism like bacteria that causes pain, swelling, redness, and sometimes fever.

Inflammation:

Swelling that happens when parts of your body become infected or injured.

IV infusion:

When medicine is given to you directly into a vein using a needle or tube.

Kidney disease:

The loss of some or all of your kidney function.

Kidney failure:

The stage of kidney disease at which dialysis or a transplant is needed to stay alive.

Kidney transplant:

An operation that places a healthy kidney in your body. It is one of the basic forms of treatment for kidney failure.

Menopause:

When a woman stops having menstrual periods forever.

Remission:

Disappearance of the signs and symptoms of a disease. Remission can be temporary or forever.

Symptoms:

A physical or mental change that indicates illness or disease.

Uric Acid:

A normal waste product that comes from the breakdown of your body's cells and certain foods.

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How did I get gout?

There isn't anything you did wrong to cause the development of gout—like other rheumatic diseases, there are a variety of potential factors at play. Genetic factors may play a role since gout tends to run in families. Diet can also be a factor, especially excess consumption of alcohol, consuming beverages that have high-fructose corn syrup, or eating foods such as red meats that are high in purines, which break down into uric acid.

Certain demographics may also put you at higher risk of developing gout and complications related to the condition. For example, middle-aged men, postmenopausal women, and individuals with kidney disease seem to develop gout more frequently than other groups.

There is also thought to be a possible link between gout and health conditions such as hypertension, high cholesterol, insulin resistance, diabetes, congestive heart failure, and obesity. It is important to know that you are not alone. There are millions of patients around the world who have gout and are able to keep their disease under control.

Will my gout ever go away?

Unfortunately, according to the U.S. Centers for Disease Control and Prevention (CDC), gout is not considered a curable disease. However, you may be reassured to hear that many people with gout live happy, productive,

and relatively pain-free lives thanks to lifestyle modifications, judicious use of pain medication, and adherence to treatment plans that incorporate the use of urate-lowering therapy.

Your healthcare team will help you effectively navigate your condition with a treatment plan that includes self-management strategies and medication as needed. It is important that we work together to come up with a treatment plan that is right for you and sensible for your lifestyle.

Once you have your plan, it's important to follow it carefully. Following a treatment plan will be particularly important if you have other health conditions such as diabetes and/or heart disease. Furthermore, there are a number of low- or no-cost self-care strategies that can help you maintain or improve your quality of life while living with gout, including education classes on living with inflammatory arthritic conditions. If you can, engage in moderate physical activity (at least 150 minutes per week) and set a goal of maintaining a healthy weight to reduce joint pressure, improve function, and slow gout progression.

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Gout Risk Factors and Causes You Need to Know About

Uric Acid and the Onset of Gout

“Gout is caused by an elevation in the chemical uric acid,” says Kenneth Saag, MD, professor of medicine in the division of clinical immunology and rheumatology at the University of Alabama at Birmingham. “Uric acid builds up in the body and deposits in the joints, which causes a severe inflammatory reaction.”

Uric acid is a normal breakdown product of your body’s metabolism. Most of the time uric acid just gets eliminated in urine. When that process goes awry, however, excess uric acid forms crystals in one or more joints, says Joseph Huffstutter, MD, a rheumatologist with Arthritis Associates in Hixson, Tennessee.

The body recognizes the crystals as foreign, so it attacks them.

Sometimes this uric acid build-up happens simply because of aging, since as you get older your kidneys (which filter waste into urine) can become less efficient, says Dr. Huffstutter. But that doesn’t mean that gout impacts only the elderly: Men are most apt to develop gout between age 30 and 50; for women, gout is more common after menopause (which usually occurs in the early fifties).

Age aside, there are several other risk factors that can increase your chances of developing this painful condition.

Not sure that’s causing your pain?

