

CYNTHIA GREER / Staff Artist

Coping with scent distortion

The COVID side effect is baffling. Some sufferers find community on social media.

By Maggie Hennessy
FOR THE INQUIRER

After weeks of smell loss and distortion of her senses due to COVID-19 in February 2021, Marie Cheslik took to TikTok for relief.

For nurse, sommelier and founder of wine education platform Slick Wines, the metallic taste of onions signaled something was wrong. Because for millions of people like Chicago-based Cheslik (who wasn't yet vaccinated when she contracted COVID-19 last year), food suddenly tasted and smelled like everything from rotting meat to gasoline.

Parosmia, or smell distortion, can affect 7 to 12% of COVID-19 patients, according to various international researchers in the United Kingdom, Italy, and Iran. Though it's not exactly known why the virus causes smell loss, people are looking for answers where they can.

On TikTok, the hashtags “postcovidparosmia” and “parosmiapostcovid” have racked millions of views as users share their experiences, look for help, or find some shared community in the experience. Facebook has become a go-to gathering place as well, with online groups popping up for people to share avenues of relief for people “desperate for solutions,” as noted in one group called Parosmia- Post COVID Support Group.

Though some experts say that symptoms can last anywhere between three and six months on the long end, TikTok user Hannah B. Cano shared that she's been suffering from smell distortion for 10 months since getting COVID.

Describing her life as “a living hell” in a video clocking in at 13 million views, Cano said that anything she eats smells and tastes like “rotting flesh, and garbage and sewage,” but parosmia and doesn't have to be noxious to be disconcerting. One person interviewed for this story reported all soda has tasted like perfume for months, while some people are even haunted by phantom smells, with reports ranging from rotting onions to corn chips.

Peanut butter ranks high on Santo Scavuzzo's list of favorite foods. At least it did until about two months ago, when he sat down to a bowl of Peanut Butter Chex cereal and noticed a faint, almost chemical smell and taste.

“At first I thought the milk expired,” said Scavuzzo, who works as people coordinator at Boka Restaurant Group in Chicago. “I went to check the expiration date, and it was totally fine. I thought, well maybe it's me. A week later, I went to eat some peanut butter and it hit me hard, like a punch in the face.”

He describes the smell as ammonia-like, reminiscent of certain hair solutions. Scavuzzo pegged COVID-19 as the likely culprit. Back in September 2021, he completely lost his senses of smell and taste for a week after testing positive for the virus (he was fully vaccinated). He realized all nuts now smelled and tasted like chemicals, and has since resorted to buying sunflower butter. “It's good, but it's not peanut butter.”

Smell loss and distortion is isolating and unnerving, linked to decreased quality of life, negative impacts on the diet, increased anxiety about personal hygiene, and depression, as noted in one study published in the peer-reviewed *European Archives of Oto-Rhino-Laryngology*. On a practical level, the overt dangers of not being able to discern a fire or gas leak in your

home can also be potential issues.

Smell loss or anosmia (the absence of smell) is a telltale COVID-19 symptom, listed as a symptom by both the Centers for Disease Control and World Health Organization, affecting between 30 and 80% of patients, often accompanied by loss of taste, according to McGill University in Quebec. A group of researchers from Philadelphia's Monell Chemical Senses Center found that number to be closer to 77% when qualifying objective data across worldwide studies.

Some researchers believe that parosmia and its attendant distortion of smells is part of the recovery process — one's sense of smell may be returning, but with a “miswiring” of the nerves responsible for communicating the smell to the brain. Though most people do recover their sense of smell within weeks, some 1.6 million people in the United States are experiencing chronic smell loss or distortion due to COVID, according to a study published in November 2021 in the journal *JAMA Otolaryngology—Head & Neck Surgery*.

And doctors can't say for sure when, or if, it will return.

“We had really hoped that people would gradually and consistently get better, and many do,” said Danielle Reed, associate director of the Monell Chemical Senses Center in Philadelphia, an independent nonprofit research center that studies taste and smell in relation to early disease detection, prevention, treatment, and overall well-being. “The bad news is, not only do some people not get better in the sense that they lose their sense of smell, they get worse in that when their smell comes back, it comes back incorrectly.”

