PATIENT RESOURCES:

Navigating the Physical and Mental Health Impact of Gout







INTRODUCTION

Gout takes a toll on patients — both physically and mentally. Explore the physical and mental health aspects of gout in this resource guide with materials from the Alliance for Gout Awareness and its partner organizations.

By heightening public awareness and addressing common misconceptions, patients can be empowered to acknowledge the disease's impact and to seek the treatment they need.



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What is Gout?

Gout is a form of inflammatory arthritis caused by a buildup of uric acid crystals in the joints that can lead to sudden, intense pain—often called a gout flare—and swollen joints that may become red and/or hot. While statistics show that more than 50 percent of gout flares start in the big toe, the uric acid crystals associated with gout are also commonly found in knees, hands, and feet, and can deposit in organs throughout the body, such as the kidney, causing kidney stones.



Causes

It's normal for everyone to have at least some uric acid in their bodies. However,

too much uric acid can build up and increase the risk of developing gout. Uric acid typically dissolves in the blood and then passes through the kidneys, where it is eventually removed through urine.

Approximately two-thirds of uric acid is produced by the body naturally; the rest comes from diet, often in the form of purines, which are substances in animal and plant foods that the body converts to uric acid. A family history of gout, as well as other health issues such as high blood pressure, diabetes, or kidney disease, can increase risk for developing gout. Certain medications can also trigger gout.





Gout Symptoms

The signs and symptoms of gout almost always occur suddenly, and often at night.

Signs and symptoms of gout include:



Intense pain and swelling—usually in one or two joints in the feet or legs, most commonly the big toe. During a gout flare (gout attack), the intensity of the pain in the affected joint is usually described as excruciating (8 to 10 out of 10).



Limited joint function—After five or more years of recurrent gout attacks, people with gout may develop tophi crystals under the skin and around joints. While generally not painful, tophi can be disfiguring and interfere with normal joint function. The presence of tophi close to bones can lead to bone and cartilage destruction creating further deformities in the affected joint.



Chronic persistent arthritis—During the early stages of gout, the inflammatory arthritis is intermittent and during the periods between gout attacks, the affected joint may feel and function normally. Years to decades after the initial flare (gout attack), flares may continue to be a recurrent problem but the intervals between gout attacks become painful on a daily basis.

Adequate treatment with appropriate uric acid-lowering therapies early on in the course of gout should prevent or eliminate gout attacks, tophus formation, and bony erosions from occurring.

Gout symptoms can be very painful. During initial onset, it's imperative to treat symptoms of gout immediately or it could get much worse.





Gout Treatment

Treatment of Gout

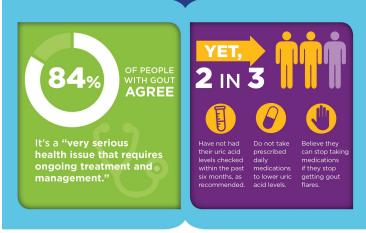
It is important to talk to your doctor about the symptoms of gout and their cause. Understanding the mechanisms responsible for gout is the first step in good management of this disease.

Treatment of gout, also known as gouty arthritis, should include both pain management and uric acid-lowering medications. It is important to distinguish these two classes of drugs for treating gout.

How to Relieve Gout Pain

As the most common form of inflammatory arthritis, gout flares are typically accompanied by severe pain at the site of the affected joint where gout symptoms cause it to be red, swollen and very tender to the touch. During

GOUT PATIENTS AREN'TGETTING THE TREATMENT THEY NEED





these flares, the anti-inflammatory medications used to lessen the pain and swelling are most effective if started as soon as possible after the onset of the flare or attack.

Lifelong Gout Management

Like many other medications used for treating chronic conditions such as high blood pressure or high cholesterol, uric acid-lowering medicines are meant to be taken daily for life in order to lower uric acid levels and prevent the progression of the disease. They should not be discontinued, even if a gout flare occurs.

While gout is a lifelong condition, it can be managed—or even completely controlled—by sticking with a proper treatment plan. The combination of the right medications and lifestyle changes for lowering uric acid will stop the build-up of more uric acid crystals, which cause the excruciating pain of gout attacks and the crippling arthritis associated with uncontrolled gout over years and decades.



healthywomen

Fast Facts: What Women Need to Know About Gout

Gout rates in women are going up

You may wonder if women can get gout, and the answer is yes. In fact, 2 million women in the U.S. have gout, and the cases of gout in women have more than doubled in the last 20 years.

Gout is an inflammatory form of arthritis that occurs when uric acid levels in your blood get too high. Since estrogen helps flush uric acid out of the body, women tend to get gout after they've gone through menopause, which causes them to lose estrogen.



Women who haven't gone through menopause can still get gout, but it's less common. Women who are living with chronic kidney disease are also at a higher risk.

