Rheumatology Nurses Society Professional Education Series

### HANDLING THE HARD QUESTIONS:

# What Our Patients Are Asking Us About



## The Purpose of This Document

Gout, which affects an estimated 9 million individuals in the United States, is caused by elevated levels of uric acid that lead to crystal formation, inflammation, and joint damage. Rheumatology nurses, nurse practitioners, and physician assistants play a key role in helping patients with gout understand their condition and establish treatment plans.

Many patients with gout have questions about their condition and treatment options, particularly following a recent diagnosis. By providing patients with evidence-based answers to common questions, providers can help alleviate patient concerns and emphasize the importance of interventions that can help prevent flares and long-term damage.

However, many providers may find it challenging to give clear and substantial answers to some of the questions commonly asked by patients with gout. This pocket guide is designed to provide you with helpful responses to common and challenging questions you may hear from patients and their caregivers. We hope you find this guide informative and useful not only for your professional development, but also in daily clinical practice.



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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.<sup>1</sup>

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.<sup>1,2</sup>

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. Now that you have been appropriately diagnosed, it's important to understand the steps you can take to prevent attacks and long-term damage associated with gout.

- National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). Gout Symptoms, Causes & Diet Recommendations. Available at www.niams.nih.gov/ health-topics/gout. Accessed March 9, 2021.
- Centers for Disease Control and Prevention. What causes gout? Last reviewed July 27, 2020. Available at www.cdc.gov/arthritis/basics/gout.html. Accessed March 9, 2021.

### How do you know I have gout and not something else?

Making a diagnosis of gout is definitely challenging. If you have joint swelling, pain, and redness, we

want to be sure it's not another disease or form of arthritis that looks like gout but isn't (Table 1). If you don't already have a definitive diagnosis of gout, it's very important that we look carefully at your symptoms and perform a comprehensive workup.<sup>1,2</sup>

To get that done, we need to first take a careful medical history and physical exam. Blood tests are important. Often, the diagnosis of gout is confirmed based on the

<b>Table 1</b> GOUT: DIFFERENTIAL DIAGNOSIS
Pseudogout
Septic arthritis
Psoriatic arthritis
Rheumatoid arthritis
Erosive osteoarthritis
Bacterial cellulitis
Sarcoid arthropathy

### Table 2 ACR/EULAR Gout Classification Criteria<sup>4</sup>



finding of uric acid-based crystals observed under a microscope in fluid extracted from an affected joint. If your gout is more advanced, uric acid crystals may accumulate in hardened deposits under your skin called tophi. X-ray, ultrasound, and computed tomography (CT) scans can also aid in the diagnosis of gout (Table 2).<sup>2</sup> Of note, gout can sometimes be confused with calcium pyrophosphate dihydrate disease (CPPD), otherwise known as pseudogout. One telling difference is that gout usually affects a single joint at a time—most often the big toe, but also sometimes the ankle, foot, knee, elbow, wrist, or finger. By contrast, pseudogout typically affects more than one joint and is seen in the knee, wrist, or ankle, and occasionally in spinal ligaments.<sup>3</sup>

It is especially critical to distinguish between gout and pseudogout because of the need to get you on appropriate therapy quickly. While acute flare-ups of gout and pseudogout can both be managed with non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen, corticosteroids, and colchicine, the longer term effects of gout often require dietary changes and uric-acid lowering therapy to prevent future attacks.<sup>3</sup>

- Centers for Disease Control and Prevention. What causes gout? Last reviewed July 27, 2020. Available at www.cdc.gov/arthritis/basics/gout.html. Accessed March 9, 2021.
- American College of Rheumatology. How is gout diagnosed? Updated March 2019. Available at www. rheumatology.org/I-Am-A/Patient-Caregiver/Diseases-Conditions/Gout. Accessed March 9, 2021.
- Arthritis Foundation. Gout or pseudogout? Available at www.arthritis.org/diseases/more-about/gout-orpseudogout. Accessed March 9, 2021
- Neogi T, Jansen TL, Dalbeth N, et al. 2015 Gout Classification Criteria: an American College of Rheumatology/European League Against Rheumatism collaborative initiative. *Arthritis Rheumatol*. 2015;67(10):2557-2568.