As we constantly take in odors (aka volatiles) from our environment, olfactory sensory neurons, or smell cells, in the nose process the information and send signals to the brain. Some volatiles go through the mouth — wherein lies the nuanced joy of eating, as aromas lend complexity to the sweet, sour, salty, and umami sensations on our taste buds.

“Because olfactory sensory neurons are the only type of neuron directly exposed to the outside world, they sustain an unusual amount of damage,” Reed said. “They're also a rare part of your nervous system that is able to renew itself.”

Researchers believe the coronavirus doesn't attack the smell cells directly, but rather the nourishing cells supporting them, which secrete a signal causing the smell cells to shut down. As those receptors reawaken, they might misfire sensory signals that are then misread by the brain.

“If the nose or brain is confused about what's coming in, the safe default is bad, which explains why people with parosmia aren't usually smelling flowers,” Reed added.

Emotions and memories are intricately connected to smell; simply conjure the nostalgic aroma of cinnamon-tinted apples or a former lover's cologne. Losing such olfactory links to the world can result in feeling detached from reality — walking into your house without its soothing aromatic embrace or suddenly recoiling at a favorite meal.

Reed has fielded dozens of letters from COVID-19 patients who haven't yet recovered and are seeking answers, or simply space to air their

grief and feelings of isolation.

She directs them to smell and taste loss support and advocacy groups like Fifth Sense, the Smell and Taste Association of North America, and Ab-Scient (which started a COVID-19 smell and taste loss Facebook group that now has over 34,000 members). She also urges them to keep up with real-time research and therapeutic updates on Monell's website and at clinicaltrials.gov. Among them, New York's Mount Sinai Hospital is conducting a clinical trial to see whether taking fish oil helps restore the sense of smell, as omega-3 fatty acids therein may protect nerve cells from further damage or help regenerate nerve growth.

Still, Reed understands the frustration at not having answers to such pressing questions as: Will it end? Is there a cure? Why does it affect some long term and not others? And, more recently, does this not occur with delta and omicron? (Reed explains that researchers have yet to untangle the effects of vaccination and variants on parosmia.)

“Part of the problem is we don't have a baseline for assessing people's ability to smell and taste as a measure of wellness,” said Mackenzie Hannum, a postdoctoral fellow at Monell specializing in survey methodology and human research. Taste and smell tests are “not included in doctor visits.”

Hannum and Reed were part of a team that developed a rapid test to screen for smell loss in COVID patients. The SCENTinel 1.0 test measures detection, intensity, and identification through three odor patches participants smell and answer questions about on their phones. They're working on a more general smell assessment test, thanks to renewed interest in and funding for smell research.

But in the absence of approved treatments, some are turning to home remedies, which have flooded social media.

For instance, wine educator Cheslik turned to TikTok-supplied cures like chewing on spices and eating spicy foods daily “for a solid four weeks before I got [smell and taste] 90% back.” She even tried one home remedy TikTokker Kumar Gary swears by, which involves burning an orange on a gas stove, peeling it, mashing the flesh with brown sugar, and eating it. (The video has since racked up almost 4 million views.)

Cheslik thinks it helped briefly but offered some hope. “It helped me feel like it wasn't going to be forever.”

While Hannum said there's no scientific backing to the burnt-orange claim, there is some evidence to support the validity of smell training, or routinely inhaling strong scents like lavender, cinnamon, and citrus while concentrating hard to remember those smells.

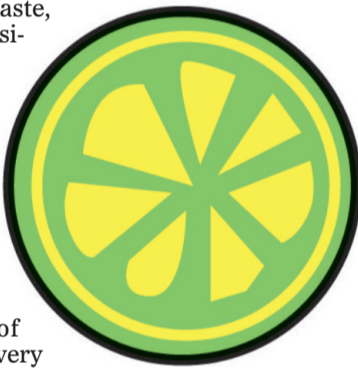
“Try to do it every day to retrain those muscles as much as you can,” she said. “It also feels like you're doing something active, and I think that's a huge help to your health.”

Scavuzzo likewise did smell training with coffee beans and pumpkin spice during his anosmia but hadn't gone near peanut butter since the December incident.

“I'm opening up peanut butter right now,” he said. “It's weird because it's like, if I take a big whiff, at first it smells like peanut butter, and then it smells like chemicals.”

He tasted a spoonful and was quiet for several agonizing seconds.

“It's muted, which is not as bad as it was,” he said. “That's promising! I gotta do more peanut butter training.”



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