Gout may signal other health risks, especially for women

Knowing your gout risk is important because gout often goes along with other health risks. One study showed that women with gout were 39% more likely to have a heart attack than women without gout. Another study found that women with gout were more likely than men with gout to have high blood pressure, diabetes, kidney disease and obesity.

Gout symptoms in women

Intense pain in the big toe is a classic sign of gout, but women often get pain in their hands instead. As a result, healthcare providers can sometimes mistake gout for inflammatory osteoarthritis, which causes swelling and pain in the fingers.

While gout often comes on suddenly and intensely, women are more likely than men to have joint pain that starts more slowly and affects several joints at a time. These joints include the knees, toes, wrists and fingers.

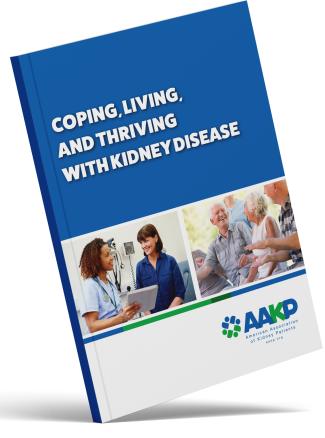
Women are often dismissed or ignored by healthcare providers overall. This can come into play in a condition like gout, which is often misdiagnosed, especially in women who don't always have the telltale symptoms. So, it's important to advocate for yourself if you suspect you have gout. One way to do that is to ask for a blood test to measure your uric acid levels. If your level is above 6 mg/dl and you're experiencing flares, you may have gout.





Coping, Living and Thriving with Gout & Kidney Disease

Chronic kidney disease (CKD) and gout are two conditions that are closely intertwined, forming a complex relationship. CKD can actually increase the risk of developing gout, while gout itself can contribute to the progression of CKD. Both CKD and gout can be incredibly debilitating, significantly impacting one's quality of life. Did you know there are ways to effectively manage these conditions and continue living a fulfilling life? By implementing certain lifestyle changes and following key strategies, individuals with gout can take control of their health and thrive.



Check out the American Association of Kidney Patients' (AAKP) Coping, Living, and Thriving with Kidney Disease brochure! This incredible resource is packed with tools and strategies that will help you not just cope, but truly thrive, despite your CKD and/or gout diagnosis.

Take charge of your health and embrace a life full of possibilities. With the AAKP's guidance, you'll be equipped face the challenges ahead of you.





The Mind-Body Divide

Clinical psychologist Rachel Zoffness, MA, MS, PhD, believes physicians unfamiliar with chronic, sometimes-invisible diseases often focus only on a single aspect of care.

"There's no such thing as a condition that affects a human being that only targets the body and doesn't impact how we're doing or feeling," says Zoffness, who has personal experience with a chronic condition and whose subspecialty is pain psychology.

Pain is biopsychosocial, Zoffness says:
Biological, psychological, and sociological
factors all influence its manifestation.
Neuroscience has revealed that the limbic
system—the emotional center of the human
brain—is connected to pain. So negative
emotions, experiences, or trauma "actually
amplify the pain you feel," she says. Without



considering this, doctors may struggle to provide effective care.

Lucy Dunning, BS, MEd, EdS, is a therapist and owner of Blue Sky Family Counseling and Coaching, which serves North Carolina, South Carolina, and Georgia. Dunning, who has type II complex regional pain syndrome (CRPS) and neuropathy, believes some doctors overemphasize or misunderstand psychological symptoms. Anxiety and depression can be pre-existing conditions, but they aren't always. Doctors may read pain-related psychological symptoms as psychiatric rather than as resulting from a chronic health condition.

Zoffness and Dunning concur that people with chronic health conditions experience anxiety and depression differently, and as such, medical professionals must alter their approach to care for those patients. "I have yet to meet anyone with a life-changing condition who is not anxious and depressed," Dunning says.





Arthritis and Mental Health

Depression, anxiety and other mental health issues are common among people living with gout.

Depression is a mental health issue that has a negative effect on the way you feel, think, and act. It can cause you to lose interest in activities you once enjoyed.

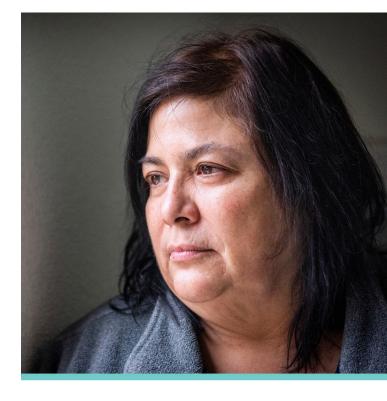
The symptoms of depression differ for each person and may overlap with the side effects of gout and gout treatment. Some of the symptoms include:

- **Depressed mood** most of the day
- Reduced interest or loss of pleasure in almost all activities
- Major weight change or increase or decrease in appetite
- Sleep issues (insomnia or hypersomnia)
- A slowing down of thought and decreased physical movement
- Fatigue or loss of energy
- Feelings of worthlessness
- Reduced ability to think or concentrate, being indecisive
- Repeated thoughts of death, repeated thoughts of considering or planning suicide without a specific plan, or a suicide attempt or specific plan for committing suicide

It is normal to feel sad due to the life-changing experiences that happen when living with gout. But you should talk to your health care team (including your doctor, nurse or social worker) if you experience five or more symptoms for two weeks or longer.