## Why is my big toe so swollen?

The big toe is the most common joint affected by gout attacks, though lesser toe joints, ankles, knees, and other joints may also be affected.<sup>1,2</sup> Beyond the swelling, you may also experience intense pain, redness, and warmth in the affected joint.<sup>3</sup>

Gout-related joint issues are caused by a condition called hyperuricemia, which involves the excess accumulation of a waste product (i.e., uric acid) in the blood. With time, elevated uric acid levels in the blood may lead to deposits of needle-like crystals in and around the affected joint. The crystals may attract and activate white blood cells, causing severe and painful gout attacks, as well as chronic arthritis. You may also experience kidney stones as uric acid deposits form in the urinary tract.<sup>4</sup> Most often, hyperuricemia occurs because your kidneys are not eliminating uric acid from the body as rapidly as they need to, although it also may be due to increased production of uric acid in the body. Uric acid levels may increase not only due to consumption of certain foods and alcohol,

### Four Stages of Gout<sup>6</sup>



### STAGE 1: Asymptomatic Gout

- Early Stage
- Hyperuricemia
- No other noticeable symptoms



### STAGE 3: Intercritical Gout

- Between acute gout attacks
- No visible symptoms
- Uric acid crystals continue to accumulate



### STAGE 2: Acute Intermittent Gout

- Sodium urate crystal deposits in joint spaces
- Pain, swelling, and redness
- Severe attacks, (commonly at night)



STAGE 4: Chronic Tophaceous Gout

- Most debilitating form
- Permanent damage to the cartilage and bone
- Kidney stones and other damage possible

but also with use of some medications, diuretics, and immunosuppressants such as cyclosporine. Low-dose aspirin can also increase uric acid production, though due to its potential benefits (i.e., reduced risk of heart attack and stroke), we do not recommend that you stop taking aspirin.<sup>5</sup>

- National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). Gout Symptoms, Causes & Diet Recommendations. Available at www.niams.nih.gov/ health-topics/gout. Accessed March 9, 2021.
- Centers for Disease Control and Prevention. What increases your chances of gout? Available at www.cdc. gov/arthritis/basics/gout.html. Accessed March 9, 2021.
- Johns Hopkins Arthritis Center. Symptoms and Diagnosis of Gout. Available at www.hopkinsarthritis. org/arthritis-info/gout/clinical-presentation-of-gout/. Accessed March 10, 2021.
- Arthritis Research Foundation. Gout Research. Available at curearthritis.org/gout-research/. Accessed March 10, 2021.
- American College of Rheumatology. What causes gout? Available at www.rheumatology.org/I-Am-A/ Patient-Caregiver/Diseases-Conditions/Gout. Accessed March 9, 2021.
- Ragab G, Elshahaly M, Bardin T. Gout: An old disease in new perspective - A review. J Adv Res. 2017;8(5):495-511.

# Why is it so important that you monitor my uric acid levels?

Gout occurs when high levels of uric acid in the blood lead to formation of needle-shaped crystals that accumulate in and around a joint. That buildup can lead to inflammation and arthritis.<sup>1</sup> Because of that, it's very important to monitor and keep your serum uric acid levels under control.

Current gout treatment guidelines recommend that we use urate-lowering drugs to try to keep your blood levels of uric acid below 6 mg/dl. This should help minimize the number of gout attacks you experience and may prevent long-term damage from occurring. You should have your blood levels of uric acid checked regularly over a reasonable time frame (eg, every few weeks or months) to

Greater than	Hyperuricemia, which can lead to
6.8	gout, is defined as a serum urate
mg/dl	level of ≥6.8 mg/dl.
Less than 6 mg/dl	For patients with gout, the American College of Rheumatology recommends a treat-to-target strategy with urate-lowering therapy to keep serum urate <6 mg/dl.
Greater than	Patients with serum urate levels of
9	≥9 mg/dl have a greater risk of gout
mg/dl	progression.

make sure your treatment is working. If your blood levels of uric acid stay high despite use of a conventional urate-lowering drug, that's a sign that it may be time to consider switching therapy, particularly if you continue to experience frequent gout flares or have tophi that won't resolve.<sup>2</sup>

While it's important to monitor uric acid levels in your blood over time, the measurements sometimes can be misleading or difficult even for healthcare professionals to interpret, particularly when taken right around the time of an acute gout attack when levels may read out as normal or even low. Imaging can be helpful and complementary. For example, X-rays may show joint damage if you have long-standing gout, and a certain type of CT scan may detect early signs of gouty joint involvement.<sup>3</sup>

- National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). What is gout? Available at www.niams.nih.gov/health-topics/gout. Accessed March 9, 2021.
- FitzGerald JD, Dalbeth N, Mikuls T, et al. 2020 American College of Rheumatology guideline for the management of gout. *Arthritis Care Res (Hoboken)*. 2020;72(6):744-760.
- American College of Rheumatology. How is gout diagnosed? Available at www.rheumatology.org/l-Am-A/Patient-Caregiver/Diseases-Conditions/Gout. Accessed March 9, 2021.

