

# Raising the Voice of Patients

# THE PATIENT'S GUIDE TO TREATING AND MANAGING GOUT

First Edition

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# PART ONE Welcome

Welcome to the first edition of CreakyJoints' patient guide for living with and managing gout. This original guide offers comprehensive, easy-to-understand information on gout and its treatment: what causes gout, how it can affect your body in different ways and progress, how it's treated and the steps you can take on your own to prevent flares and manage your symptoms.

CreakyJoints is a non-profit patient advocacy organization that empowers patients like you to raise your voice with key decision-makers you'll encounter while living with gout. This guide is the first of its kind, and it has been developed by leading experts, including doctors who specialize in gout management, other healthcare providers and patients like you. This unique guide is a roadmap for living with gout that's designed just for you. We hope that the information contained in this guide will help you navigate daily life with gout, helping you get what you want, need and deserve from your treatment and management. You'll find detailed, accessible explanations of gout symptoms and what causes them, treatment options for gout, lifestyle changes you can make to manage or prevent gout outbreaks, as well as how to talk to your insurance company about coverage for your treatments. We'll also share tips to help you talk with your family, friends and coworkers about gout and how it impacts vour life.

This first edition has been edited by leading doctors and healthcare experts, and will be updated and improved regularly as new research, information, and treatments on gout become available. These patient guidelines for gout management are one of a series that CreakyJoints produces, and there are new editions focused on other autoimmune diseases coming out soon.

Remember: The information in these guidelines should never replace the information and advice from your treating physician. This guide will help add to the discussion that you have with your healthcare professionals and others who play a role in your care and well-being with gout. CONCHO GREEN

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## PART TWO Patient Charter

CreakyJoints is a patient-powered community of people with arthritis (and their families) that is part of the nonprofit Global Healthy Living Foundation (GHLF). The CreakyJoints patient charter reflects our guiding principles, or the deeply held beliefs that drive our community's many efforts in arthritis education, support, advocacy, and research.

## WE BELIEVE:

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The patient experience is at the heart of medicine; thus the patient must be at the center of all medical decision making.

The medical process should stay between the patient and their care provider.

The patient should have access to all treatments deemed appropriate by their care provider.

Access to care should not be limited by external forces, financial or otherwise.

Patients should be empowered and educated with the tools needed to make their voices heard.

Elected officials, insurance providers, drug manufacturers, and all those associated with the healthcare system shall make it their goal to ensure the patient is the focus of all decisions.

The medical team should strive not only to do no physical harm, but to do no emotional, mental, or financial harm to the patient.

Patients should be treated with dignity, transparency, and respect by everyone involved in the healthcare process.

The information in these guidelines should never replace the information and advice from your treating physician. It is meant to inform the discussion that you have with healthcare professionals, as well as others who play a role in your care and well-being.

#### **RAISE YOUR VOICE:** Get Active, Advocate, and Take Charge of Your Healthcare!

**Speak up** at each doctor's appointment. **Bring a notebook** with you or **use your smartphone's Notes app** to write down information about your treatments, as well as your questions and concerns.

**Ask a friend or family member** to come to your appointments with you. It's easy to miss some details or instructions that your doctor gives you, so your helper can write everything down while you listen or ask questions.

Write down questions or concerns ahead of time so you don't forget them at your appointments.

**Always ask** about the possible side effects and the costs of each potential treatment. You can ask either your doctor or nurses these questions, or share any concerns you have with them.

Join other arthritis patients in local or national advocacy groups like CreakyJoints' 50-State Network.

**Be an advocate** to make sure your opinions and concerns are always heard by the people who create healthcare laws.

Use the power of technology! **Email or direct-message** other arthritis patients online on CreakyJoints. org's Facebook or Twitter page, or on other social media platforms. As you get to know other patients, start one-on-one conversations on the phone or via text so you stay informed.

**Add your name or sign online petitions** with a simple click. You will make every advocacy effort stronger by joining with others.

**Stay informed** on social media and lend your voice to arthritis advocacy or healthcare issues when the time is right for you. Go online, sign up, join phone or email chats, share your thoughts and attend live arthritis advocacy events when you can. Check out **P** Facebook.com/CreakyJoints or **P** @CreakyJoints on Twitter.

**Share your opinion or experiences.** Fill out patient surveys. Talk to arthritis advocacy groups looking for patient input on important healthcare issues. Offer your thoughts on Facebook or other social media, but remember that nothing is private online so think about what you want others to know. You don't always have to give your name, but when it's appropriate, let others — including elected officials in your state government and at the national level — know that you are a constituent, you vote, and you care about these issues! Choose email, mail, postcards, social media, phone calls, or in-person meetings — whatever works best for you.

**Stay informed and up to date**. There may be ways for you to get help affording your treatments, new treatments that may be more effective or affordable for you, or clinical trials going on in your area. Follow CreakyJoints at readed www.creakyjoints.org for news and articles about patients like you to find out how others are dealing with treatments or coverage challenges. Follow readed with the CreakyJoints **Facebook** page to hear news updates and share your thoughts. Also, check out the American College of Rheumatology's website, readed www.rheumatology.org, for news updates on OA and new treatment approvals.

**Speak up** about your side effects or concerns about your treatments. Don't tell yourself that you just have to put up with it or downplay these effects. Your doctor may be able to make changes to your treatment plan to help ease your side effects.

#### **Patient Charter**

**Look for patient assistance programs** from your drug's manufacturer if you struggle to afford copayments or coinsurance costs. Ask your doctor's office or pharmacy about any coupons or rebates available for you. Go online to find your drug's website, where these programs will be listed. You may be eligible for these programs, so find out! A great resource is:

**Ask your doctor about clinical trials** for new or existing treatments that may be available for you. Ask about current trials, and if you qualify for one, ask about any costs you may have to bear (such as travel to a clinic), or the trial's possible risks and benefits for you.

**Talk to your rheumatologist about all of your treatment options.** There are a number of medications used to manage gout, treat symptoms or even prevent gout attacks. If you're concerned about either the efficacy or the cost of your prescription, ask your doctor or nurse if you have other options. They may be able to prescribe another effective treatment at lower cost. Not every drug is right for every patient, but never hesitate to talk to your doctor about your concerns. Rising drug costs are a major issue in healthcare today.

**Treat your emotional and mental health symptoms as seriously** as your physical symptoms. Tell your rheumatologist and nurses if you're anxious, depressed, blue, not sleeping at night or worried about your long-term health. While gout is manageable, you may be concerned about future attacks or how you think others view you. Seek care from a mental-health professional or counselor if you feel you need help. Find support and comfort from other patients in local groups or online. Remember that you are not alone.

Take advantage of any program that could help you afford the gout treatments you need and deserve. Ask your doctor or nurses about copay assistance programs like coupons or rebates from your treatment's manufacturer. Also, go online to find your drug's website. Look for patient assistance programs there that may help you lower your out-of-pocket costs if you qualify. Also, call your insurance company to ask about the details of your drug coverage, talk to your pharmacist to ask about your options or possible discounts. Compare pharmacies' prices if that's an option for your drug coverage. There are number of websites that compare prices for gout drugs at various pharmacies with just a few clicks. Information is power.

**Ask your employer's HR department** if your insurer has a patient advocate or employee assistance programs as part of your coverage. These advocates or advocacy programs are designed to work on your behalf to provide information or assistance related to your healthcare.

#### PART THREE

# What Are Treatment Guidelines?

This guide is based on current treatment recommendations, or "guidelines," for patients with gout. These are also called clinical practice guidelines, and they're current recommendations for physicians and other healthcare professionals who treat and manage patients with this condition. Guidelines are meant for medical professionals, and they're written in language that reflects that. All guidelines are developed in a lengthy, detailed group consensus process by a panel of leading experts on that medical condition – which should include one or more patients and, sometimes, caregivers (such as a parent of a child with a juvenile disease).

The panel produces the recommendations for treatment and management included in clinical practice guidelines after reviewing data from large numbers of studies published in reputable medical journals. This information is carefully vetted and weighed by the panel to ensure that it is accurate, relevant, unbiased and from a reputable source. Every medical study is different, so the panelists review how the study was constructed, what factors were used to recruit or eliminate participants, who funded the study, and other factors. This process usually takes several years, but in the end, the recommendations carry a lot of weight. Your doctor, nurse or other healthcare professional may use the guidelines to prescribe your treatments.

The current clinical practice guidelines for gout management were created and published by the American College of Rheumatology, the professional association of rheumatologists and rheumatology health professionals in the United States. These guidelines have two parts. The first part focuses on managing your hyperuricemia, the levels of high uric acid in your blood that plays a major role in gout development and regular gout episodes. The second part focuses on therapy to treat the symptoms and inflammation of acute gouty arthritis. These guidelines contain recommendations on the medications your doctor may prescribe, and what steps to include in your overall treatment plan to control your gout, prevent acute gout attacks, and reduce your chances of developing long-term or "chronic" gouty arthritis, which could involve joint damage and deformity.

However, guidelines are recommendations, not rules or firm policies that every doctor will follow to the letter. Each patient is a person with a disease, not just a list of symptoms and test results. You are unique, and your treatment plan should be designed for you. Your doctor may not follow the guidelines exactly when prescribing your treatment. The goal should be to manage your disease and symptoms, and to improve your quality of life, not to follow a set plan and never veer from it. Your treating physician will assess you as an individual—your gout, your overall health, your medical history or family history, your lifestyle—and prescribe treatments based on your needs.

Several factors may influence your treatment plan. You may have certain comorbidities, or other health conditions in addition to your gout. That's very common for people with gout. For example, you may also have type-2 diabetes, obesity, kidney or liver function problems, or hypertension (high blood pressure). These other health conditions are common among people with gout. You may already be taking medications to treat those conditions. Your doctor will take your overall health and any other medications you take into consideration when making any decisions about your prescription medications or lifestyle recommendations.

Another factor that influences your treatment plan is cost. Some medications are very costly, and this is increasingly recognized as a problem and even a barrier to access to care in our country. We will provide tips and resources you can use to try to lower your out-of-pocket prescription drug costs, but there are still costs that each person must consider. Talk with your physician if you have concerns about the cost of your drugs, and if those concerns cause you to consider skipping doses, splitting pills or not fulfilling prescriptions. There may be more affordable medications that are effective options for you.

### PART FOUR What Is Gout?

Gout is a type of arthritis. It usually causes severe, sudden attacks of inflammation in a joint. Gout symptoms include severe, sharp pain; redness; swelling; and/or tenderness in your joint. Your joint may be visibly swollen and even feel warm when you touch it. Gout episodes may come on very quickly. They often happen at night or when you wake up in the morning. You may go to bed feeling fine and wake up with severe gout symptoms.

Gout typically affects a single joint – about half the time, it strikes in your big toe. Gout can affect more than one joint at the same time in some people. A gout attack can come on very quickly, and last anywhere from a few days to up to 10 days or longer.

Gout may affect other joints in your lower extremities too, such as your foot, ankle or knee. It may affect joints higher on your body too, such as your elbow, hand or wrist, or even small joints in your fingers. Your spine is rarely affected by gout. Gout may also affect soft tissues, like your bursae (fluid-filled sacs that cushion joints like your shoulder, elbow or hip) or the sheaths around your tendons (fibrous, rope-like tissue that connects bones and helps your joints move).

Gout attacks often subside on their own after a week or two, but medications can help speed up healing. More importantly, medications that lower your uric acid (also called urate) levels, when used regularly over time, are very effective in preventing future gout flares.

Gout may affect the same joint over and over, or you may have symptoms that crop up in different joints over time. Without treatment, your gout flares could become more frequent, spread to other joints, and become more severe. These attacks could damage the affected joint over time. Also, you can develop tophi, or large swellings near the affected joint or in other locations. Tophi are made up of a substance called urate that hardens. Tophi look and feel like hard lumps under your skin. They release inflammatory chemicals that may damage your joint if you don't get treatment.

If you have gout that isn't controlled by treatment and persists for years, you could develop chronic gouty arthritis.



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This can result in permanent joint damage, joint deformity and persistent pain. However, available treatments for gout can prevent this in most people. Don't ignore your gout, but don't worry that there is no hope for getting it under control. Getting control of your gout early is ideal, but treatments can help gout at any point.

Acute gout episodes can cause severe pain that keeps you from your normal activities during that time. You may be in so much pain that you have to stay home from work. Many people can't put on their shoe during an episode of gout due to the severe pain and swelling in their joint. You may struggle to get up and down the stairs of your house, or to do your household chores like laundry or standing at the stove to cook your family a meal. You may not be able to do something as simple as accompany your kids to the school bus stop or walk your dog during an acute episode of gout. Depending on your situation, gout attacks could be a "big deal," even if others around you don't really understand what you're going through.

If gout attacks become more frequent or severe, or if you develop chronic arthritis due to your gout, it can have a strongly negative impact on your life. Pain and disability could become a chronic problem that disrupts your work and home life. That's why treatment and management are so important. Don't dismiss gout as just "something you have to live with" for the rest of your life – your physician can help you control these attacks and effectively manage gout.