Check out PainSpot, our pain locator tool.
<https://www.painspot.com/>

7 Gout Symptoms You Might Be Ignoring

- ✓ Pain that rapidly worsens
- ✓ Pain in knees, ankles, wrists, and/or elbows
- ✓ Kidney Stones
- ✓ Strange lumps around your joints (tophi)
- ✓ Pain in the big toe
- ✓ Fatigue/lack of energy
- ✓ Intense pain in the middle of the night

Risk Factors

- ⚡ Kidney Disease
- ⚡ High Blood Pressure
- ⚡ Obesity
- ⚡ Drinking Alcohol
- ⚡ Family History

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Questions to Ask While Talking With Your Doctor About Gout

- ✦ Do I definitely have gout?
 - How was the diagnosis made?
- ✦ How often should I get my uric acid level checked?
- ✦ What is my uric acid level now?
- ✦ What should my target uric acid level be?
- ✦ Will I need to go on medication to lower my uric acid level?
 - What is the right medication for me?
 - What will the dosage be?
 - How many times a day will it be needed?
 - What do I do if I miss a dose?
 - What do I do if I accidentally take too much?
 - How long will I need to be on this medication?
 - Will there be any side effects when I start treatment? Are there any long-term side effects?
 - Are there any possible drug interactions with the other medications I am taking?
 - What happens when I reach my uric acid target?
- ✦ What about medications for pain?
 - What is the right medication for me?
 - Are the pain medications over-the-counter or by prescription?
 - How much can I take and how often?
- Are there any side effects?
- What is the minimum amount I can take and still see results?
- What if I am taking the maximum amount and I am still in pain?
- Are there any possible drug interactions with the other medications I am taking?
- ✦ Are there any changes or limitations to the foods I eat?
- ✦ Are there any limitations to the beverages I drink?
- ✦ Should I be exercising, and how often?
- ✦ Do I need to lose weight?
- ✦ What should I do when I have another flare?
- ✦ What should I do if I have reached my target uric acid level, but am still having flares?

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Diagnosis and Treatment

Gout can be diagnosed through examination, a blood test, or by analyzing joint fluid.

While gout is treatable, it is not curable. Anti-inflammatory drugs or corticosteroids may be prescribed to help with the joint pain. For some, signs and symptoms may continue to occur despite taking oral uric acid-lowering medicines. In these scenarios, an intravenous medication may be recommended by doctors to decrease the buildup of uric acid in the body.

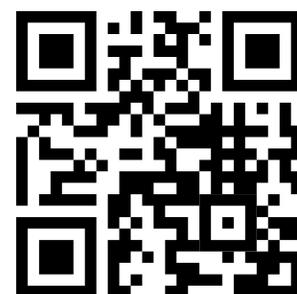
Your podiatrist may also recommend lifestyle changes that can help decrease symptoms. These include weight loss, decreasing alcohol consumption, and diet modification.



When to Visit a Podiatrist

If you believe you have experienced a gout flare or have developed tophi, consult with a podiatrist by visiting www.apma.org/findapodiatrist.

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Gout & Medication

What is the difference between treating an attack and managing chronic gout?

Treatment during a gout flare is focused on reducing symptoms like pain and inflammation. However, treating only the flare ignores the underlying cause. Gout attacks stem from persistently high uric acid levels. Gout arthritis can be effectively managed with medication that maintains a “normal” uric acid level. Painful flares, long-term joint erosion and other serious risks can be avoided if uric acid is controlled.

What types of medication treat a gout attack?

NSAIDs, or nonsteroidal anti-inflammatory agents, are used to reduce inflammation and pain. They are the most common medications for immediate relief during an attack. Examples include naproxen and ibuprofen.

Colchicine has been used for many years to treat and help prevent gout attacks. However, it does not lower uric acid or eliminate deposits or uric acid in the joints. Colchicine can be used along with uric acid-reducing medications to prevent future attacks.

Corticosteroids help reduce inflammation and pain associated with gout attacks. They can be administered intravenously, as pills or by injection.

What medications help regulate uric acid levels?

Maintaining a healthy uric acid level is the only way to manage gout long term, and medication is the most effective way to do so. Some medications reduce uric acid production, while others increase uric acid excretion.

Allopurinol, the standard first-line treatment, works by reducing the body’s production of uric acid. **Febuxostat** is a similar drug that may work for people who don’t respond well to allopurinol.

Probenecid helps your body clear uric acid so it doesn’t build up.

All of these medications are aimed at preventing painful attacks by getting uric acid levels to the American College of Rheumatology’s recommended 6mg/dL.