## Is there anything I should change about my diet?

There are definitely steps you can take in modifying what you eat, which may help improve your gout. One very important step is to limit your intake of foods that are high in purines, which can trigger a gout flareup. Purine-rich foods include red meat, organ meats like liver, and certain kinds of seafoods such as anchovies, tuna, and mussels. It may also help to limit intake of any kind of alcohol, especially beer and hard liquor, and avoid consuming food and drinks that are high in fructose (Table).<sup>1</sup>

If your blood levels of uric acid are only mildly elevated, changing what you eat and drink may be enough to keep your gout under control. However, even strict adherence to a gout-specific diet will only reduce elevated uric acid levels by so much, meaning that additional measures may be needed to prevent uric acid from settling in your joints and causing a gout flare.<sup>2</sup>

We encourage you to do all you can to combat gout, not only with dietary modification but also with regular exercise and weight loss. Patients who gain weight over time have been shown to be at





Sugary foods and beverages including soda, sweetened cereals, baked goods, and candies

increased risk of developing gout while obesity has been shown to increase levels of uric acid in the blood. By contrast, studies have demonstrated that losing weight can reduce uric acid levels.<sup>3</sup>

- Centers for Disease Control and Prevention. How is gout treated? Available at www.cdc.gov/arthritis/basics/ gout.html. Accessed March 9, 2021.
- Fields TR. Gout: risk factors, diagnosis and treatment. Hospital for Special Surgery. Available at www.hss.edu/ conditions\_gout-risk-factors-diagnosis-treatment.asp. Accessed March 9, 2021.
- 3. Saag KG, Choi H. Epidemiology, risk factors, and lifestyle modifications for gout. *Arthritis Res Ther.* 2006;8 Suppl 1:S2.
- Mayo Clinic. Nutrition and healthy eating. Available at www.mayoclinic.org/healthy-lifestyle/nutritionand-healthy-eating/in-depth/gout-diet/art-20048524. Accessed March 16, 2021.

## What are my options to treat gout?

You may be encouraged to hear that gout is one of the most controllable forms of arthritis, particularly if it's caught early and treated promptly with anti-inflammatory drugs and urate-lowering therapy.<sup>1</sup> There are, however, hurdles to the medical management of gout, particularly because many patients with gout aren't prescribed uratelowering therapy or they fail to take it as directed. If urate-lowering therapy is right for you, it's important that you take it consistently and as indicated by your healthcare provider.<sup>2</sup>

While we will tailor your treatment plan to your own specific needs, in general, the goals of gout treatment are the same for everyone. These include pain relief from flares, prevention of future flares, stopping joint damage, and managing gout-related conditions or complications.<sup>1</sup>

Pain flare management is relatively straightforward. We can rely on the use of anti-inflammatory drugs such as ibuprofen, steroids, and an anti-gout agent called colchicine. To prevent future flares, it may help to make dietary and lifestyle changes, and avoid certain medications such as diuretics that are linked to excess uric acid in the blood.<sup>3</sup>

If you experience frequent acute flares or chronic gout, there are treatments such as allopurinol, febuxostat, probenecid, and pegloticase that may help to lower blood levels of uric acid and avoid further complications and long-term damage.<sup>3</sup>

Allopurinol and febuxostat are commonly used treatments that block the production of uric acid. While they can be effective for many patients, there are side effects such as fever, rash, nausea, and liver or kidney issues that we'll need to monitor. Another option, probenecid, is one of a class of drugs called uricosurics that improve uric acid removal. These agents are associated with potential side effects such as rash, stomach pain, and kidney stones.<sup>4</sup>

Pegloticase is a uric acid-specific enzyme that is typically prescribed for patients who do not achieve effective treatment of gout symptoms with conventional therapies such as allopurinol, febuxostat, or probenecid. Pegloticase works by metabolizing uric acid to an inert chemical compound called allantoin that is eliminated in urine, effectively lowering uric acid levels in the blood.<sup>5</sup>

