



In Their Own Voices

Lived Experiences of Gout Patients



Introduction

Gout is a form of arthritis that leads to sudden, intense pain and swollen joints that may become red and hot. Though the experience of gout can be isolating, the disease is quite common. **Gout affects more than 9 million Americans.**

Gout's painful attacks can have debilitating effects on patients' lives. It is common for gout patients to have trouble walking, climbing stairs or completing everyday tasks like household chores or caring for family members. As a result, gout also impacts patients' workplaces, homes and communities.

To help illuminate the challenges gout patients face, the Alliance for Gout Awareness brought together patients from across the country to participate in a virtual focus group. This document shares their collective experiences.

Findings

Gout Impacts All Aspects of Patients' Lives

Patients reported that the pain of gout flares upended their daily lives. For some, the pain was so debilitating they had trouble walking and going to work. Gout flares caused patients to miss important events and withdraw from social activities.

One patient described how debilitating gout attacks were a contributing factor in ending his career as an EMT and forced him to a physically less demanding position. Another patient explained that getting to work every day required him to wear shoes three times his normal size because of the swelling and pain he experienced.

Another patient described how, when she has a severe gout attack, she can't be in the same room with her husband or family because of the pressure sensitivity she experiences.

“When my gout wasn't under control, it completely stopped my life.”

“I was in the best shape of my life. I never expected it was gout.”

Symptoms and Flares Vary by Patient

Gout flares can be intensely painful and disabling. They can start suddenly, often in the middle of the night or early morning, and can last days or weeks. Most patients experience gout pain in their feet, though some described experiencing flares in other joints throughout their entire body.

One patient compared her gout pain to the pain of natural childbirth, saying the gout flare was actually worse for her. Another patient described flares as feeling like fire flowing through his blood.

Patients reported different frequencies of gout flares. Some patients recalled that, in the early days of their gout, they got flares more sporadically, perhaps once every two or three years. As the gout worsened, however, patients experienced more frequent flares, with some reporting multiple flares each month.





“I couldn’t walk from the excruciating leg pain and had to call an ambulance to go to the hospital.”

Patients Also Face Other Conditions

Gout is associated with a number of comorbidities, a connection that was reflected by the experiences of focus group participants. Several patients reported having high cholesterol or high blood pressure, while others described living with chronic kidney disease and cardiovascular disease.

Comorbidities can complicate the experience of living with and treating gout. Patients may juggle multiple medical appointments with different health care providers, and they likely take multiple prescription medications to treat their different conditions. In some cases, treatment options for gout depend upon comorbidities and the other medications patients take to treat them.

For example, certain medications for gout aren’t viable treatment options for patients who also have kidney disease.

Patients also indicated that having other health conditions makes it difficult to pinpoint the source of their pain sometimes.

“It’s difficult to know where my pain is coming from—is it gout or is it something else?”

Patients Struggle to Get Diagnosed

A common factor in each patient's experience with gout was the lengthy process of receiving a diagnosis.

Most patients saw a primary care provider when their symptoms first began, but few found answers about what they were experiencing. Many patients described going years without receiving a proper diagnosis.

Several patients explained that seeing a rheumatology provider was transformative. With the expertise and insight of their rheumatologist, several patients were able to identify gout as the cause of their pain and find a treatment plan that worked for them.

“It took years of dealing with flares before I saw a rheumatologist and got proper treatment for my gout.”

“It took two years to get a diagnosis because I was a female in my 20s. Nobody suspected I had gout.”



Finding the Right Treatment Takes Time

Managing gout comes with many challenges, as patients described. It is often a lengthy trial-and-error process where patients' pain persists until they find a treatment that works.

“Ultimately, the pain becomes so intense that you become desperate to find treatment.”

Some patients looked to lifestyle changes for treatment. Incorporating a healthy diet and exercise into their routine helped several patients decrease gout flares.

Patients also found that prescribed medication helped. Patients described taking medications like colchicine, allopurinol or steroids to get their gout under

control. For several patients whose gout persisted despite these treatments, infused medication called pegloticase helped reduce flares and control their gout. Most patients found they had to try multiple medications before they found one, or a combination, that worked for them.