#### WHAT CAUSES GOUT?

Gout is caused when an excessive amount of urate builds up in your blood. Urate (also called uric acid) is a natural substance or chemical. Urate is produced by your own body as it metabolizes, or breaks down, a substance in the foods and drinks you consume called purines.

Purines are found in many foods and drinks, and they're also made naturally by your body. Certain foods and drinks are very high in purines. These include red meats, organ meats like liver or kidneys, shellfish like mussels or scallops, thick soups and gravies, oily fish like mackerel or anchovies, and beer. Excessive consumption of purine-rich foods s can increase your risk of getting gout, since the purines are broken down in your body to make urate.

Genetics are a key part of how we get gout (see further discussion under "Who Gets Gout?" below). About 10% of people with gout make too much urate due to genetic factors. About 90% of people with gout reabsorb too much urate in their kidneys because of genetic factors. People with decreased kidney function for any reason (such as hypertension or diabetes) can increase their urate since the kidney has more trouble filtering the urate from the blood.

People who either make too much or excrete too little urate are especially sensitive to foods, drinks or medications that increase urate levels. This is what happens when you drink alcoholic beverages: they stimulate the kidney to pull more urate back into your bloodstream. The same thing happens when you take medications such as some diuretics, like hydrochlorothiazide (Hydrodiuril®) or furosemide (Lasix ®). Beer increases urate level in two ways. It contains proteins that are broken down to form purines that then break down to form urate in your body. As with all alcoholic drinks, it also makes your kidney reabsorb more urate. That's why beer is often talked about as a potent stimulus for gout flares.

High-fructose corn syrup, which is found in many sweetened soft drinks and other beverages, can raise urate levels too. People with gout are often surprised when their friends who eat or drink the same things they do don't get gout. Why does this happen? The reason is that people who develop gout have a genetic tendency to high urate (for either of the reasons discussed above) and are much more sensitive to the further increase that comes from particular foods or drinks.

Once you have high urate in your blood, the urate crystals can deposit in your joints (and other locations). When

#### What Is Gout?



the urate crystals in your joints are recognized by your immune system, they are identified as "foreign bodies" and are attacked the way bacteria would be. This involves all the signs of inflammation: redness, heat and swelling, with white blood cells rapidly entering the joint. Urate crystals also can build up and form hard deposits called tophi (or the singular, tophus). That's why gout is considered a "crystal" arthritis or crystal disease. Urate crystals can also form kidney stones, which can be extremely painful to "pass" through your urine.

High urate in your blood is also called hyperuricemia. One of the

goals of your gout treatment plan, including medications and diet/lifestyle changes, will be to keep your uric acid level below 6.0 milliliters per deciliter, or mg/dL. People with gout with tophi will have a lower urate goal, which is below 5 mg/dL. Your doctor can test your uric acid levels at regular appointments so you know your current number. You should always ask about your urate level and know that your goal is below 6.0.

When you have a gout flare, and the body sees the urate crystals as "foreign," you are seeing the results of your body's attempts to destroy the crystals. White blood cells attack and ingest the crystals, and inflammatory chemicals are released that bring in even more white blood cells. The result is inflammation. Your big toe (gout's favorite spot) may swell up suddenly, turning red and hot, so you think it may be infected or even fractured. It's not an infection or a fracture, however – it's inflammation.

Whether a person with gout makes too much urate or their kidneys excrete too little, the end result is high blood urate, and lowering it is the key treatment goal. Adjusting your diet and keeping well hydrated are important, but for most people with gout, one or multiple medications will be needed to get the urate to goal.

#### WHO GETS GOUT?

Gout is a very common disease in the developed world. A major study conducted 10 years ago found that as many as 8.3 million U.S adults have been diagnosed with gout, or 3.9 percent of the adult population. That includes 6.1 million men and 2.2 million women. It's extremely rare in children.

The number of adults with gout is rising. This may be due to some lifestyle-related risk factors for gout, like obesity, high sugar consumption and heavy alcohol drinking. As obesity rates have spiked in the U.S., so have gout rates. In a study of U.S. adults tracking gout rates from 1988-1994, only 2.7 percent had been diagnosed with the disease.

Gout was once called the "rich man's disease" or the "disease of kings." This is probably because famous men like King Henry VIII of England and American Founding Father Benjamin Franklin had gout. People often assumed that only wealthy men who could afford to eat diets full of "rich" delicacies and drinks developed gout. Today, people of all socioeconomic levels have gout, so don't buy into the myth that gout is only a problem that affects

#### What Is Gout?

rich people. Gout has more to do with how your body metabolizes uric acid than your bank account.

High levels of uric acid in your blood, can cause the monosodium urate crystals to form, leading to gout, but not every person with a high uric acid test result does get the disease. What factors make a person more likely to get gout?

One risk factor for gout is being male. Men get gout at much higher rates than women – men are anywhere from five to 10 times more likely to get gout, especially in younger age groups. Before they reach menopause, women are far less likely to get gout because female sex hormones have a protective effect on uric acid levels. But after menopause, women's risk of gout increases.

Other risk factors for gout include:

- Obesity, or having a body-mass index over 30 kg/m2
- Heavy, habitual drinking
- Some medications, including diuretics, which treat high blood pressure, and cyclosporine
- High consumption of foods rich in purines
- High purine foods include: red meats, organ meats and certain types of seafood (anchovies, herring, sardines, mussels, scallops, trout, haddock, mackerel and tuna).
- High consumption of sugar-rich drinks (like sweet tea or soda pop) or foods
- Certain chronic health conditions, like high blood pressure, diabetes mellitus, insulin resistance, congestive heart failure, metabolic syndrome and kidney disease
- Family history of gout, such as if your dad, granddad or brother had gout

Certain racial and ethnic groups may have higher prevalence of gout, and this is likely to be driven by genetic factors. There are particular genes associated with greater susceptibility to develop gout. African-Americans have higher gout rates than white Americans. Higher gout prevalence is also associated with the Maori ethnic group from New Zealand and the Hmong ethnic group from China.

Because several gout risk factors are related to your lifestyle and diet, you can take steps to change them. If you already have gout, medications can help prevent further attacks and lower your uric acid levels. But changing some dietary and lifestyle habits add further protection. Cutting back on your alcohol consumption, getting more exercise, and losing weight with a healthy diet emphasizing fresh fruits and vegetables over red meats and processed foods are excellent habits for your overall health. These steps may help you prevent future gout attacks too, because they can help lower uric acid levels. Uric acid levels in your blood are not static. You can fight back against gout.

Diet (including how much alcohol you drink) and exercise are risk factors you can control – but you may need a little help to make those changes stick. Your doctor is your partner in managing your gout and preventing long-term problems, but other members of your healthcare team, such as nurses, physical therapists, nutritionists and others, can play a major role as well. We'll talk more about lifestyle changes this later in this guide.

#### **HOW IS GOUT DIAGNOSED?**

The symptoms of an initial, acute gout episode—sudden, severe pain and swelling in a joint like your toe--are telltale. If you experience these symptoms, or tell your spouse or friends what's happening, they may respond, "It's gout. You can be sure it's gout."

But how can you be sure it's gout? If you notice these signs, see your doctor right away to get an accurate diagnosis and start treatment. Your primary-care physician can diagnose gout in most cases. You may also be referred to a rheumatologist, a specialist in the diagnosis, treatment and long-term management of arthritis and related rheumatic diseases, which includes gout.

# PART FIVE Monitoring

#### **TESTS YOU'LL NEED**

There is no single, simple test to confirm diagnosis of gout. First, your doctor will give you a physical examination to assess your overall health, and to get the history of your joint pain and other symptoms that suggest gout. He or she may check for pain or swelling in other joints too. If you have signs of possible gout in several joints, that's called polyarticular disease. However, early on, many people have gout symptoms in just one or possibly two joints.

You may be asked more about your family history, your diet and drinking habits, and other medical conditions you may have. Be as open and clear as possible. Questions about how much or how often you drink alcohol, or how much or what you eat are not meant as a way to judge your lifestyle, but to gain a complete picture of potential gout risk factors. Also, don't downplay how much pain you are feeling. Some people don't like to admit they are in pain or that they can't work through it. Be honest about the intensity and impact of your pain, so your doctor can take this into account when prescribing your treatments.

Your doctor will give you a blood test can measure your uric acid levels to see if they are elevated. It's important to know that any urate level above 6 is too high for a person with gout, even if their result is within the lab's "normal range" for urate. However, many people with elevated uric acid do not get gout or experience gout flares. Essentially all gout patients will have a urate level above 6.0 mg/dL, but many people with high urate levels don't get gout. Be aware that your urate level can go down during a gout flare, so if the level is above 6.0 during an attack it will generally be repeated two weeks after the flare is over to see your true urate "baseline" level.

To diagnose gout, your doctor may look for monosodium urate crystals in the synovial fluid of your swollen joint. Your doctor will insert a needle to draw out some fluid, and examine it under a polarized microscope to look for needle-like crystals that suggest gout. If you don't have visible monosodium urate crystals in your joint after one flare, that doesn't necessarily mean you don't have gout. At times joint fluid may need to be re-evaluated during a future flare to finally see the crystals. Seeing urate crystals gives an absolute diagnosis of gout. However, it is quite possible to diagnose gout without removing joint fluid in people with "classical" gout symptoms, physical exam and elevated urate levels. Removing and analyzing joint fluid for urate crystals is especially important when the doctor needs to separate gout from other conditions, such as infections or other types of crystal-related arthritis.

Your doctor may also take some images of your affected joint. These include ultrasound or dual energy computed tomography scans (CT), which help show signs of early gout. If you've had gout for a while, X-rays can show more long-term joint damage. Imaging tests are helpful for confirming the diagnosis along with the joint fluid test, blood test and physical exam.

It's very important that you do not try to self-diagnose yourself with gout based simply on how your joint looks and feels, and then try to treat it on your own with supplements, herbal treatments or fad diets. See your doctor to get an accurate diagnosis and start treatment.

## PART SIX Treatments for Acute Gout

Gout is a disease that can be effectively treated and managed. Prompt diagnosis and initiation of treatment can, in most cases, alleviate your acute gout symptoms: pain, swelling and inflammation in the affected joint. You may start to feel better quickly, even within a day or two. You may be able to quickly return to work and other daily activities. Controlling those acute symptoms is the first, immediate goal for gout treatment.

What about after that? Once you get the acute, painful attack under control, don't consider gout to be out of sight, out of mind. Your doctor can prescribe treatments for you with these long-term goals in mind:

- Prevent future gout attacks of pain and inflammation
- Prevent tophi from developing, as these could damage your joint
- Lowering your uric acid levels and controlling hyperuricemia over the long term to prevent not just gout, but also kidney problems such as kidney stones
- Addressing any lifestyle factors, like diet, obesity or alcohol consumption, that may contribute to high uric acid levels and/or gout

So your gout treatment plan will include medications and recommendations for both your immediate symptom relief and your long-term management of gout. Your treatment plan will likely include more than just medications. Your physician may also make recommendations about lifestyle changes you can make to help prevent gout attacks and manage your urate levels (along with your urate-lowering medications). These may include:

- Diet tips, like cutting back on or avoiding foods high in purines, along with a handy list of these foods
- Keeping a food diary
- Recommendations to lose weight, like a daily eating plan or "diet," or a referral to a formal weight-loss program or registered dietitian if you need help
- Limiting your alcohol intake
- Quitting smoking
- Exercise or physical activity
- Physical therapy

We'll go over lifestyle changes for gout management later in this guide. If you need professional help to lose weight, manage overeating or emotional eating, controlling your drinking, quit smoking or get more physical activity, your physician can also refer you to healthcare professionals who specialize in these areas of treatment. You don't have to go it alone. Change is not easy. In fact, it's very hard for most people! While a gout attack may feel like a warning sign that you need to cut back on your alcohol intake or lose weight, actually achieving those goals and maintaining them is challenging. So ask for the help, assistance, and support you need.

#### TREATMENTS FOR ACUTE GOUT FLARES

Your first warning sign that you have gout is likely a sudden, acute flare of gouty arthritis. This is also called synovitis. It's the inflammation of tissue in your joint caused when your body's immune system triggers white blood cells to attack the crystals that have settled in your joint.

The first, immediate step in your treatment plan is to treat that inflammation. This should quickly ease your symptoms. Current treatment guidelines for gout suggest that your doctor prescribe treatment to control your inflammation within 24 hours if possible. So don't delay contacting your doctor's office when you have signs of a gout attack! Toughing it out is generally a very bad strategy for managing gout, since this gives more time for the inflammatory process to build up a head of steam. It is also a good idea to keep a supply of anti-inflammatory medications at home for immediate treatment.

Medications used to treat inflammation in an acute gout flare include:

- Nonsteroidal anti-inflammatory drugs (NSAIDs)
- Corticosteroids (also called glucocorticoids or "steroids" for short) by mouth, by intramuscular injection or injected directly into a joint
- Oral colchicine

If your gout attack is limited to one or two joints, and your pain is mild to moderate, you may only need one of these medications to control the inflammation. However, if your pain is severe, and if one or more of your larger joints (not just a toe) are involved, you may need a combination of treatments to get it under control.

