

## Thanks to Reddit, a new diagnosis is bubbling up across the nation

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Credit: Pixabay/CC0 Public Domain

In a video posted to Reddit this summer, Lucie Rosenthal's face starts focused and uncertain, looking intently into the camera, before it happens.



She releases a succinct, croak-like belch.

Then, it's wide-eyed surprise, followed by rollicking laughter. "I got it!" the Denver resident says after what was her second burp ever.

"It's really rocking my mind that I am fully introducing a new bodily function at 26 years old," Rosenthal later told KFF Health News while working remotely, because, as great as the burping was, it was now happening uncontrollably. "Sorry, excuse me. Oh, my god. That was a burp. Did you hear it?"

Rosenthal is among more than a thousand people who have received a procedure to help them burp since 2019, when an Illinois doctor first reported the steps of the intervention in a medical journal.

The inability to belch can cause bloating, pain, gurgling in the neck and chest, and excessive flatulence as built-up air seeks an alternate exit route. One Reddit user described the gurgling sound as an "alien trying to escape me," and pain like a heart attack that goes away with a fart.

The procedure has spread, primarily thanks to increasingly loud rumblings in the bowels of Reddit. Membership in a subreddit for people with or interested in the condition has ballooned to about 31,000 people, to become one of the platform's larger groups.

Since 2019, the condition has had an official name: retrograde cricopharyngeus dysfunction, also known as "abelchia" or "no-burp syndrome." The syndrome is caused by a quirk in the muscle that acts as the gatekeeper to the esophagus, the roughly 10-inch-long muscular tube that moves food between the throat and the stomach.

The procedure to fix it involves a doctor injecting 50 to 100 units of Botox—more than twice the amount often used to smooth forehead



wrinkles—into the upper cricopharyngeal muscle.

Michael King, the physician who treated Rosenthal, said he hadn't heard of the disorder until 2020, when a teenager, armed with a list of academic papers found on Reddit, asked him to do the procedure.

It wasn't a stretch. King, a laryngologist with Peak ENT and Voice Center, had been injecting Botox in the same muscle to treat people having a hard time swallowing after a stroke.

Now he's among doctors from Norway to Thailand listed on the subreddit, r/noburp, as offering the procedure. Other doctors, commenters have noted, have occasionally laughed at them or made them feel they were being melodramatic.

To be fair, doctors and researchers don't understand why the same muscle that lets food move down won't let air move up.

"It's very odd," King said.

Doctors also aren't sure why many patients keep burping long after the Botox wears off after a few months. Robert Bastian, a laryngologist outside of Chicago, named the condition and came up with the procedure. He estimates he and his colleagues have treated about 1,800 people, charging about \$4,000 a pop.

"We hear that in Southern California it's \$25,000, in Seattle \$16,000, in New York City \$25,000," Bastian said.

Because <u>insurance companies</u> viewed Botox charges as a "red flag," he said, his patients now pay \$650 to cover the medication so it can be excluded from the <u>insurance claims</u>.



The pioneering patient is Daryl Moody, a car technician who has worked at the same Toyota dealership in Houston for half his life. The 34-year-old said that by 2015 he had become "desperate" for relief. The bloating and gurgling wasn't just a painful shadow over his day; it was cramping his new hobby: skydiving.

"I hadn't done anything fun or interesting with my life," he said.

That is, until he tried skydiving. But as he gained altitude on the way up, his stomach would inflate like a bag of chips on a flight.

"I went to 10 doctors," he said. "Nobody seemed to believe me that this problem even existed."

Then he stumbled upon a YouTube video by Bastian describing how Botox injections can fix some throat conditions. Moody asked if Bastian could try it to cure his burping problem. Bastian agreed.

Moody's insurance considered it "experimental and unnecessary," he recalled, so he had to pay about \$2,700 out-of-pocket.

"This is honestly going to change everything," he posted on his Facebook page in December 2015, about his trip to Illinois.

The year after his procedure, Moody helped break a national record for participating in the largest group of people to skydive together while wearing wingsuits, those getups that turn people into flying squirrels. He has jumped about 400 times now.

People have been plagued by this issue for at least a few millennia. Two thousand years ago, the Roman philosopher Pliny the Elder described a man named Pomponius who could not belch. And 840 years ago, Johannes de Hauvilla included the tidbit in a poem, writing, "The



steaming face of Pomponius could find no relief by belching."

It took a few more centuries for clinical examples to pop up. In the 1980s, a few case reports in the U.S. described people who couldn't burp and had no memory of vomiting. One woman, doctors wrote, was "unable to voluntarily belch along with her childhood friends when this was a popular game."

The patients were in a great deal of pain, though doctors couldn't find anything wrong with their anatomy. But the doctors confirmed using a method called manometry that patients' upper esophageal sphincters simply would not relax—not after a meal of a sandwich, glass of milk, and candy bar, nor after doctors used a catheter to squirt several ounces of air beneath the stubborn valve.

André Smout, a gastroenterologist at the University of Amsterdam in the Netherlands, said he read those reports when they came out.

"But we never saw the condition, so we didn't believe that it existed in real life," he said.

Smout's doubts persisted until he and colleagues studied a small group of patients a few years ago. The researchers gave eight patients with a reported inability to burp a "belch provocation" in the form of carbonated water, and used pressure sensors to observe how their throats moved. Indeed, the air stayed trapped. A Botox injection resolved their problems by giving them the ability to burp, or, to use an academic term, eructate.

"We had to admit that it really existed," Smout said.

He <u>wrote</u> in *Current Opinion in Gastroenterology* that the syndrome "may not be as rare as thought hitherto." He credits Reddit with alerting



patients and medical professionals to its existence.

But he wonders how often the treatment might cause a placebo effect. He pointed to studies finding that with conditions such as irritable bowel syndrome, 40% or more of patients who receive placebo treatment feel their symptoms improve. Awareness is also growing about "cyberchondria," when people search desperately online for answers to their ailments—putting them at risk of unnecessary treatment or further distress.

In Denver, Rosenthal, the new burper, is open to the idea that the placebo effect could be at play for her. But even if that's the case, she feels much better.

"I felt perpetual nausea, and that has subsided a lot since I got the procedure done," she said. So has the bloating and stomach pain. She can drink a beer at happy hour and not feel ill.

She's pleased insurance covered the procedure, and she's getting a handle on the involuntary burping. She cannot, however, burp the alphabet.

"Not yet," she said.

**More information:** André Smout et al, Inability to belch syndrome: what the gastroenterologist needs to know, *Current Opinion in Gastroenterology* (2024). DOI: 10.1097/MOG.0000000000001022

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