Typically, these medications must be taken long term to prevent painful attacks, buildup of uric acid and arthritic complications.

What if traditional medications haven’t worked?

Some patients struggle to find success with traditional oral treatments. If you are one of those patients, you still have options.

Pegloticase is a medication specifically for these type of patients. The therapy is administered via infusion every two weeks and works by converting uric acid into a compound that can be more easily excreted.

The medication is often given for several months. During this time the large deposits of uric acid that have accumulated on bones and joints dissolve. How can someone living with gout know which medications to take? People with gout should work with their health care provider, preferably a gout specialist, to personalize their care plan – aimed at treating their gout, rather than just fighting through a flare.

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How does infusion work?

As opposed to taking medication orally, infused medicines are administered through a small tube called a catheter that is placed in your hand or arm. Completing an infusion treatment usually takes a couple hours because the medicine is very slowly put directly into your bloodstream.

Aren't infusions just for cancer patients?

While infusions are often associated with chemotherapy, they are also commonly used to treat many other conditions and diseases. People with gout, migraines and chronic pain are among those who can benefit from infusion therapy.

Do I have to go to the hospital for an infusion?

Until the 1980s, getting an infusion meant a hospital stay. But that's no longer true. Free-standing infusion centers and hospital outpatient centers allow gout patients to come in for just their infusion, then go home after a brief monitoring period.

Do all gout patients need infusion treatments?

While not all gout patients need infusions, they are common and effective for a subset of patients, specifically those who are not responding well to other oral treatments aimed at lowering uric acid.

Do infusions hurt?

Getting an infusion can be slightly uncomfortable, but bringing a family member or friend to talk to can make it easier. Reading a book, watching a show or listening to music can also help pass the time. Many infusion centers offer amenities such as snacks, reclining infusion chairs, and blankets to make the infusion process more comfortable.

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Chronic Pain Facts

What is Chronic Pain?

Chronic pain can be defined as pain that persists most days or every day for six months or more. For some individuals, pain can last a lifetime.

Chronic Pain can take many forms:

-  MILD TO SEVERE
-  INTERMITTENT TO CONTINUOUS
-  ANNOYING TO DISABLING

Prevalence:

- **50 million** American adults, or 20% of the population, live with chronic pain.
- **20 million** or 7% of American adults live with high-impact pain, or pain that frequently limits life or work activities.
- Pain is the **number one** reason Americans access the health care system.

Impact and Cost:

- Chronic pain is **the leading cause** of long-term disability in the United States.
- The nation spends up to **\$635 billion each year** on chronic pain in terms of medical treatment, disability payments, and lost productivity.
- Chronic pain has biopsychosocial implications. It is associated with **reduced quality of life**, including increased risk of anxiety and depression.



CHRONIC PAIN PATIENTS ARE OFTEN OVERLOOKED AND UNDERTREATED.

 <p>Veterinary students SPEND 5X as many education hours focused on pain management as medical students.</p>	 <p>At least 10 PERCENT of all suicide cases in America involve someone with chronic pain.</p>
 <p>For every 10,000 PEOPLE with severe pain, there is only ONE BOARD-CERTIFIED pain specialist.</p>	 <p>Patients receive an average of ONLY 30% PAIN REDUCTION from their various treatments.</p>
 <p>The National Institutes of Health dedicates approximately 2 PERCENT of its funding to pain research.</p>	 <p>Studies have shown that MINORITY GROUPS and other marginalized populations are at risk of receiving suboptimal pain management.</p>

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Kidney Disease and Gout



- **1 in 3** American adults is at risk for kidney disease



- **26 million** American adults have kidney disease, and most don't know it. If not treated early, kidney disease can often lead to kidney failure.



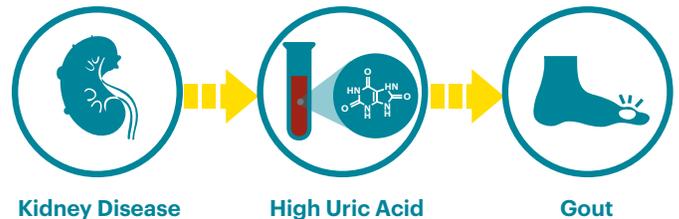
- **8.3 million** American adults have gout. If not treated early, gout can lead to joint damage that doesn't get better.