Also, if one drug doesn't work well enough to treat your gout attack symptoms, your doctor may either switch you to a different medication or try a combination of medications. There are several options for treating gout attacks, so your doctor will decide which one is best for you. An inadequate response to your first medication is:

- About less than 20 percent improvement in your pain (measured and scored on a standard questionnaire) within 24 hours, or
- Less than 50 percent improvement in your pain after 24 hours or later.

#### Colchicine

Colchicine (Colcrys<sup>®</sup> or Mitigare<sup>®</sup>) is a prescription, oral anti-inflammatory medication that's prescribed to treat gout and other types of crystal-related arthritis. There are some unusual conditions that colchicine also treats, but it's not an anti-inflammatory medication that works for things like headaches or joint injury. Colchicine may be the first choice to treat your acute gout flare and ease your symptoms if it's within 36 hours of the onset of your symptoms.

Colchicine may also be prescribed at lower doses as a preventive medicine to reduce your likelihood of a future flare. This lower-dose strategy is often used during the first six months of treatment with a medication that lowers the urate level, when we know that "mobilization flares" are common and a person can actually have more gout flares than previously thought. Colchicine does not lower the urate level in the body, so it really isn't a long-term solution to gouty arthritis.

#### What We Already Know

Colchicine (Colcrys<sup>®</sup> or Mitigare<sup>®</sup>) is the only medication approved by the FDA to both treat and prevent gout flares. It interferes with the interactions between monosodium urate crystals and the surfaces of cells they encounter in your joint, so it "interrupts" the inflammatory reaction to these crystals. It also appears to stop inflammatory white blood cells from activating and moving to attack the crystals, where they cause your sudden, severe gout symptoms.

Colchicine is also used as a long-term treatment to prevent future or recurrent gout flares, by chronically lowering the ability of urate crystals to cause inflammation. It doesn't lower uric acid levels in your blood, though. Also, colchicine does not treat joint or tissue damage from chronic gout.

#### Why Am I Taking Colchicine?

Colchicine (Colcrys<sup>®</sup>) is prescribed as either a short-term medication to relieve your acute gout flare or as an ongoing, preventive treatment during the early stages of taking another medication to lower urate. Your doctor can prescribe colchicine to keep on hand in case you do have a gout flare.

Don't take colchicine to relieve other types of arthritis pain or back pain. It's effective in treating treat gout pain, but most types of arthritis don't respond to colchicine. Colchicine comes in a tablet that you swallow. You can take colchicine with or without food, but some people find it easier on the stomach to take with food. For an acute gout attack, it's usually taken twice a day. You take one dose of colchicine (usually 1.2 mg) when you first notice the symptoms, followed by a smaller dose (usually 0.6 mg) one hour later, with no further doses for at least 12 hours.

This may be followed with doses of 0.6 mg once or twice daily (every 12 hours). If you don't get relief within a few days, let your doctor know. You may need to switch to or add another medication.

**Follow your prescription directions closely when you take colchicine.** Don't take more of this medication than your doctor prescribes or directs for a gout flare. If your doctor prescribes colchicine for you to take regularly to prevent gout flares, and you have an acute gout flare while on this treatment, contact your doctor immediately. Your doctor may direct you to take a temporarily higher dose of colchicine to treat the flare, or add another medication to treat it. Follow your doctor's directions exactly so you don't take too much medication.

Let your doctor know if you are allergic to any of these medications that could interact with colchicine:

- Antibiotics like azithromycin (Zithromax<sup>®</sup>), clarithromycin (Biaxin<sup>®</sup>), erythromycin (E-Mycin<sup>®</sup>) and telithromycin (Ketek<sup>®</sup>). Be aware that the drug interaction with clarithromycin is much more significant than the other types of antibiotics. Make sure to tell your doctor if you are prescribed colchicine and clarithromycin at the same time.
- Antifungal medications like fluconazole (Diflucan<sup>®</sup>), itroconazole (Sporanox<sup>®</sup>) and ketoconazole (Nizoral<sup>®</sup>)
- Aprepitant (Emend<sup>®</sup>)
- Statins: Be aware that the interaction of statins with colchicine is different depending on the statin you take. For example, rosuvastatin (Crestor<sup>®</sup>) has no significant interaction with colchicine, and atorvastatin (Lipitor<sup>®</sup>) has a relatively minor interaction that may be addressed with a lower colchicine dose. Tell your doctor about all of your prescription medications, including anything new you're prescribed while talking colchicine.
- Cyclosporine (Neoral<sup>®</sup>, Sandimmune<sup>®</sup>)
- Digoxin (Digitek<sup>®</sup>)
- Diltiazem (Cardizem<sup>®</sup>, Dilocor<sup>®</sup>)
- ▶ Fibrates
- Medications to treat AIDS or HIV
- Nefazodone
- Ranolazine (Ranexa<sup>®</sup>)
- Verapamil (Calan<sup>®</sup>, Covera<sup>®</sup>, Isoptin<sup>®</sup>, Veralan<sup>®</sup>)

Also, let your doctor know if you have ever had kidney disease, liver disease, or, for women, if you're pregnant, plan to become pregnant, or are breastfeeding. If you become pregnant while taking colchicine for gout, let your doctor know right away.

Don't drink grapefruit juice or eat fresh grapefruit while taking colchicine. Grapefruit juice can cause a mild increase in colchicine dose. Occasional small amounts of grapefruit or grapefruit juice are unlikely to cause a major problem.

If you miss your dose of colchicine, take your dose as soon as you remember. Don't take your next dose for 12 hours.

If you're very close to the time when you would take your next dose (if taking regularly for gout attack prevention), just wait until the time for your next dose and stay on your regular dosing schedule. Don't "double-dose" colchicine to make up for the dose you missed.

# Overdosing on colchicine may be fatal. Take your medication only as prescribed. Do not share colchicine with other people you know who have gout or seem to have gout attack symptoms.

#### What Are the Possible Side Effects of Colchicine?

Colchicine may cause some side effects, such as:

Diarrhea

#### Nausea

- Stomach pain or cramping
- Vomiting

If these persist for hours or are severe, let your doctor know. Also, if you experience any of these side effects, alert your doctor's office immediately:

- Muscle pain or muscle weakness
- Signs of an infection: sore throat, fever, chills, body aches
- Fatigue or weakness
- Numb fingers or toes
- Strange bruising or bleeding that seems unusual
- Unusually pale lips or tongue

#### NSAIDs

Nonsteroidal anti-inflammatory drugs, or NSAIDs, are the most commonly used treatments for inflammation and pain in conditions like gout or other types of arthritis. NSAIDs are generally safe to use for acute flares of pain and inflammation. For a gout attack, you may need a short-term, high-dose prescription NSAID.

It's not ideal to take NSAIDs regularly for pain that persists, as they can cause serious side effects, including ulcers, diarrhea or stomach pain.

#### What We Already Know

NSAIDs block proteins called enzymes that help your body produce lipids that are called prostaglandins. These lipids, such as COX-1 and COX-2, play a role in the processes of inflammation and pain. NSAIDs help control pain, swelling, redness and fever.

Most traditional NSAIDs block both COX-1 and COX-2. But COX-1 also helps keep your stomach acid under control. There is one NSAID available in the U.S., celecoxib (Celebrex<sup>®</sup>), that is more selective, and only blocks COX-2. It may be gentler on your stomach than other NSAIDs. Your doctor will decide which NSAID is right for you.

Common NSAIDs your doctor may prescribe for gout attacks and symptom relief:

- Indomethacin (Indocin<sup>®</sup>)
- Naproxen (Naprosyn<sup>®</sup>)
- Sulindac (Clinoril<sup>®</sup>)
- Naproxen sodium (Aleve®)
- Celecoxib (Celebrex<sup>®</sup>)

#### OR

- ▶ Ibuprofen (Advil<sup>®</sup>, Motrin<sup>®</sup>)
- Diclofenac sodium (Voltaren<sup>®</sup>)
- Ketoprofen (Actron<sup>®</sup>, Orudis<sup>®</sup>)
- Piroxicam (Feldene<sup>®</sup>)
- Meloxicam (Mobic<sup>®</sup>)

Some NSAIDs are available over the counter (OTC), generally at lower doses for mild pain. These include aspirin, ibuprofen and naproxen sodium. You can also buy generic or "store brand" versions of these medicines. For an acute gout attack, you'll likely need a prescription NSAID. So don't try to just self-treat your gout with OTC medicine. Small doses of NSAIDs may still cause side effects, yet be inadequate to handle a gout flare. Also, don't take an over-the-counter NSAID on your own if you're already taking a prescription NSAID. You could easily take too much

medicine and put yourself at high risk for side effects like stomach pain or bleeding.

#### Why Am I Taking an NSAID?

NSAIDs are used for short-term relief of inflammation and pain. A high-dose NSAID may take care of your gout attack symptoms quickly. You should not have to take your NSAIDs long term. Using an NSAID long term increases the risk of side effects.

#### What Are Possible Side Effects of NSAIDs?

NSAIDs are generally safe and easy to tolerate. The most common side effect of taking NSAIDs is stomach pain or heartburn. Others include:

- Bleeding
- Ulcers
- Raised blood pressure
- Increased risk of heart attack or stroke
- Ringing in your ears
- Lightheadedness or dizziness
- Headaches
- Allergic reactions, or liver and kidney problems (rarely)

If you notice any of these symptoms, get medical care right away:

- Vomiting
- Swollen ankles, hands or feet from fluid retention
- Black or bloody stool
- Unusual weight gain

Your risk of side effects goes up if you take higher doses of NSAIDs or take these drugs over long periods of time. Also, people who are older or have a history of ulcers may be at higher risk for stomach problems with NSAID use.

Celecoxib treats joint pain as effectively as other NSAIDs, but because it only blocks COX-2 and not COX-1, it may be easier on your stomach. COX-1 is a prostaglandin that protects the lining of your stomach. So celecoxib may ease your pain without the added risk of stomach pain or ulcers. People who are allergic to sulfa drugs generally need to avoid celecoxib. Also, celecoxib may have some of the same heart-related risks that other NSAIDs do.

Let your doctor know if you have side effects like heartburn or stomach pain. Don't "grin and bear it." Your doctor may prescribe another medicine for your pain. Don't try to treat severe stomach pain or heartburn on your own. Tell your doctor. Your doctor may be able to add another medicine to lower your stomach acid. These include omeprazole (Prilosec® or Nexium®) and misoprostol (Cytotec®). You can buy these over the counter or get a prescription.

Some simple ways you may ease NSAIDs' side effects include:

- Take your medicine with food, such as with your normal meals or a snack like crackers.
- Try coated pills instead of uncoated.
- Take the lowest possible dose you need to manage your pain.
- Don't keep taking NSAIDs, even OTC brands, for a long time if your pain does not subside. Talk to your doctor about other options.

#### Corticosteroids

Corticosteroids are also called glucocorticoids or "steroids" for short. They may be a good choice to treat your acute gout symptoms if you can't take NSAIDs for any reason. Corticosteroids for gout treatment may be oral (pills you

swallow) or injected (into a muscle or into the affected joint). Prednisone, methylprednisolone and triamcinolone acetonide are corticosteroids used to treat gout.

#### What We Already Know

Corticosteroids are strong, fast-acting anti-inflammatory medications. They are synthetic versions of a natural hormone made in your body's adrenal glands called cortisol. When you take a higher dose of this hormone than your body is used to, it can reduce inflammation. They also suppress your immune system.

Corticosteroids are prescribed for many different diseases, and they are one option for treating the inflammation in gout. They are one choice for initial monotherapy, or a single treatment, of your acute gout symptoms. They may be also be used in combination with other treatments if pain is more severe or there are multiple joints involved.

Your doctor will look at the number of joints involved, and the severity of the flare, to determine what form of corticosteroid therapy is right for you. If multiple joints are inflamed, systemic therapy such as oral corticosteroids are the best option. Initially, you'll take 0.5 mg/kg (of your body weight) of oral prednisone for five to 10 days and then stop, or take this dose for two to five days, and then taper (slowly reduce it each day) the dose for seven to 10 days. Another option is an oral dose-pack of methylprednisolone, which is tapered each day, and easy to follow. There are many acceptable dosing plans for corticosteroids in gout. The main thing is to be clear on exactly which regimen your doctor prescribes and to report back to the doctor if you are not improving. Sometimes, a higher dose is needed. Also, if you take corticosteroids for a gout flare and it completely resolves, check with your doctor about whether you should complete the full course. Sometimes, the dosing can be more rapidly tapered once your flare has resolved. An alternative or oral corticosteroid is an intramuscular injection of a steroid such as triamcinolone acetonide (usually a 60 mg dose) followed by oral corticosteroids as needed.

However, if a single joint is involved (such as a toe, ankle or knee), you may be treated with an intra-articular corticosteroid. The dose of intra-articular corticosteroids may vary depending on the size of the affected joint. The advantage of local injection is that it concentrates the corticosteroid at the point of inflammation and reduces the amount of steroid effects on your body as a whole.

#### Why Am I Taking Corticosteroids?

Corticosteroids in various forms are used for short-term, fast-acting relief of inflammation. These drugs can provide quick, powerful relief of your symptoms: pain, swelling, redness and warmth. High-dose corticosteroids are not meant for long-term use in gout. On occasion, low doses of prednisone are used to prevent gout flares when people start medications such as allopurinol, but colchicine is used much more often for this purpose. Corticosteroids, like NSAIDs and colchicine, do not lower your uric acid levels, so they do nothing to help to get rid of the urate crystals in your body. All of these treatments can help stop urate crystals from causing inflammation, but other types of treatment are needed to actually remove the crystals from your joints.