Scan for information.







As the largest nonprofit organization focused on arthritis and related conditions, the Arthritis Foundation has led the way in supporting people with arthritis and their caregivers for nearly eight decades.

Depression and Chronic Disease

Many studies have clearly shown that people with arthritis with the highest pain levels are the most likely to be anxious or depressed. Exactly why higher pain severity is associated with depression is not clear. It seems to be a two-way street.



Pain incites depression. Living with daily pain is physically and emotionally stressful. Chronic stress is known to change your levels of brain and nervous system chemicals. These stress hormones and neurochemicals — like cortisol, serotonin and norepinephrine — affect your mood, thinking and behavior. Disrupting your body's balance of these chemicals can bring on depression in some people.





Depression makes pain worse. Depression weakens a person's ability to deal and cope with pain. A person's perception about their condition, for example, back pain, might become more negative when compared with individuals who are not depressed.

Jon T. Giles, MD, an assistant professor of medicine at Columbia University and rheumatologist at New York Presbyterian Hospital in New York City, says "Painful sensations are relayed through the brain in a very complex way, and can be modulated up or down." Stress, poor sleep, anxiety and depression all influence pain levels, he explains.









Ways to boost resilience:



Focus on the positives: Studies have shown that the more hopeful you are, the more resilient you will be. Look at your experiences in a new way. Be aware of the negatives that chronic illness brings to your life, but focus on the positives too. Stay optimistic about your treatment plan working well so you can get back to a normal, active life that you enjoy.



Learn from experience: Keep track of how different treatments impact you and what works best for your body. This will help you understand how to manage your disease, making you stronger and more confident about your future.



Expand your knowledge: Read up on your chronic illness and how to manage it. The more you know about your condition, the more power you will have to control its effect on your life and well-being.



Stay active in life: Make time to find and do things that you enjoy. Find new activities that are easy to do, like reading, watching movies, taking gentle walks, or visiting with friends.



Exercise: Movement is not just great for your joints and muscles, it's also known to improve your mood and decrease anxiety.



Get support: Turn to family or friends when you are struggling with your emotions or feel like you're in despair. Learn how to explain your health condition with your loved ones. Support networks like CreakyJoints allow you to connect with other people who are living with rheumatic diseases like RA.



Count your blessings: Gratitude can make you feel more connected with life. Be grateful for the things in your life that make you feel good. Focus on the people and activities that make you happy.





Finding Community

Unbearable. Frustrating. If you have gout, you know that that's how the disease can sometimes feel.

Finding support from friends and family can make a big difference. But gout patients may feel embarrassed to bring up their condition.

If you are struggling to talk about gout with your loved ones, these tips can help you get started.



Plan a time to talk.

Find time to talk to your friends and family about your condition. It doesn't have to be formal, but it should be in a space where you feel comfortable sharing your journey. The more comfortable you feel in your surroundings, the easier it will be to talk to them.



Explain the disease.

Take some time to explain the disease and how it affects you. Many people do not know what gout is. Make it clear that gout is not funny or self-induced, but rather a form of arthritis that can be debilitating.



Share your experience.

Describe what a gout attack feels like. Show them how this disease has affected your life. Maybe you can no longer participate in your favorite hobby. Maybe it's gotten in the way of your career. Your friends and family may not be able to relate to your pain, but they can come to understand how the condition affects your life.



Continue the conversation.

Conversations about gout are not "one and done." It's normal for your gout experiences to come up in casual and ongoing conversations. Make sure that your friends and family know that they can always ask you questions. Don't be afraid to lean on them when you are experiencing an attack.

Living with gout can be challenging, but the support of your loved ones goes a long way. And don't forget that a community of gout patients is just one click away on the Gout Support Group of America Facebook page. We are here to help and support you in your journey.





What can I do to manage my stress?

It is very difficult, if not impossible, to completely get rid of stress, or to never have any physical reactions to stress.