Get Checked

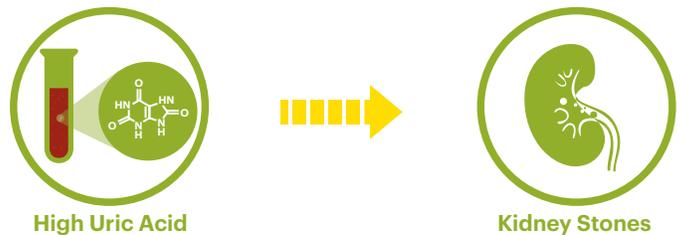
If you have these symptoms, you should get checked for gout by your healthcare professional:

- ☑ Joints that are swollen, tender, warm, or red.
- ☑ Gout usually occurs in the large joint of your big toe, but it can also occur in your feet, ankles, knees, wrists, and hands
- ☑ Symptoms are important to know because some people have gout even if their uric acid level is normal.

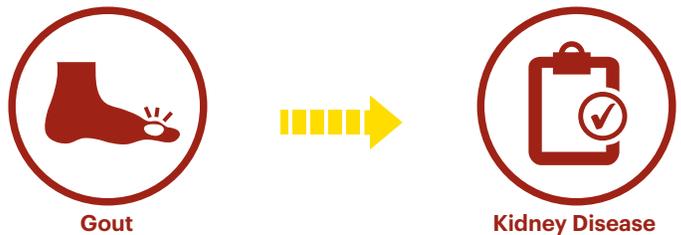
The Kidney, Gout, and Uric Acid Connection



Kidney disease sometimes leads to high uric acid in the blood. High uric acid may cause gout in some people.



High uric acid may also cause kidney stones in some people.



If you have gout, you should be checked for kidney disease.

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Programs & Services of the American Kidney Fund

The American Kidney Fund (AKF) fights kidney disease and helps people live healthier lives.

Our programs address the full spectrum of kidney disease through prevention and the support of all people affected by kidney disease, from the early stages to dialysis and kidney transplant.



- An estimated **37 MILLION** Americans are living with kidney disease.



- **1 IN 3** U.S. adults is at risk for the disease.



- More than **700,000 people** are living on dialysis or with kidney transplant in the U.S.



- AFK makes health care possible, financially supporting hundreds of transplant recipients and **1 in 5** dialysis patients in the country.



- **96%** of people with early stage kidney disease do not know they have it. Kidney disease can be detected through simple blood and urine tests.

Prevention & Early Detection

Kidney Action Week: a weeklong, virtual kidney disease awareness and education event dedicated to informing and empowering patients, caregivers, and professionals towards self-advocacy, effective patient-provider communication, and improved health-outcomes.

Kidney Action Week brings together top nephrologist's, dietitians, patients, caregivers, and other kidney experts to provide information, tools and resources to help prevent kidney disease or help you take care of yourself if you have it. Participants can choose from a week-long schedule of events focusing on prevention, dialysis, transplantation, kidney disease management, nutrition, and other kidney health related topics.

Direct Financial Assistance

Health Insurance Premium Program: Lifesaving financial assistance program that keeps low-income dialysis and transplant patients insured through grants for health insurance premiums.

Safety Net Program: Provides small grants to low-income dialysis patients to assist with transportation to treatment, medications, copays and other needs.

Disaster Relief Program: A rapid-response program that provides emergency grants to dialysis patients when catastrophic events such as floods, hurricanes, wildfires and other natural disasters threaten their health. Grants are used for transportation, temporary housing, food, medications and replacing personal essentials.

Post Transplant Testing Program: Talk to your doctor about the new and less invasive donor-derived cell-free DNA tests that can detect early damage or rejection in your transplanted kidney. The American Kidney Fund (AKF) is providing financial assistance to cover these innovative new blood tests that offer ongoing monitoring of the health of your transplanted kidney without the need for a kidney biopsy. The tests are accurate and can be done every few months, giving your transplant team a good way to monitor your transplant long term.

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About the Alliance for Gout Awareness

Alliance for Gout Awareness proudly partners with a wide variety of advocacy group members to help further gout education and awareness.