#### What Are the Possible Side Effects of Corticosteroids?

Corticosteroids can have side effects, especially if you take the oral form of the drug (as opposed to a local injection). The side effects you experience depend on the dose and how long you take corticosteroids. For many people, side effects may be mild and temporary.

Possible side effects of oral corticosteroids may include:

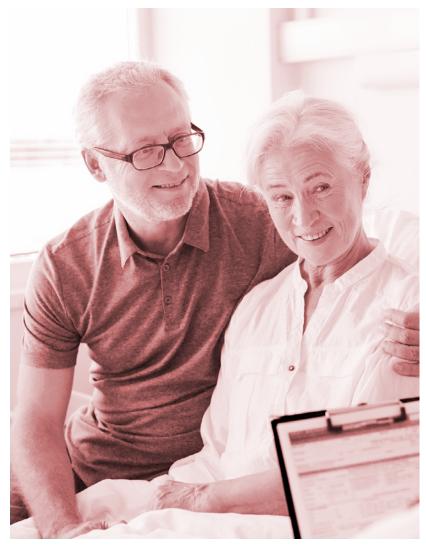
- Mood or memory problems
- High blood pressure
- Weight gain
- Fluid buildup that causes leg swelling
- Glaucoma

Corticosteroids could elevate blood sugar, especially if taken longer-term, and this could either trigger or worsen diabetes. Other side effects more associated with long-term corticosteroid use are osteoporosis, cataracts, easy bruising, thinning of the skin, poor wound healing and suppressed adrenal gland hormone production. These are not likely to happen to you with a short-term dose for gout.

Injected corticosteroids into an affected joint are not likely to cause the same side effects as the oral drugs. Possibly, you may have a temporary reaction, such as thinning or loss of color in the skin around the injection site, flushing of your face, insomnia (lack of sleep) or elevated blood sugar. You should not receive more than three or four injections of corticosteroid a year for any type of joint pain. Repeated corticosteroid shots are not recommended as a way to treat recurrent gout attacks. Multiple attacks are a warning that you need medication to reduce your urate levels.

#### Corticotropin or Adrenocorticotrophic Hormone (Acthar<sup>®</sup>, H.P. Acthar Gel<sup>®</sup>)

Another possible first-line therapy for an acute gout attack is adrenocorticotropic hormone, or corticotropin or ACTH (Acthar®, H.P. Acthar Gel®). It's not a common first-line treatment for a gout attack, but it's a possible option for some people, particularly those who cannot take oral NSAIDs, colchicine or corticosteroids for some reason, or who are hospitalized.



What We Already Know

Adrenocorticotrophic hormone (Acthar<sup>®</sup>, H.P. Acthar Gel<sup>®</sup>) is also called corticotropin or systemic corticotropin. It belongs to a group of proteins in your body called melanocortins. It regulates the function of your adrenal cortex and influences your body's secretion of steroid hormones.

#### Why Am I Taking ACTH?

An ACTH injection is given to relieve a severe flare of inflammation in gout. It's a subcutaneous injection of a dose of 25 to 40 international units (IU).

# What Are the Possible Side Effects of ACTH?

Corticotropin or ACTH injections are relatively safe when used for gout treatment. Possible side effects of this drug when injected at this dosage include hyperglycemia (high blood sugar), hypokalemia (low potassium in your blood) and edema (swelling), as well as increased infection risk, ulcers, mood changes, insomnia, acne, dry skin, thinning skin, bruising, poor wound healing, sweating, headaches, dizziness

#### A NOTE ON SIDE EFFECTS OF ANY DRUG

Do long lists of possible side effects included on your prescription package insert scare you? You're not alone!

Remember: Side effects of any particular drug are only possible – you may not have them at all. In other cases, they may be mild and temporary. They are listed on the drug's website, medical information websites or your prescription insert because they are possible for some people in some situations (even very rarely).

Your doctor and nurses are aware of all the possible side effects of your drugs, and they will go over the most likely side effects you may experience when you receive your prescription. If you don't understand what a particular word or term means, how the side effect actually feels or how likely you are to experience the side effect at this dose, ASK! You can also ask your pharmacist when you fill a prescription for oral medications. Don't be shy when you are receiving any prescription medication for your gout. Ask questions about side effects, risks vs. benefits, and what signs should alert you to call your doctor. Your doctor and/ or nurses will tell you what you need to know about your drugs, including how to take them and what side effects are likely or possible, but speak up if you need further explanation or if you have concerns.

When you are reading about the possible side effects of medications to treat a gout flare, remember that side effects relate not just to which medication you are taking, but also to the dose and duration. Fortunately, most gout flares can be controlled quickly, especially if treatment is started early after the flare starts. Because of this, most people can take medications such as NSAIDs or corticosteroids for a gout flare and tolerate them very well, despite the fact that these medications might have caused problems if used long term.

Medications for gout flare are a good example of a situation where the individual patient needs to be taken in consideration when the medication is chosen. For example, if you have an active ulcer or poor kidney function, an NSAID may not be best for you. If you have poorly controlled diabetes, corticosteroids may not be a good option for you. Make sure that you give your healthcare provider your full medical history when you talk about prescription medicines for your gout. and upset stomach.

Call your doctor immediately if you notice any of these side effects: vision problems, edema, rapid weight gain, shortness of breath, severe depression or thoughts of suicide, seizures, bloody or tar-like stool, coughing up blood, severe pain in your upper abdomen, confusion or signs of very high blood pressure (ringing in your ears, dizziness, headache, chest pain, uneven heartbeat, etc.).

Acute Gout Flares: What Else You Can Do While your prescription gout medication should quickly treat your joint pain, swelling and redness, there are things you can do on your own in addition to taking your medicine.

**Ice it.** Treat your swollen joint with topical ice for a short period of time (no more than 10 minutes at one time) if you need a little extra relief. Ice can ease pain and swelling. Wrap ice or an ice pack in a soft towel or cloth before placing it on your skin. Don't place ice directly onto your joint, even if it's inside a plastic bag.

**Elevate it.** If your big toe or foot is affected, prop it up on pillows while you rest on the sofa. Keep your joint elevated above the level of your heart for the best effect.

**Give it a rest.** It's OK to take it easy for a day or two while your symptoms are at their worst. Rest if you can. Try not to use your affected joint until your medications can reduce the inflammation. Gout flares often get worse if you try to ignore them and stress your affected joint.

**Treatments for Hyperuricemia** 

As we mentioned, once your acute gout flare is treated, your doctor will work with you to try to prevent recurrent attacks or the development of tophi, and to lower your urate levels. As we mentioned, many people with gout take colchicine to prevent gout flares.

However, colchicine does not lower your urate.

Not everyone who has one gout flare or receives a gout diagnosis needs to go on long-term medications to manage their gout. In some cases, you may be able to take a short-term treatment for your one gout attack to get the inflammation under control, and make changes to your diet and lifestyle that help you manage your uric acid levels and prevent future attacks. However, if the flares become more frequent, you will likely need to add a medication to control your urate levels.

People who have the following concerns may need to take medications to control their hyperuricemia and gout:

- ▶ If you have two or more gout flares each year
- If your gout flares are so severe that you're not able to work or perform your daily tasks if so, you may not need to wait until two attacks in a year.
- ▶ If your doctor determines that you have damaged your joint(s) on X-ray or other imaging study due to gouty arthritis
- ▶ If you have tophi, or the hardened, lumpy uric acid crystals that can damage joints
- If you have kidney damage, kidney stones, or if you excrete high amounts of uric acid in your urine. The American College of Rheumatology recommends medication to lower urate levels after one flare of gout, if the person has abnormal kidney function.

High uric acid or hyperuricemia is what causes gout, and there are several medications used to help you lower these "serum urate" levels. This is also called urate-lowering therapy (ULT). There are two kinds of medications that your doctor can prescribe to try to keep your uric acid at a healthy level:

- Xanthine oxidase inhibitors (XOIs): These drugs are used to lower the uric acid in your blood.
- **Uricosuric agents:** These drugs work to help your kidneys more efficiently filter out uric acid.
- **Enzymes that break down uric acid:** This is very effective, but presently available only as an intravenous treatment to be used when other ways to lower urate are unsuccessful or inappropriate.

**Treating Gout to Target:** Your doctor and you will work as partners in an effort to reach a "target" goal for your serum urate or uric acid levels. Your doctor will create and, if necessary, adjust your treatment plan to reach this target and keep you there. You can take an active part in this effort by taking your medications as prescribed, and following whatever lifestyle recommendations your doctor suggests.

For long-term gout management, your goal is to lower your serum urate level to **less than 6 mg/dL at minimum**. Some people may need to lower their level to less than 5 mg/dL to control their gout (this lower goal is generally for people with tophi, the "lumps" of urate that can be felt on the body). Make sure you know your goal urate level, and work with your doctor to get there!

What happens if one urate-lowering medication doesn't work well enough for you? Your doctor can assess your progress, and if one drug isn't working, you can either increase the dosage, switch to a different medication, or add a uricosuric agent to help your kidneys work more effectively to filter out uric acid, so you can excrete it when you urinate.

These drugs may take many months to achieve full effect and control your gout. So you may have gout attacks during that time. To treat these acute attacks, your doctor can prescribe colchicine or NSAIDs or corticosteroids to take short-term. Don't stop taking your XOI or uricosoric drug if you have a gout flare. Talk with your doctor to get treatment for the inflammation and ease your pain. When you first start a medication to lower your uric acid, it's good to plan ahead for possible flares of gout with your doctor. Know ahead of time what medication you should

take if a flare occurs. Have that medication with you when you travel and be ready to start quickly if a flare occurs. Rapidly treated gout flares often resolve quickly, while those given time to build up a full level of inflammation can take much longer to get better (and require a lot more medication).

#### Allopurinol

Allopurinol (Aloprim<sup>®</sup>, Lopurim<sup>®</sup> and Zyloprim<sup>®</sup>) is a drug used to treat gout, lower uric acid levels in your blood, and also to prevent kidney stones. It's one of the recommended, first-line urate-lowering therapies to help you manage your gout. Allopurinol prevents gout flares, but doesn't treat the symptoms of the flare.

#### What We Already Know

Allopurinol (Aloprim<sup>®</sup>, Lopurim<sup>®</sup> and Zyloprim<sup>®</sup>) is a xanthine oxidase inhibitor. It blocks the process of turning a substance called hypoxanthine into xanthine, and also the next step of turning xanthine into uric acid. Allopurinol lowers uric acid levels in your body, and if the levels are lowered sufficiently the risk of gout flares and urate-related kidney stones is dramatically reduced. It comes in tablet form, and you take it once or twice daily after a meal. For doses of 300 mg or lower, you can take all your allopurinol at once. Even for higher doses, the main possible issue of taking it all at once is gastrointestinal (GI) upset. If you can tolerate 400 mg of allopurinol all at once, it may be more convenient to take it that way.

Your starting dose of allopurinol is no more than 100 mg a day. People who have moderate to severe chronic kidney disease (CKD) should start with a lower dose (for example, 50 mg), followed by gradual, upward titration of a maintenance dose, which could exceed 300 mg a day. Your doctor will check your urate levels as the dose is increased to see when you have reached your goal (most commonly below 6.0 mg/dL), and be sure that the dosing is the right one for you.

Prior to starting allopurinol, you may receive screening for a certain gene marker called HLA-B\*5801. This is also called rapid polymerase chain reaction-based HLA-B\*5801 screening, especially if you are in certain ethnic groups, such as people of Han Chinese or Thai descent, or Koreans with stage 3 or worse kidney disease. Some recent data suggests that African-Americans also have a high enough chance of having this genetic marker that they should be tested for it (although the American College of Rheumatology guidelines only mention the three groups above). This allele (genetic marker) could put you at higher risk for a severe sensitivity reaction to allopurinol. Your doctor will determine if you need this screening or not.

It is recommended to start allopurinol with a low dose and increase, as discussed above, because lowering the urate level gradually may lead to fewer gout flares. We know that when you first start lowering the blood urate, crystals start getting released from the lining of the joint and can cause flares of gout. These flares are called mobilization flares. To try and prevent or reduce mobilization flares, your doctor may also prescribe colchicine to take with your allopurinol to prevent those attacks. Colchicine is generally given for the first six months of allopurinol therapy, since that is the time when the mobilization flares are most common. Sometimes a low dose of an NSAID or a small dose of corticosteroid is used instead of colchicine during this first six months.

Don't stop taking your allopurinol just because you start to feel better. It's a good idea to drink plenty of water or other fluids (about eight glasses each day) when taking allopurinol.