However, there are steps you can take to manage stress and help control your body's response to stress. Some simple ways to reduce stress include:

- Eat healthier foods
- Limit salt and caffeine (especially if you have high blood pressure)
- Limit sugar (especially if you have diabetes), and fats (especially if you are at risk for heart and blood vessel disease)
- Set aside time to relax
- Relaxation techniques (yoga, meditation, etc.)
- Prayer
- Talk to a friend, loved one, spiritual leader, or healthcare professional
- Write down your problems and think about the best solution for each of them. A list can help you evaluate and prioritize what issues need to be addressed.
- Set realistic goals and expectations
- Get enough sleep and maintain a regular sleep schedule
- Maintain a positive attitude and outlook
- Vacation
- Regular exercise and more physical activity

No matter the technique, managing your stress can help you feel better and live a healthier life.









A Comprehensive Approach to Treatment

The physical pain caused by gout, a common form of inflammatory arthritis, can be debilitating. But gout can also take a toll on patients' mental health. The stigma associated with the disease can lead to isolation, causing those living with gout to suffer in silence. That's why a comprehensive approach that addresses both physical symptoms and mental health is critical for successfully managing gout.

Survey Says

According to a recent survey, gout affects people's ability to:

- 41% Do their job
- 30% Care for their children, spouse or other family members
- 50% Participate in hobbies or community activities

- 28% Maintain friendships and stay socially active
- 56% Enjoy their life

58% experienced anxiety, depression or hopelessness because of gout pain and its impact on daily life.

A comprehensive approach includes:

- **Seeking treatment** for both physical AND mental symptoms. Be proactive and don't wait for a flare to make an appointment. Be honest with your health care provider about your symptoms and how you are feeling.
- 2 Finding mental health support by joining patient groups and visiting a mental health professional. Talking about your experience can help you feel better and remind you that you are not alone.
- 3 Sharing your diagnosis with family, friends and employers. There is no shame in being diagnosed with gout. Being honest about your condition with others allows them to provide the support you need and empowers other patients to do the same.

Gout can take a physical and mental toll on patients, but there is hope. A comprehensive approach to treatment can help patients successfully manage the condition and regain their quality of life.





Policies to Improve Mental Health Care

Making the decision to seek assistance with one's mental and emotional health can be extraordinarily difficult for many patients.

The fear of stigma or repercussions—whether real or imagined, external or internal—has historically discouraged some people from seeking mental health care at all. It is imperative, then, that those seeking help have every opportunity to access the care they need, regardless of the entry point, and be guided toward their optimal pathway for care.

Governments, schools, educators, medical professionals and employers all need to stress that seeking mental health care is not just acceptable but encouraged in the interest of general mental wellbeing. They can also collaborate on policy solutions.



Opportunities for mental health care education. While not every medical professional can specialize in mental health care, frontline clinicians providing primary and emergency care need the education and tools to identify potential mental health issues and link patients with skilled mental health providers.



Stronger mental health care network. Policies must prioritize strengthening the mental health care network. With the launch of the 988 hotline, federal, state and local governments must allocate appropriate funds to support helplines, as well as mobile crisis centers and public and community clinics. Policymakers should also search for ways to encourage people to pursue careers in the field of mental health, where they can support the increasing number of patients who need care.



Robust access to telemedicine. Modern telemedicine has opened opportunities for patients to access mental care regardless of their location, language or financial status. It is fast, easily accessed with a smartphone and has been proven to work time and time again. Practitioners need the ability and authority to help their patients regardless of their physical location, whether they're across the table or across state lines. And coverage must ensure parity for mental health patients who use telemedicines services.

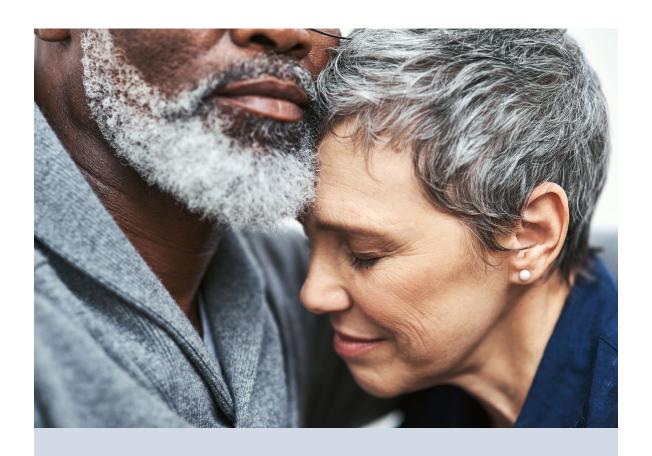


Policies that support patient-centered care. As with any other medical issue, insurers must not interfere with the diagnosis and treatment of patients as prescribed by a provider. Imposing prior authorizations, step

therapy or non-medical switching can slow treatment and weaken the bond of trust between provider and patient.







There is hope.



If you or someone you know needs support now, call or text 988 or chat 988lifeline.org

988 SUICIDE & CRISIS LIFELINE



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