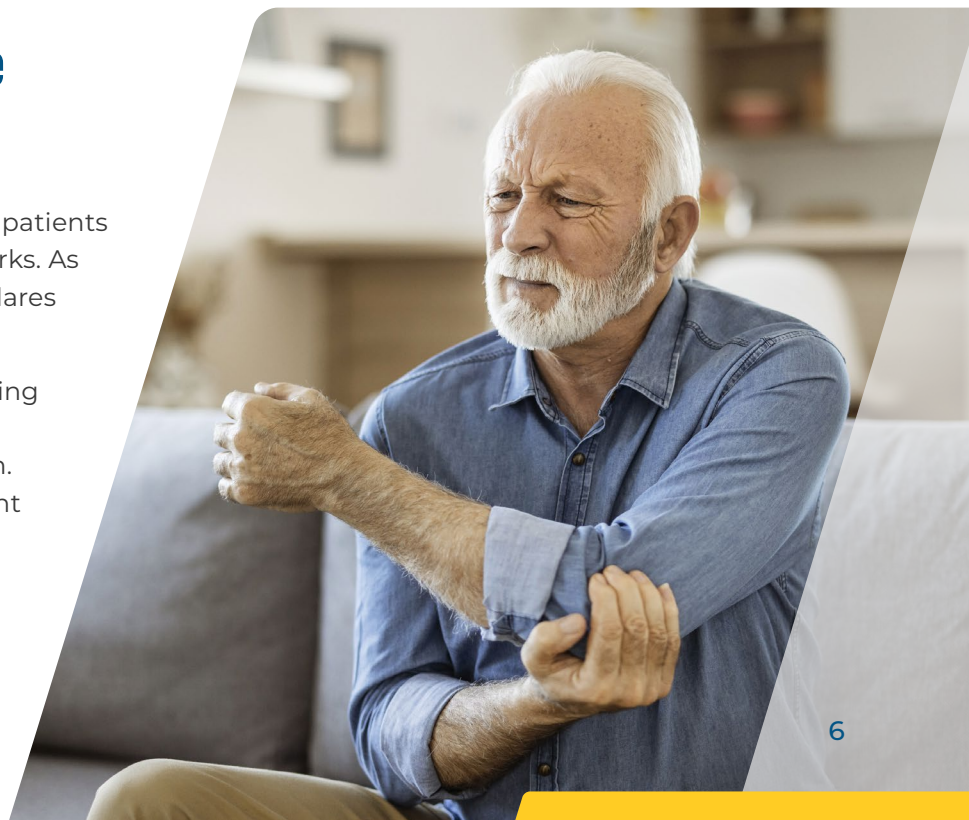
Some patients also experienced problems with insurance coverage. Before their health plan would pay for the medication prescribed by their health care provider, they were made to try and potentially fail on other medications first. This process prolonged their gout pain, patients explained, and delayed access to effective medication to manage their gout.


“After trying what felt like hundreds of meds, I finally found something that works.”

Some Patients Still Face Unmet Needs

Due to a variety of challenges, some patients have yet to find a treatment that works. As a result, they continue to face gout flares as part of daily life.

Uncontrolled gout can be discouraging and detrimental to patients, who continue to experience extreme pain. Continued research and development is imperative for getting help to the more than 9 million Americans living with gout.





“I used to hear my grandmother talk about gout, but I never thought it would affect me.”

Misconceptions About Gout Persist

Incorrect assumptions about gout have existed for as long as the disease itself has. Patients described facing misconceptions about the disease — and even harboring a few themselves.

Several patients reported that, before receiving a diagnosis, they thought gout affected only older people. They did not expect to receive a gout diagnosis early in life.

Patients also described believing that gout affects only chronic alcohol users and people with unhealthy lifestyles. Some patients said that even their health care providers had these same misconceptions about gout, which prevented them from reaching a diagnosis sooner.

Few patients had an accurate understanding or knowledge of gout before their diagnosis. And many had to do their own research to find the answers they sought. Some mentioned that support groups on social media provided valuable resources for learning more. Others reported that their gout specialists provided the best information and resources for gout education.

“These misconceptions are damaging and are stopping patients from receiving adequate care.”

“I had no idea what gout was. I don’t know if I had ever heard the word ‘gout’ until I was diagnosed.”

Reflections on Life with Gout

Patients were asked to sum up their experience with gout in a single sentence.

"It went from horrible to balanced."

"Adventurous and unkind."

"I'm hopeful but reserved."

"A great discovery and understanding."

"An immense amount of pain to an immense discovery."



 ALLIANCE FOR
Gout Awareness

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

To learn more visit goutalliance.org