Let your doctor know if you are taking any of the following medications before starting allopurinol:

- Antibiotics like amoxicillin or ampicillin
- Blood thinners like warfarin (Coumadin<sup>®</sup>)
- Cyclophosphamide (Cytoxan<sup>®</sup>)
- Mercaptopurine (Purinethol®)

- Chlorpropamide (Diabinese<sup>®</sup>)
- Diuretics
- Azathioprine (Imuran<sup>®</sup>)
- Cyclosporine (Neoral<sup>®</sup>, Sandimmune<sup>®</sup>)
- Any other gout medications

Your doctor will also ask you if you've ever had kidney disease, liver disease, heart failure, or if you're female, if you're pregnant, are planning to become pregnant or are breastfeeding.

#### Why Am I Taking Allopurinol?

Allopurinol is a urate-lowering therapy that should control your uric acid levels to prevent gout attacks. However, it does not treat a gout attack or ease your symptoms if you have a flare.

#### What Are the Possible Side Effects of Allopurinol?

Allopurinol can make you drowsy. Don't drive a car or operate any machinery until you know how allopurinol affects you. Other possible side effects include diarrhea and upset stomach. Taking your medication with food or after a meal may help ease stomach upset.

Alcohol may also decrease allopurinol's effectiveness, so talk to your doctor if you plan to drink while on allopurinol. Alcohol raises urate levels and can set off gout flares.

Other uncommon side effects of allopurinol that could be serious include: skin rashes, pain when urinating, blood in the urine, irritated eyes, swollen lips or mouth, signs of infection (fever, chills, sore throat), itching, weight loss or loss of appetite.

#### Febuxostat

Febuxostat (Uloric<sup>®</sup>) is another, newer xanthine oxidase inhibitor (XOI). It's used to manage your gout by lowering levels of uric acid. It can prevent gout attacks but not treat an active gout attack or its symptoms.

#### What We Already Know

Febuxostat (Uloric<sup>®</sup>), like allopurinol, inhibits your body's formation of uric acid by blocking the process ofturning hypoxanthine into xanthine, and then blocking the turning of xanthine into uric acid. Febuxostat blocks the same enzyme that allopurinol does, but at a different spot on the enzyme. We don't know the effectiveness of combining allopurinol and febuxostat, and the combination is not advised.

Studies have shown that 80 mg of febuxostat is more effective at getting patients to their goal of less than 6.0 mg/dL than 300 mg of allopurinol, but it hasn't been compared to higher doses of allopurinol. Some people can't tolerate allopurinol, or it is not effective for them, making febuxostat a good alternative. Allopurinol is excreted from the body mainly by the kidneys and febuxostat mainly by the liver, so some doctors prefer febuxostat in people with decreased kidney function.

A recent study of the cardiovascular (heart-related) safety of allopurinol versus febuxostat, which was done in gout patients with history of cardiovascular disease, had as its primary endpoint a combination of cardiovascular outcomes (stroke, heart failure, need for urgent stenting and cardiovascular death). Overall, these endpoints were the same for allopurinol and febuxostat. The study also looked at cardiovascular death (or deaths due to cardiovascular causes), and this outcome was higher with febuxostat. There is no obvious mechanism for increased cardiac risk with febuxostat, and there are a number of issues that make this study hard to interpret. For the moment, this data requires extra consideration when starting febuxostat in patients with gout who have known cardiovascular disease. Because of the limitations of this study, people on febuxostat who tolerate it may benefit from staying on this medication in most cases, even if they have a history of cardiovascular disease.

Febuxostat is a tablet you swallow once a day, with or without food. The most common dose is 40 mg per day, although some people will take 80 mg per day. After two weeks of taking febuxostat, your doctor will test your uric acid levels to see if you need a higher dosage.

Febuxostat may take many months to be fully effective in stopping gout flares. During that time, you may have an increase in gout attacks, so your doctor may prescribe either colchicine or an NSAID or corticosteroid to help you treat them. You should keep taking your febuxostat even if you have these attacks in those early months on the drug, as the attacks do not mean febuxostat isn't working.

Febuxostat interacts with two other drugs, and this can raise the level of those drugs in your body. If you take azathioprine (Imuran<sup>®</sup>), mercaptopurine (Purinethol<sup>®</sup>), your doctor will need caution in prescribing febuxostat for you. Note that these medications have the same interaction with allopurinol.

Let your doctor know if you have ever had one of the following health conditions: chest pain, cancer, stroke, organ transplant, heart disease, kidney disease, liver disease, or Lesch-Nyhan syndrome, a disorder that causes high uric acid levels in the blood and other symptoms). Also, if you're female, tell your doctor if you're pregnant, planning to become pregnant or are breastfeeding before you start febuxostat.

**NOTE:** Regarding the data discussed above under "What We Already Know" about the cardiovascular safety of febuxostat versus allopurinol, the FDA issued an alert on this matter in November 2017, and in March 2018, data from the study was published in the New England Journal of Medicine. If your doctor prescribes febuxostat, he or she will discuss the risks and benefits of the drug over other options, like allopurinol. Ask questions if you are concerned about possible risks of taking febuxostat, or if you don't understand what this risk or FDA alert means.

#### What Are the Possible Side Effects of Febuxostat?

Febuxostat (Uloric<sup>®</sup>) may cause side effects like nausea or joint pain (most likely related to a gout flare). It may raise your liver enzymes, so your doctor will monitor this with regular blood tests to be sure your drug is not causing damage to your liver. If you notice side effects like chest pain, rashes, shortness of breath, dizziness, slow or slurred speech, or weakness or numbness in your arm or leg, seek medical attention right away.

#### **Uricosoric Medications**

As we discussed earlier, if your XOI medication does not work well enough for you—to help you achieve a serum urate level of 6 mg/dL or below, your doctor may wish to either increase your dosage or combine your XOI with a uricosuric agent. These drugs are used to help your kidneys flush out or filter out uric acid more effectively.

#### Probenecid

Probenecid (Benemid<sup>®</sup>, Probalan<sup>®</sup>) is a uricosuric agent or drug to treat and manage hyperuricemia. If you can't take XOIs for any reason or don't tolerate them well (if they cause severe side effects, for example), it may be an alternative first-line gout management treatment for you. Or, your doctor may prescribe it to you along with an XOI if that drug doesn't work well enough for you to achieve your serum urate target. Most commonly, probenecid is used as an "add-on" medication to an XOI, such as allopurinol or febuxostat.

#### What We Already Know

Probenecid (Benemid<sup>®</sup>, Probalan<sup>®</sup>) is used to help your kidneys more effectively filter out uric acid. This drug should help your body naturally eliminate uric acid in your urine, so you keep the uric acid levels in your body at a healthy level.

Probenecid may help you prevent that excess uric acid build-up from causing crystals to form, settle in your joints,



and cause painful gout attacks. So it's used as a longterm drug to manage your gout and prevent attacks. It's not designed to treat a gout attacks, treat inflammation, or ease symptoms like pain or swelling.

Probenecid comes in tablet form you take by mouth. It's a good idea to take with food because it could cause an upset stomach. Adults with chronic gout usually take 250 mg of probenecid twice a day, and increase to 500 mg two times per day and higher if necessary. Your doctor can watch how well the drug works for you and how well you tolerate it.

Probenecid may take six months to a year to reach full effectiveness and prevent gout attacks. If you have gout attacks during that time, don't stop taking probenecid. Your doctor may prescribe colchicine or an NSAID or a corticosteroid for you to treat acute gout symptoms during that time.

Drink six to eight full glasses of water or other fluids each day when you take probenecid. This helps you prevent kidney stones. Drinking enough water is a good habit if you have gout, so remind yourself to reach that goal every day.

Before you start probenecid, let your doctor know if you are taking any of the following medications: aspirin, antibiotics, aminosalicylic acid, methotrexate (Rheumatrex<sup>®</sup>, Trexall<sup>®</sup>, Otrexup<sup>®</sup>), clofibrate (Atromid-S<sup>®</sup>), dapsone, diflunisal (Dolobid<sup>®</sup>), diuretics, heparin (a blood thinner), indomethacin (Indocin<sup>®</sup>), anti-anxiety medications, nitrofurantoin (Microdantin<sup>®</sup>, Macrobid<sup>®</sup>), diabetes medications, pyrazinamide, salsalate (Disalcid<sup>®</sup>), or any other vitamins or supplements.

Do not take aspirin for a headache or joint pain while you take probenecid. Aspirin can interfere with probenecid's effectiveness. Take acetaminophen (Tylenol<sup>®</sup>) instead, or ask your doctor for a recommendation.

Let your doctor know if you have or have had ulcers, kidney stones, kidney or blood disorders, are pregnant, are planning to become pregnant or are breastfeeding. Probenecid can affect some urine test results, so let any doctor know you take probenecid before you take a urine test.

#### Why Am I Taking Probenecid?

Probenecid (Benemid<sup>®</sup>, Probalan<sup>®</sup>) is used to manage hyperuricemia and prevent gout attacks. It's not designed to treat an acute gout attack or its symptoms. It's not an anti-inflammatory drug or pain reliever.

#### What Are the Side Effects of Probenecid?

Probenecid (Benemid<sup>®</sup>, Probalan<sup>®</sup>) could give you an upset stomach, so take your tablet with some food, such as after meals or with a snack. You can also take an over-the-counter antacid tablet if you have an upset stomach from your pill.

Other possible side effects include loss of appetite, vomiting, dizziness or headaches. If you notice any signs of a reaction to your drug, like skin rash, breathing difficulties, or strange bruising or bleeding, let your doctor know immediately.

Again, probenecid could affect a urine test. So if you need to take a urine test for a medical reason or when interviewing for a job, let the technician know that you take probenecid.

#### Lesinurad

Lesinurad (Zurampic<sup>®</sup>) is another urate-lowering therapy that your doctor may add to your XOI to help you get your uric acid to a healthy level to prevent gout attacks. Lesinurad is also available in a pill where it's already combined with allopurinol (Duzallo<sup>®</sup>).

#### What We Already Know

Lesinurad (Zurampic<sup>®</sup>) is a selective uric acid reabsorption inhibitor (SURI). This means that Zurampic helps the body eliminate excess uric acid via the kidneys. It's used to treat hyperuricemia in combination with an XOI drug for people with gout who have not achieved a sufficiently low uric acid level with just the XOI. XOIs help decrease the amount of uric acid your body produces.

Lesinurad is not used alone to treat hyperuricemia in people who have gout, and it's not used in people who have hyperuricemia but have not been diagnosed with gout. In fact, you should not take lesinurad without taking it in combination with an XOI, as it appears to have more of a risk for the kidney if taken alone. You should take your dose of lesinurad in the morning, with food and water.

Lesinurad is taken by mouth once a day along with your XOI. The dosage is 200 mg, and you should not take more than that each day. If you miss a dose, don't take it later in the day and don't take a double dose the next time.

Your doctor will assess your kidney (renal) function before you start lesinurad, and monitor your kidney function regularly. You should take lesinurad with food and water, and also drink about two liters of water or other fluids each day while you are on this drug.

People who have severe kidney problems, are on kidney dialysis, have had a kidney transplant, have tumor lysis syndrome (breakdown of cancer cells that may cause high uric acid levels), or have Lesch-Nyhan syndrome should not take lesinurad. Females should tell their doctors if they are pregnant, plan to become pregnant or are breastfeeding before they start lesinurad.

#### Why Am I Taking Lesinurad?

Lesinurad (Zurampic<sup>®</sup> or, combined with allopurinol, Duzallo<sup>®</sup>) is designed to help you lower your uric acid levels to manage gout and prevent gout attacks. It is not used to treat an acute gout attack or its symptoms. It is not used to treat hyperuricemia in people who do not have gout.

You may experience a gout attack (flare) when taking lesinurad. If you have gout attacks while taking lesinurad, your doctor can prescribe another treatment, such as colchicine or an NSAID or a corticosteroid, to treat the acute inflammation or its symptoms. You should not stop taking your lesinurad if you have a gout flare.



#### What Are the Possible Side Effects of Lesinurad?

Lesinurad (Zurampic<sup>®</sup> or, combined with allopurinol, Duzallo<sup>®</sup>) could cause kidney side effects if you take the drug alone without your xanthine oxidase inhibitor or if you take more than 200 mg per day.

The most common side effects of lesinurad are elevated blood creatinine levels(a measure of kidney function), headache, flu and heartburn (or GERD). People who take lesinurad may also have serious heart-related problems like heart attack or stroke, but it's unknown at this time if that is connected to lesinurad use (and in published studies, there was no increase in cardiovascular events in patients taking lesinurad with allopurinol versus patients on allopurinol alone).

Lesinurad may have interactions with other drugs, including high-dose aspirin and hormonal birth control therapy ("The Pill"). There are other drug interactions with lesinurad as well, and you should be sure that the doctor prescribing your lesinurad has a full list of all medications you are taking for any reason.

#### **Uricase Medications**

#### Pegloticase

Pegloticase (KRYSTEXXA<sup>®</sup>) is a newer medicine. It is an enzyme that rapidly converts uric acid in the blood into a substance easily eliminated by the kidneys, thus lowering the amount of uric acid in your system. Your doctor may prescribe pegloticase if you have uncontrolled gout symptoms and other urate-lowering therapies don't work well for you or you can't tolrate them for any reason. Pegloticase is also used in gout patients with visible tophi, since it is the only medication that has been shown to shrink tophi in just months for many patients. Pegloticase will generally not be the first treatment your doctor will prescribe for gout.