Recent clinical practice guidelines indicate that switching to pegloticase is strongly recommended for patients with gout who have tried conventional treatments and still have uncontrolled disease, meaning that their serum uric acid levels are still >6 mg/dl and they either continue to have frequent gout flares (2 or more a year) or have tophi that won't resolve despite treatment.<sup>2</sup>

- National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). Gout symptoms, causes & diet recommendations. Available at www.niams.nih.gov/ health-topics/gout. Accessed March 9, 2021.
- FitzGerald JD, Dalbeth N, Mikuls T, et al. 2020 American College of Rheumatology guideline for the management of gout. *Arthritis Care Res (Hoboken)*. 2020;72(6):744-760.
- Centers for Disease Control and Prevention. What causes gout? Available at www.cdc.gov/arthritis/basics/ gout.html. Accessed March 9, 2021.
- Mayo Clinic. Medications to prevent gout complications. Available at www.mayoclinic.org/ diseases-conditions/gout/diagnosis-treatment/drc-20372903. Accessed March 9, 2021.
- Pegloticase injection [prescribing information]. Initial US approval 2010; Revised January 2020

## How long will a typical gout flare last?

There is unfortunately no "typical" pattern to a gout flare, which makes its duration hard to predict for an individual patient. Gout flares often start suddenly and without warning, and they may last for days or even weeks. A flare may then be followed by symptom-free periods of remission that last weeks, months, or even years, until suddenly, a new flare occurs.<sup>1</sup>

Although gout attacks are unpredictable, we know that they occur most commonly at night, at nearly 2.5 times the rate as during the day according to one recent study.<sup>2</sup> Certain foods (e.g., red meats and other high-purine foods) are thought of as "triggers" that may push gout over the edge to a painful flare.<sup>3</sup> Other potential triggers of a gout flare include sudden joint trauma, a fever-inducing illness, undergoing an operation, having an especially large meal, or overindulging in alcohol.<sup>4</sup> Gout treatment itself may trigger an acute flare due to rapidly lowering serum urate, which underscores the importance of titrating treatment when it is started and using appropriate gout flare prophylaxis (i.e., anti-inflammatory drugs).<sup>5</sup>

Although most gout flares will typically get better within 1-2 weeks, there is no guarantee. You may have flares every month, or you may go years between flares. The bottom line, however, is that treatment of gout is key—without treatment, your flares may last longer and occur more frequently over time.<sup>6</sup>

- Centers for Disease Control and Prevention. What are the signs and symptoms of gout? Available at www.cdc. gov/arthritis/basics/gout.html. Accessed March 9, 2021.
- 2. Choi HK, Niu J, Neogi T, et al. Nocturnal risk of gout attacks. *Arthritis Rheumatol.* 2015;67(2):555-562.
- FitzGerald JD, Dalbeth N, Mikuls T, et al. 2020 American College of Rheumatology guideline for the management of gout. *Arthritis Care Res (Hoboken)*. 2020;72(6):744-760.
- Versus Arthritis. What can trigger a gout attack? Available at www.versusarthritis.org/about-arthritis/ conditions/gout/. Accessed March 10, 2021.
- Tilleman JA, DeSimone EM II, McAuliffe R. Uratelowering therapy for the prevention and treatment of gout flare. US Pharm. 2017;42(3):33-37.
- National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). Gout. Available at www.niams. nih.gov/health-topics/gout. Accessed March 9, 2021.

### Is my gout under control when I am not in an active flare?

It is important to realize that gout can be problematic even in the absence of painful flares. High serum uric acid levels can lead to further attacks even without the presence of obvious symptoms; they can also increase the risk of long-term joint damage, kidney problems, and even heart issues if left uncontrolled.<sup>1,2</sup>

If your blood levels of uric acid remain high, needle-like crystals will continue to form and settle in and around any affected joints. That can cause inflammation and potentially lead to joint damage and deformity if left unchecked. These potential issues emphasize the importance of adherence



to long-term gout treatment even when you note no clear symptoms of disease to help maintain your blood levels of uric acid <6 mg/dL to prevent formation of new crystals and dissolve old ones.<sup>3</sup>

- Healthtalk.org. Thoughts about the future and longterm effects of gout. Available at healthtalk.org/gout/ thoughts-about-the-future-and-long-term-effects-ofgout. Accessed March 10, 2021.
- National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). What are the symptoms of gout? Available at www.niams.nih.gov/health-topics/ gout. Accessed March 9, 2021.
- Ruoff G, Edwards NL. Overview of serum uric acid treatment targets in gout: why less than 6 mg/dL? *Postgrad Med.* 2016;128(7):706-715.