#### What We Already Know

Pegloticase (KRYSTEXXA®) is part of a new class of drugs called PEGylated uric acid-specific enzymes. It treats hyperuricemia that can cause gout by turning uric acid into a substance that your kidneys can more easily eliminate in urine. Pegloticase helps your body dissolve the buildup of uric acid crystals from gout over time. It can work rapidly. In clinical trials, pegloticase lowered uric acid levels to as low as 1 mg/dL (or less) within 24 hours.

Pegloticase is a drug you take to manage your gout and prevent flares, but it will not treat a gout flare or its symptoms.

Pegloticase is given intravenously (IV), administered into a vein after a catheter is inserted by your doctor or nurse. You will get your pegloticase infusion at your doctor's office or other health care setting. A healthcare professional will watch you while you receive pegloticase. It takes about two hours total to complete the treatment, and while you're on therapy you'll need an infusion every two weeks. Because of the fast onset and high effectiveness of pegloticase in lowering uric acid levels and shrinking tophi, it is usually given only for a matter of months in most patients. Your doctor may also want you to come in early to prepare you for the treatment, and watch you for an hour afterward, so plan on spending three to four hours at the doctor's office.

If you just have hyperuricemia but have not been diagnosed with gout (called asymptomatic hyperuricemia), pegloticase is not recommended. At this time, the FDA has not approved any of the medications that are used to lower urate to be used in patients with high uric acid levels, but without gout.

It may take several months to feel the full effects of pegloticase, and you may still have gout flares early in your treatment. Don't stop taking pegloticase if you have a gout flare, in fact in some patients gout flares mean pegloticase is working well to remove uric acid from the body. Your doctor can prescribe colchicine, an NSAID or a corticosteroid for you to prevent and treat the gout flares and ease your symptoms.

Your doctor will monitor your urate levels while you take pegloticase to see if the medicine is working. If your uric acid

#### SURGERY

It's a good idea to consult your primary care physician early, when you first experience a gout attack. If you start medications and lifestyle changes early, you're more likely to control your gout, treat your hyperuricemia, and prevent additional gout attacks. However, some people do not respond well to treatment, or delay their treatment for various reasons. Their gout may progress to gouty arthritis. They may develop tophi in one or more joints. This can cause damage to the joint.

In those severe cases, surgery may be necessary. Surgery is not a first-line treatment for any joint affected by gout. Surgery is only used for situations when someone has advanced gout and tophi that have led to destructive arthritis. If you haven't sought medical care or therapy for gout until now, and your pain and joint deformity have progressed so far that you cannot use your joints, your doctor may refer you to an orthopedic surgeon for treatment. It is important to note that aggressive treatment of the urate level can be quite effective, over time, in shrinking tophi. Therefore, surgical removal of tophi may only be necessary in special circumstances.

Surgery for gout-related joint damage may include:

▶ Your surgeon can remove tophi nodules that have inflamed or damaged toes or fingers, or even your bursae or tendon sheaths. Tophi could become infected in some cases, so they may need to be removed.

► Joint fusion can fuse together two small joints if one joint is badly damaged by gouty arthritis. This procedure does limit the movement of the fused joints, but it can ease the severe pain caused by the damage. It's very rare that people with gout need this type of surgery.

► Joint replacement or arthroplasty may be used to replace a damaged joint, usually a knee, that's severely damaged from gout. levels increase while you are still receiving infusions, pegloticase may not continue to work for you, or it may work for a while and then stop being effective. If your uric acidrises to above 6.0 mg/dL while on pegloticase, the doctor will discuss the therapy plan with you and may decide to stop your pegloticase infusions. Even patients who stop pegloticase therapy after a few months had important decreases in their uric acid and some resolved tophi as well.

Let your doctor know if you are already taking allopurinol or febuxostat before you start pegloticase, since they should not be taken while on pegloticase. You should also tell your doctor if you have or have ever been diagnosed with heart disease, heart failure or high blood pressure. Females should tell their doctors if they are pregnant, plan to get pregnant or are breastfeeding before starting pegloticase.

#### Why Am I Taking Pegloticase?

Pegloticase (Krystexxa<sup>®</sup>) is used to treat the high uric acid levels in gout patients, as well as to improve other manifestations of gout including tophi. It does not treat gout attacks or ease their symptoms.

# What Are the Possible Side Effects of Pegloticase?

Possible side effects of pegloticase (Krystexxa®) include gout flares and possible allergic reactions. While on pegloticase gout flares can occur in the first few months on therapy, and then tend to become less common after that. The allergic reactions that occur while pegloticase is given tend to occur in patients who have a high uric acid levels

(above 6 mg/dL) right before infusions. This is why your doctor will check your uric acid levels before each infusion after the first, and consider stopping therapy if your uric acid levels rise to above 6 mg/dL. Common symptoms of these allergic reactions include hives, chest discomfort or pain, itching, rash, or trouble breathing. Other less common side effects seen with pegloticase include bruising, chest pain, constipation, nausea, sore throat or vomiting.

Let your doctor know right away if you experience any side effects while taking this drug. Your doctor or nurse can monitor you for an allergic reaction when you are getting your treatment, and for an hour or so after to ensure each infusion goes well.

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#### **Off-Label Gout Treatments: Anakinra and Canakinumab**

Anakinra (Kineret<sup>®</sup>) and canakinumab (Ilaris<sup>®</sup>) are being used by some rheumatologists as an "off label" treatment for severe gout attacks. Anakinra and canakinumab are both interleukin-1 beta antagonists. They are used to treat some forms of inflammatory arthritis. While they are approved by the FDA for use in other types of arthritis, such as rheumatoid arthritis, anti-IL-1 beta drugs are not specifically indicated or approved to treat gout.

What does off label really mean? It means that anakinra and canakinumab have been approved as safe and effective treatments for several conditions, but that the clinical trials necessary to ensure their safety and efficacy for use as gout treatments are not yet sufficient to achieve this "indication" by the FDA. That may happen in the future, as studies of anakinra and canakinumab in gout are ongoing. It's up to your doctor and you to decide if anakinra, canakinumab or any other off-label treatment is a good option for you.

At this time, anakinra (Kineret<sup>®</sup>) and canakinumab (Ilaris<sup>®</sup>) may be prescribed off label for very severe gout attacks. This is not a urate-lowering therapy. They are designed to interrupt the inflammatory process involved in a severe gout attack and treat the attack. These drugs are also called biologics. They lower your immune system's processes in order to stop inflammation. They may work well for severe gout, but they also lower your body's ability to fight off infections. So your doctor will have to explain the balance of risks versus benefits of using this type of drug for gout.

Your doctor will not likely prescribe either anakinra (Kineret<sup>®</sup>) and canakinumab (Ilaris<sup>®</sup>) as a first-line treatment for gout flares unless you have very severe attacks. These are options for patients for whom other treatments do not work, who cannot tolerate any of the other treatments, or who have very severe gout.

## PART SEVEN Self-Management: Lifestyle Changes for Gout

When your doctor diagnoses you with gout, you will also talk about changes you can make in your daily life to help you manage your gout. These changes can help you lower your uric acid levels, prevent gout attacks, improve your overall health and feel great.

Gout has many different risk factors—factors that make one person more likely to develop gout than others and some of these are related to your lifestyle and general health. People who are obese or overweight may be

at higher risk of gout, and higher weight is associated with higher urate levels. Eating high amounts of foods and drinks rich in purines can also increase your risk of gout. That doesn't mean that your friend who drinks a lot of beer and eats red meat at every meal will necessarily get gout and you will not. But if you do have certain lifestyle factors or habits that you can modify, it can help you prevent future gout attacks or a worsening of your gout. If someone is genetically predisposed to gout, the wrong diet or too much alcohol can cause their attacks to come on sooner, and be more frequent, than they otherwise would have.

Diet, exercise and lifestyle modifications are good recommendations for anyone who wants to stay healthy and fit, but these are especially important for people with gout.



So when your doctor or nurse go over food or drinks to cut back on or avoid, or suggest you stop smoking or get more exercise, take it seriously. While your gout medications are powerful tools against hyperuricemia and gout flares, the changes you make in your daily habits can have a big impact too. We know that gout is associated with a higher risk of cardiovascular disease, so people with good should try as hard as they can to take the lifestyle steps that reduce heart disease, both from the point of view of diet and exercise. Fortunately, many of the recommended lifestyle changes that help reduce heart disease also reduce the severity of gout.

#### **DIET CHANGES: LIMIT PURINES**

Foods and drinks rich in purines (proteins in your diet are broken down to purines and pyrimidines) can contribute to the development of gout. The end product of the body's breakdown of purines is uric acid, which can form urate crystals that settle into joints, causing inflammation.

Cutting back on certain purine-rich foods and drinks are one recommendation for managing gout. In the past, doctors gave their patients with gout a long list of foods to avoid, but research has shown that this is not practical or necessary. Your doctor and nurse will go over specific recommendations for you, but here are some useful tips:

#### Avoid or limit these if possible:

- Organ meats like liver, kidney or glands of any kind (sweetbreads)
- Red meat, such as beef and pork
- Shellfish, such as mussels, scallops and oysters

#### Self-Management: Lifestyle Changes for Gout

- Excessive amounts of alcoholic beverages, including liquors, beer or wine
- Foods or drinks sweetened with high-fructose corn syrup, such as sweetened (not diet) sodas

#### It's OK to eat these:

- Purine-rich veggies like beans or lentils, asparagus, cauliflower, spinach, peas or mushrooms
- Cherries, especially fresh cherries not packed in sugary syrup, or fresh cherry juice.
  Note: Cherry juice is a popular alternative therapy for gout management, but it's not clear whether or not drinking cherry juice helps gout. In some research on healthy volunteers, cherry juice mildly lowered urate levels, but it failed to lower urate levels in people with gout. Even strong proponents of cherry juice acknowledge that its effects on urate level are small, so cherry juice **does not** replace a medication to lower your urate.
- Moderate amounts of coffee
- Vitamin C, preferably in fresh, whole fruits, but ask your doctor if you should take a supplement

# Definitely include these in your diet (for general health and to replace items reduced because of their gout risks):

- ▶ Whole grains
- Fresh fruits and vegetables
- Lean protein sources
- Low-fat or no-fat dairy products
- Plenty of water or non-sugary fluid

#### **Alcohol: Why It Matters**

You won't necessarily have to give up alcoholic beverages if you're diagnosed with gout. Why does alcohol intake matter at all? Some people who drink a lot of alcohol never get gout. Alcohol can increase levels of uric acid in your body. So it can be a strong cause of hyperuricemia and gout. Alcohol works to raise urate levels by decreasing how much urate your kidneys excrete. Beer has earned a reputation as being especially bad for gout, since it has this effect on your kidneys, but also because beer has its own proteins that are broken down to urate in the body. So drinking beer raises urate in two different ways.

Beer and liquor are especially linked to higher uric acid levels, and wine is linked to this as well. Moderate intake of alcohol is generally defined as two drinks per day for men and one drink per day for women. However, even moderate drinking on a regular basis (which is common for many adults) is associated with a higher risk of recurring gout attacks.

You may be able to drink occasionally and not experience a gout flare, but regular drinking of any type of alcohol (especially beer and liquor, and mixed drinks with sugary sodas or juices) puts you at risk. Also, heavy or even regular moderate drinking adds calories to your daily intake. It can contribute to weight gain in some people (the "beer belly" or "wine gut").

Also, when making any changes in your diet or alcohol intake related to gout, remember that timing is important. During the first 6 months of taking a urate lowering medication such as allopurinol to lower your urate, you are at especially at risk for gout attacks. This is a great time to be strict with your diet, and to limit your alcohol intake as much as possible. 6 or 12 months down the line as you continue your medication, often your gout attacks are rare or absent, and a lot of the urate has been removed from your joints. At that point, your risk of gout is less and you may well be able to a little less strict with your diet without as much risk of setting off a gout flare.

While only you can decide how much, what or when to drink alcohol, your doctor and nurses can advise you on how to make these changes in a healthy way. Keep these thoughts in mind when you talk about drinking with

your healthcare professionals:

**Be honest with your doctor and nurses about your regular alcohol intake.** Don't downplay how much or how often you drink. You are not a "bad person" if you drink. Clear information on your alcohol intake can help your healthcare professionals advise you on your risk.

**If you're not sure how much you drink** on a regular night out or don't keep track, write down what you drink in a diary or notepad for a few weeks. Share it with your healthcare professionals.

**If you're not sure how much alcohol is in a normal serving, ask.** In general, 12 ounces of beer, four fluid ounces of wine and one ounce (a jigger) of liquor is a serving. Mixers add liquid and, if they contain sugar, calories to a "drink." A great idea if you are making a drink at home is to use a liquid measuring cup, then pour the proper amount into your glass.

If you would like to cut back on your drinking—either the amount or frequency—but find that it's hard, ask for help. Talk with your doctor and nurses about ways you can reduce your intake. Ask about resources like counseling that may help you make these changes.

Want to cut back on your alcohol when you're socializing or relaxing? Here are a few tips:

**Order non-alcoholic drinks when you're out with friends or family.** Iced tea, coffee, flavored seltzers or club soda with a lime wedge may be good alternatives to beer or booze.

**Set goals.** Pick days when you will drink and days when you won't drink. Keep track of it on your calendar. Set a limit for how much you will drink that night and stick to it. Don't "save it up" for one night per week and overdo it.

**Don't keep alcoholic beverages in the house.** If they're on hand, it's easy to reach for them when you want to unwind or if you feel stressed.

**Sip, don't guzzle.** Don't rush through your drinks so they last longer. Sip or "nurse" a drink while you enjoy talking to your friends or watching the game on TV. Don't let anyone else push you to drink faster or more than you want.

**Avoid tempting scenarios.** If you typically drink a lot of alcohol in certain settings or during certain activities, such as when you meet your friends to watch sports or after work for happy hour, it's OK to skip those outings or cut way back on how many you attend.

Are people who encourage you to drink when you're trying to cut back on or avoid alcohol really your friends? If you decide to quit drinking, drink non-alcoholic beverages instead or simply cut way back on the nights when you drink, your friends and family members should support your decision. They should understand that you're doing this for your health. If they tease you or try to encourage you to drink "just this one time because it's a special occasion," try to stick with your plan not to drink. It's your body and your life. You don't need to drink any alcohol to celebrate an occasion or to have fun. While you can't change your family, you can stop hanging out with friends who don't support your decision not to drink.

**Don't get discouraged.** If you have been a moderate or even heavy drinker for years, it's not easy to suddenly quit or cut way back. Many men and women socialize or relax with drinking. Many people associate alcohol with celebrating, such as champagne at weddings or New Year's Eve, or beer when watching football games. You can make changes to how much and how often you drink, and still be a fun person who enjoys life. Don't give up! You may have setbacks at times. Ask for support if you need it.

#### **EXERCISE: IT'S GREAT FOR GOUT**

Physical activity or regular exercise is a good habit to adopt if you have gout. While you will have limitations to your exercise during an acute gout attack, once you get your symptoms under control, think about how you can incorporate more physical activity into your daily life.

#### Some basic recommendations:

**Adults should get about 150 minutes of moderate physical activity per week.** This may include walking, biking, swimming, using aerobic exercise machines at the gym (treadmills or elliptical machines), walking the dog, dancing with your spouse, or taking a water or land exercise at your local community center or church.

**Does 150 minutes a week sound like a lot?** This is really just 30 minutes of activity five days a week. If it's easier, break up the activity into 10 minutes of movement at a time during your day.

**Find activities you enjoy.** If you find exercise boring, try listening to music, or watching your favorite TV show or news program on the treadmill. Walk or bike with friends. Try a class so you can follow an instructor or meet up with others who are trying to improve their fitness. Check out various types of exercise, like yoga, tai chi, Zumba or cross-training.

**Include three types of exercise.** A comprehensive exercise program should include cardiovascular or aerobic movement (revs up your heart so you sweat and burn calories), flexibility or "range of motion" movements to keep joints and soft tissues limber, and strengthening or strength training to build muscle tone and strength.

#### **PHYSICAL THERAPY**

Need professional guidance on safe and effective ways to get fit with gout, or just managing your pain and mobility issues? Ask your primary-care physician, nurse practitioner, physician assistant or rheumatologist to refer you to a **physical therapist** or prescribe physical therapy.

Physical therapists or PTs are healthcare professionals can diagnose and treat many pain conditions with nondrug treatments like heat, cold, electrical stimulation or exercise. They can also advise you on how to increase your physical activity in ways that are safe and appropriate for you. Physical therapists are trained in treating patients with all types of musculoskeletal conditions, including gout and gouty arthritis. They can help you learn better ways to do all of your daily tasks at work or at home with less pain.

#### **OTHER LIFESTYLE CHANGES: SMOKING AND OBESITY**

What about smoking cigarettes, cigars or pipes? You may have seen some recent studies that found that in some people with gout, smoking tobacco was associated with lower serum urate levels. What?

It's true that some studies focusing on men in Asia found that smoking was associated with lower uric acid levels. In fact, in one study, men who were lean in body weight and smoked had lower serum urate levels than men who had never smoked. It wasn't seen in overweight men.

Does this mean you should smoke or start smoking to alleviate gout? **Absolutely not!** Our present medications to lower urate levels are much safer that smoking, even if further studies confirmed that smoking has any lowering effect on urate. Smoking tobacco in any form is associated with higher risk of coronary heart disease, strokes, lung cancer and other serious health problems. Smoking can cause all kinds of cancer, including cancer of the bladder, blood, kidneys, liver, larynx, trachea, throat, esophagus, stomach and colon. Smoking is absolutely bad for your health.

If you smoke now, don't keep smoking because you think it's good for gout or will lower your uric acid levels.



Smoking has so many negative effects on your health that outweigh any possible perceived benefits for hyperuricemia or gout. If you'd like to quit smoking and need help, talk to your doctor or nurses. They can recommend smoking cessation programs or resources to help you kick the habit.

What about obesity or overweight? Obesity is definitely a risk factor for developing gout. And it's a very common problem in the U.S. and other developed, Western nations. Around 36.5 percent of U.S. adults are currently obese, defined as having a body-mass index (BMI) of 30 or higher, or for a man, a waist circumference of 40 inches or more. Women who are not pregnant and have a waist circumference of 35 inches or more may be considered obese. People who are overweight have a BMI of 25.0 to 29.9.

When you see your doctor for your diagnosis of gout, you'll be weighed and learn if you are obese or overweight. If you are, your doctor may suggest that you lose weight and manage your weight moving forward. Weight loss is recommended as a good way to manage gout. Excess pounds put pressure on your

joints too. Weight loss and staying at a healthy weight is great for your overall health and reducing your risk of many serious diseases. Note, however, that weight loss by itself is rarely enough to get a person with gout to their goal level of uric acid (below 6 mg/dL). Weight loss is highly recommended in overweight gout patients, with many benefits, but it won't replace urate lowering therapy for the vast majority of people.

If you're overweight or obese, you're at higher risk for developing many health problems, including:

- Type-2 diabetes
- Coronary heart disease
- High blood pressure
- High cholesterol
- Stroke
- ▶ Gallbladder disease
- Sleep apnea or other sleeping problems
- Osteoarthritis
- Some types of cancer
- Depression
- Pain and impaired mobility

**Weight loss is not easy.** Many people struggle to lose weight. Actually, most people struggle to lose weight! Losing weight takes time, dedication and, in many cases, help and support. If your doctor and nurses recommend that you lose weight, ask them for specific suggestions. There are many diets, diet programs and diet books on the market, so find out what type of "diet" or healthy eating plan you should try. It's important to lose weight safely and keep it off, not to go on a crash or fad diet that may put your health at risk. Also, if you try to lose weight in a drastic or

extreme way quickly, you're more likely to give up and stay overweight. Gradual change may be easier to maintain.

While this guide cannot give you a comprehensive approach to weight loss for gout management, here are a few general tips:

- The best ways to lose weight are to eat a healthy diet that reduces your calorie intake, and to increase your physical activity. Just one or the other may not do the trick.
- Even modest weight loss can have a big benefit. Set realistic goals.
- Try small adjustments, like using a smaller plate for meals or dividing up each of your servings by half to save for later.
- Eliminating some foods like sugar may seem difficult, but after two weeks you will notice your cravings going away.
- ► Take stock of your challenges. If you're an emotional or stress eater, find ways to manage your stress that don't involve overeating. If you starve all day long and gorge on huge meals at night, try to eat smaller meals throughout the day or eat healthy snacks.
- Go easy on yourself. Weight loss is very challenging. Reward yourself (not with dessert) when you reach a weight-loss goal. Surround yourself with people who encourage and support you. Don't listen to people who tell you weight loss is a lost cause or impossible.
- Get help if you need it. Join a weight loss program recommended by your doctor. Check out motivational support groups of other people trying to lose weight or manage their eating. Make an appointment with a registered dietitian (RD) or nutritionist.

# PART EIGHT Affording Your Treatments

In today's healthcare environment, co-payments and outof-pocket costs for drugs are on the rise in many cases. Your drug co-pay is the amount you will pay out of pocket for your prescription drugs — what's not covered by your insurance. This is one of the most important and hotly debated issues of our day.

If you struggle to afford your gout medications, you may be less likely to take them at all or as prescribed. That will only make your gout or hyperuricemia worse. You'll be more likely to have recurrent gout attacks, or worsening gout that leads to tophi that cause gouty arthritis and joint damage.



While some gout drugs are generic, others are only available in brand-name versions at this time. And even generic drugs like colchicine may be rising in price for many people. Is there any hope?

If you find that your gout drugs or other medications are hard or impossible to afford, first speak with your doctor and nurses. They may be able to do one of the following:

- Prescribe another, less costly treatment that also works for your gout.
- Contact your insurance company to negotiate with them if they will not cover the drug or approve another treatment.
- Suggest co-pay support programs or discounts that you can use to lower your out-of-pocket costs You can find these online, through your pharmaceutical company's website or through non profit organizations built to provide help paying for medications.
- Direct you to drug discount websites, or online resources and smartphone apps like GoodRX.com that help you locate the cheapest pharmacy price for your drug

Drug co-pay support programs are offered by the drugs' manufacturers, and these programs can help many people afford their treatments. Co-pay card programs are generally not accepted for use if you have any type of government insurance covering your medication such as Medicare, Medicaid or Tricare. However, if you have private insurance through your employer or state exchanges, you may be able to use these programs.

Check out these three types of co-pay support: co-pay assistance programs that are like coupons for your drugs; pharmaceutical companies' assistance programs; and patient assistance foundation programs. CreakyJoints.org has a great deal of information on these programs for arthritis patients: 🗗 creakyjoints.org/ support/arthritis-copay-cards-assistance

Or, you can email us at info@creakyjoints.org to ask any questions about assistance in obtaining your gout medications.

Check out the websites for your individual drugs to find out if the manufacturer offers a co-pay assistance program, such as a coupon, rebate, drug card, or other options. Unfortunately, these programs are not available if you are on Medicare. You can find your drug's website by entering the brand name into any internet search engine (such as Google), but usually, they're the brand name of the drug followed by .com.

**In addition, speak with your pharmacist.** Ask if there are ways to purchase your drugs at a lower price. Recently, a number of high-profile media stories revealed that at many pharmacies in many states, some prescription medications cost less if purchased with cash or a personal credit card (such as a Visa,

#### **Affording Your Treatments**

MasterCard or American Express) than if purchased through insurance with a drug co-pay. We all assume that our out-of-pocket cost will be less if we purchase our prescription with insurance than if we paid cash for the drug at the pharmacy counter, but this hasn't always been true for every medication. Ask your pharmacist or pharmacy tech if there are two different prices, and insist on being charged the lower price no matter what. Contact your insurance company and lodge a complaint if your out-of-pocket cost with a co-pay through your policy is higher than the cash price.

**It's also a good idea to shop around.** Many gout drugs, like NSAIDs, oral corticosteroids, colchicine and allopurinol are generics. Different pharmacies or mail-order pharmacies may have different prices for the same drug. Do a little research online or call some pharmacies to ask their price for your drug.

#### What you should NOT do if at all possible:

- Stop refilling your prescriptions or taking your gout medications
- Split or space out your dose to "stretch" a bottle of medications
- Stay quiet and do nothing

Speak up, ask your doctor and nurses for help, and check out all the available prescription drug coupons, discount programs and other resources that may help you afford your gout medications. It's important to let your doctor know if the medication you are taking for gout is costing you too much, since there may well be options for changing medications, getting an insurance company to approve a medication it previously denied, or to get the medication at lower cost.

# PART NINE Make Your Voice Heard!

Living with a chronic disease like gout may impact many areas of your life. On top of communicating with your healthcare team, you will also need to be able to speak with your insurance provider, employer, support network and elected officials.

Get to know who's who in your doctor's office, which usually includes multiple staff members who have multiple roles in your treatment and care.

#### WHO'S WHO IN THE OFFICE

**Receptionist:** They will usually be the first person you interact with when you enter the office. Be nice to them, they can help ensure that others on the healthcare team are made aware of your situation. They handle the majority of the paperwork and process your insurance information.

**Office Manager:** The office manager is there to ensure that the facilities are safe, up to date, and able to provide the best quality care to you. They are there to coordinate the goals of the medical staff, ensuring that each has you at its center.

**Technician:** Performs your medical tests, such as X-rays or blood tests, and relays the results to your physician. While they certainly can offer advice, know that technicians can't offer a definitive diagnosis.

**Medical Assistant:** Will not provide any medical advice, but may show you to an examination room and measure your height, weight, and blood pressure. They record information relevant to your visit and relay the information to your physician.

**Nurse (RN):** Depending on the size or specialty of your doctor's office, your nurse will perform different actions. They are usually the ones who coordinate your care with other doctors and medical professionals. They can administer vaccinations and, in some cases, can perform biopsies and other interventions.

**Nurse Practitioner (NP):** Your doctor's office may have a nurse practitioner or NP. This is a nurse with additional graduate training, such as a master's degree or doctorate, beyond their registered nurse degree. They may have specialized training or knowledge in certain types of clinical care. NPs can order and interpret your tests, diagnose conditions like high blood pressure or an infection, or prescribe your medications in certain situations.