### 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.<sup>1</sup> 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.<sup>2</sup>

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.<sup>1</sup>

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 (Table).<sup>1</sup>

- Centers for Disease Control and Prevention. How can I manage my gout and improve my quality of life? Available at www.cdc.gov/arthritis/basics/gout.html. Accessed March 9, 2021.
- FitzGerald JD, Dalbeth N, Mikuls T, et al. 2020 American College of Rheumatology guideline for the management of gout. *Arthritis Care Res (Hoboken)*. 2020;72(6):744-760.
- Physical Activity for Arthritis. Centers for Disease Control and Prevention. Available at www.cdc. gov/arthritis/basics/physical-activity-overview.html. Accessed March 15, 2021

## Table Exercising Safely with Arthritis: SMART Tips<sup>3</sup>

Patients with gout should protect their joints with low impact activities that have a low risk of injury. Provide your patients with these S.M.A.R.T. tips to safely exercise and enjoy the benefits of increased physical activity.



#### Start low, go slow

Pay attention to how your body tolerates physical activity. Then try to add a little more (eg, ~10 minutes more). Allow your body to adjust to the new level before adding even more.



## <u>M</u>odify activity when arthritis symptoms increase, try to stay active

Gout symptoms such as joint pain and swelling may come and go. You may have good days and bad days. Try to stay as active as possible without making your symptoms worse.



### Activities should be "joint friendly"

Choose activities that are easy on the joints like walking, bicycling, water aerobics, or dancing. These activities have a low risk of injury and do not twist or "pound" the joints too much.



### <u>Recognize</u> safe places and ways to be active

Consider joining an exercise class. If you plan and direct your own activity, find safe places to be active, such as walking on sidewalks or pathways that are well-lit, level, free from obstructions, and separated from heavy traffic.



### <u>Talk to a health professional</u> or certified exercise specialist

Health care professionals and certified exercise professionals are a good source of information about physical activity. They can answer your questions about how much and what types of activity match your abilities and health goals What are the risks if I decide I don't want to take medication to treat my gout?

While multiple effective treatments are available, adherence to urate-lowering therapy has been found in studies to be poor among patients diagnosed with gout. Rates of medication adherence are, in fact, worse in patients with gout than for many other chronic medical conditions, including hypertension, high cholesterol, hypothyroidism, and type 2 diabetes.<sup>1</sup>

It is vital that patients understand both the shortand long-term negative impacts of untreated gout, including the potential for joint damage and disfigurement. When left untreated, gout flares

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can happen more often and frequently last for a longer duration of time.<sup>2</sup> There are also broader health impacts of uncontrolled gout, including links to high blood pressure, heart disease, and kidney disease, among other issues.<sup>3</sup>

Many patients with gout hope that changes to their diet will be a magic bullet for their health problems. That is unfortunately not often the case, as modifications to what a patient eats and drinks may not be enough to bring uric acid levels in the blood down to the target goal of <6 mg/dl.<sup>4</sup>

Factors that may affect patient adherence to urate-lowering therapy include complicated work schedules, unstable living environments, lack of adequate access to healthcare, or limited financial means. In addition, failure of previous treatment may negatively impact adherence, so providers should be sure to proactively and promptly consider switching medication when patients have poorly controlled gout on a specific therapeutic regimen.<sup>5</sup>

- Briesacher BA, Andrade SE, Fouayzi H, Chan KA. Comparison of drug adherence rates among patients with seven different medical conditions. *Pharmacotherapy*. 2008;28(4):437-443.
- National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). Gout. Available at www.niams. nih.gov/health-topics/gout. Accessed March 9, 2021.
- American College of Rheumatology. How is gout diagnosed? Available at www.rheumatology.org/l-Am-A/Patient-Caregiver/Diseases-Conditions/Gout. Accessed March 9, 2021.
- Fields TR. Gout: Risk Factors, Diagnosis and Treatment. Hospital for Special Surgery. Available at www.hss.edu/ conditions\_gout-risk-factors-diagnosis-treatment.asp. Accessed March 9, 2021.
- FitzGerald JD, Dalbeth N, Mikuls T, et al. 2020 American College of Rheumatology guideline for the management of gout. *Arthritis Care Res (Hoboken)*. 2020;72(6):744-760.

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