**Physician's Assistant (PA):** They have a license to practice medicine, but only under a physician's guidance. They can interpret your lab results, treat injuries, and also perform exams. Some are able to prescribe medicine in certain situations.



**Physician:** This is the one you're probably most familiar with. If you have gout, you may only see your primary-care physician or family physician, but you may also see a rheumatologist, a doctor who specializes in arthritis and related disorders. They will perform tests and diagnoses, and prescribe appropriate drugs. They have had the most schooling of those on this list.

It is important to disclose all information regarding medications, diet, and lifestyle choices to your physician. In order to make the best treatment recommendation, they have to consider a lot of information specific to you. Leaving out an important detail, like a medication, could lead to adverse side effects on a certain treatment. Never hesitate to ask your physician any questions you may have about your treatment or gout in general. They are there to help!

To see CreakyJoints' resource page on the healthcare team, go here: 🗗 <u>creakyjoints.org/education/what-is-the-healthcare-team</u>

#### HOW TO TALK TO YOUR INSURANCE PROVIDER

Before your talk with your provider, take a look at your plan and develop an understanding of what is covered. To do this, look at your list of benefits, or medical services that are covered. You may also find a list of closed benefits, which means your provider will not pay for the cost of any treatment not on the benefit list. On top of a benefits list you may find a "formulary," which is a list of prescription drugs the health plan covers. It can include medications that are both brand name and generic. An "open formulary" or "preferred drug list" often has a greater choice of covered drugs. A "formulary exclusion list" is a list of prescription drugs not covered by a health plan. If you need a treatment or drug that is not on your benefits list or formulary, you and/or your doctor must ask the plan to cover it as an exception. Even if your prescribed medication is on your plan's formulary, it will only cover that drug if it is deemed medically necessary through standards or research that states what care is most effective.

"Medically necessary" can also be referred to as "medically necessary services" or "medical necessity." To keep track of what services your provider has covered and what money you may owe them, you can review your explanation of benefits (EOB) — a statement usually sent by mail or email from your health plan. You may find you owe money through a copay or coinsurance fee. Coinsurance is the percentage of health care expenses you pay after your deductible. Copay is the dollar amount you pay for health care expenses, most often after you meet your deductible limit.

When you speak with your insurance provider on the phone, be sure to have a good understanding of what your plan covers. If certain medications or treatments are deemed necessary by your doctor but not covered, there are appeals processes you can make to prove medical necessity.

For more information on how to talk to your insurance provider, go here: 🗗 www.ghlf.org/switching-survey-glossary.

#### HOW TO TALK TO YOUR EMPLOYER

Gout flares, as well as appointments you need to treat and manage your gout, mean you can experience few interruptions of your daily life. However, living with gout can sometimes impact your ability to work at all, such as during an acute gout flare. It depends on the severity of your symptoms and your particular type of work. If you drive a truck or have to stand behind a retail store counter all day in a suit, you may not be able to do that during an acute gout attack. You may not even be able to put on your shoe.

Employers may not understand the pain, swelling and physical limitations that gout can cause, because they may not be familiar with your disease. You may wish to have a conversation with your employer explaining your diagnosis and how it might impact your job occasionally. Here are some general tips:

- First, understand whom you should speak with. In many cases, a supervisor and your human resource department are good starting points.
- Explain your diagnosis, what that means for you, and why you feel they should know.
- Become familiar with your company's disability plan and insurance policy.
- Know your rights:
  - Understand that the Family and Medical Leave Act (FMLA) allows you to take up to 12 weeks off each year for medical emergencies. This is unpaid, but will at least allow for job security.
  - > The Americans with Disabilities Act (ADA) requires employers to make reasonable adjustments for disabled workers.

#### Ways to Make Your Voice Heard

- ▶ If you need to, request time off while you deal with a gout flare or adjust to your treatments.
- **b** Go over your benefit plan with HR if you receive health insurance from your employer.
- ▶ If interviewing, it is suggested to not disclose your disease history it could compromise your standing.

Here is a list of helpful websites you can use to research options should your condition impact your work:

State Legislature: 
Www.dol.gov/odep/contact/state.htm
Job Accommodation Network: 
Askjan.org
FMLA: 
Www.dol.gov/whd/regs/compliance/whdfs28.htm#.UNHq\_2\_hrFk
ADA: 
Www.eeoc.gov/facts/fs-ada.html

**RAISE YOUR VOICE:** If you're insured through your job, ask your HR department if your company or its insurer has a patient advocate or employee assistance programs as part of your coverage. These advocates or related to your behalf to provide information or assistance related to your healthcare.

#### HOW TO TALK TO YOUR ELECTED OFFICIALS

Your elected officials at the federal, state, and most importantly the local level are interested in helping you. After all, YOU are their constituent, and their job is to represent their constituents. Getting in contact with your elected officials' offices can help speed up the insurance claim process, help improve existing guidelines of care, and will send a message to your government that your issue is real, and needs to be taken seriously.

There are a number of reasons to contact your elected officials, and it's important to understand that many will work to help you, but mostly on an individual level as a "constituent service." As much as you and they may want sweeping change to the laws, change takes time and sustained interest from constituents.

So now that we've tempered your expectations about government, how should you go about contacting your local officials, and what can they help you with?

First you need to find them. To do so, follow this link: 🗗 openstates.org

Your state senator, house representative, or assembly person can work to be a powerful advocate in clearing up insurance coverage issues. Furthermore, sharing your story will provide your representatives a picture of their constituents that will help inform their decisions on future legislation.

How should you share your story? While a personal hand-written letter is the most impactful way of sharing

**RAISE YOUR VOICE:** Everyone involved in healthcare — including elected officials, insurance providers, drug manufacturers, hospitals, pharmacies, and physician groups — should focus on you, the patient, when setting any policies or making any decisions. Healthcare is about you — your health, your treatment options, your quality of care, and your needs. Speak up if you feel that a new law, regulation, or policy will make it harder for you to access the best care. Or speak up on behalf of legislation that you believe will make getting the best care easier! Use social media, email, phone, letters, or postcards to let your voice be heard at all times.



your story, a phone call or personal email is a more practical way of contacting your elected official.

You can also get involved with the 50-State Network, a national organization of patients just like you who want to make their voices heard by their elected officials. Learn more and sign up at 🗗 www.50statenetwork.org\_ this is a program developed and run by GHLF, the parent non-profit of CreakyJoints.

The American College of Rheumatology (ACR) also brings together patients like you, rheumatologists and health professionals, and families of kids with rheumatic diseases

to Washington each fall to lobby members of Congress about important legislative issues. You can find out more about joining this trip at 🗗 www.rheumatology.org/Advocatey/Advocates-for-Arthritis

#### HOW TO TALK TO YOUR FAMILY AND FRIENDS

When you have gout, you may not always look like you're sick or in pain. People around you may not realize what gout is or why it causes an acute attack that can limit your mobility and cause severe pain.

They may not realize that you have to take medications regularly, control your diet and alcohol intake, or that some activities are harder for you to do. They may not know that you sometimes feel stressed, anxious or even depressed because you have a chronic disease.

Talk to your friends and family about your gout so they understand what's going on with you. Let them know some ways that they can help you cope better with the challenges of your disease, particularly if they want to be there for you. Find out which people in your life will be good sources of support when you have an acute gout flare, or when you feel like living with gout is a lot to handle. Some family members or friends could be great exercise buddies too.

Here are a few tips for talking with your family and friends about your gout, and getting help when you need it:

- Explain a little bit about your disease, like how gout affects your body, what inflammation and uric acid are, and how your joints could be at risk for serious damage if you don't control your gout. Don't try to unload an encyclopedia of information on others just give them a few ways that gout affects you. Use specific examples, like during a gout flare you cannot put on your shoe or stand on your feet for too long.
- Don't hide your pain or other symptoms from those you love. It's OK to admit that you are having a flare or struggling to get tasks done. Ask for help if and when you need it. Let people know ahead of time if you need help with tasks like walking the dog or mailing a package.
- Keep your close friends and family up to date about your gout treatments. Make a list of the drugs and dosages you take, and give it to a couple of people in your inner circle that you trust. They may need to have this information handy in a medical emergency. Also, people that care about you want to know what you are doing to treat your disease, and how you're doing. They can be the best cheerleaders for your treatment success!

# PART TEN Conclusion

Gout is a chronic disease, but in most cases, is manageable and highly treatable. Remember: the majority of gout patients who stick with their treatment regimens, over time, will stop having gout flares completely. However, the early phases of gout treatment can difficult, and you may still need to deal with gout flares. Be patient and stick with your treatment regimen, including medications, and any diet or lifestyle changes your doctor recommends.

Many people in your life may not understand gout or how it affects you, so tell them what you're going through right now. Welcome the support of the people around you, as well as other people who have gout. Gout is a common condition, so there's a good chance you already know quite a few people who have gout...but they may have never mentioned it.

Your physician, nurses and other healthcare professionals are your teammates in treating and managing your gout. They want you to feel better, prevent gout flares, have a great quality of life and avoid any long-term problems or joint damage. There are medications that are highly effective for treating gout flares and symptoms, managing hyperuricemia, and preventing recurrent gout flares or gouty arthritis. Your physicians, including a rheumatologist, can help you find the best treatment for your gout, and advise you on how you can change your lifestyle to reduce your risk of a gout flare or worsening gout.

You are not alone! Never feel that gout is something to feel ashamed of or guilty about. Gout is treatable and manageable for most people. If one treatment doesn't work well for you, your doctor can suggest something else. You can also take an active, impactful role in your gout management with a healthy diet, managing your alcohol intake, getting regular exercise and keeping your weight at a healthy level. If you need help with any of these changes, ask your doctor and nurses for recommendations or referrals to other healthcare professionals, like a physical therapist or registered dietitian, or alcohol treatment program if you need it. Like any profession, try to obtain the most qualified professional. Always evaluate the treatment you're getting, as no one knows your body like you do. The healthcare team, with you at its center, is there to help you succeed and manage your gout, and live a healthy, active life.



#### **DR. THEODORE FIELDS**

Theodore Fields, MD, FACP, is an Attending Rheumatologist at Hospital for Special Surgery and Professor of Clinical Medicine at Weill Cornell Medical College. He is the rheumatology medical editor of <u>www.hss.edu</u>, the HSS website providing comprehensive education on musculoskeletal disease treatment and prevention for physicians and patients. He is the Clinical Director of the Early Arthritis Initiative at HSS, which focuses on education of patients and physicians about early intervention in inflammatory arthritis. His special clinical interests are rheumatoid arthritis and gout. His most recent publications have focused on clinical aspects of gout and on improving education for patients with gout.



#### WILLA BRYER-DOUGLAS

Willa Bryer-Douglas was diagnosed with gout in 2013. Since then, she has researched the condition thoroughly on credited sources like PubMed or major hospital and medical school websites. She is a member of our CreakyJoints Gout Patient Council and hopes that these patient guidelines can help others living with gout control their disease.

These gout patient guidelines were made possible by the generous support of Horizon Pharma and Ironwood Pharmaceuticals.

**Bursae** – the fluid filled sacs or cavities between areas where tissue, like bone and muscle, meet to reduce friction. They are commonly in your joints and help make movement easy.

**Copay Assistance Programs** – Copay assistance programs are set up by manufacturers of medications to provide help to those who could not otherwise afford their treatment options.

**Crystals** – crystals are formed when uric acid collects in your blood or bursae. They can form hard lumps, like kidney stones, or collect in joints and cause painful inflammation.

**Flare** – a flare is a sudden increase in intensity of symptoms. In gout, a flare can typically last from three to ten days.

Hyperuricemia - hyperuricemia is when there is more uric acid than is considered healthy in your blood.

**Inflammation** – inflammation is your body's response to injury or infection. It is a sign of your immune system trying to protect your body, but when it is out of control it can cause reddening, swelling, a feeling of heat, and pain.

Intra-articular - intra-articular refers to any space between two joints.

**Kidney stones** – kidney stones can form from minerals or salts, like uric acid, within your kidneys. They are a collection of these crystals and can be painful and difficult to pass.

Metabolize - to metabolize means to break down something, often food, into its base levels of energy.

**Mobilization flare** – these flares occur during the first phase of treatment, when your body is adjusting to your medication. They may happen more often than your flares used to, but they are temporary.

**Polyarticular disease** – Polyarticular disease is when gout impacts more than just one joint.

**Purine** – purine is a substance produced naturally by your body, but can also be found in high levels in certain foods. When purines are broken down, they produce urate, which can cause gout in high levels.

**Steroid** – a steroid is a type of medication that reduces inflammation

**Synovitis** – this is inflammation or infection of the synovial membrane, or the membrane that lines certain joints. This can cause pain, especially when you move your joint.

**Tophus** – a tophus, or tophi (plural), is a deposit of uric acid crystals and other substances right at the surface of some of your joints, skin, or cartilage. They can appear to be bumps that may get painful during flares.

**Uric acid (urate)** – urate, or uric acid, is formed when your body breaks down purines. Most often, it is dissolved in your blood and flushed out of your body through your urine. In gout, people have high levels of uric acid that can cause pain, swelling, and difficulty moving some joints.

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