

## Since COVID, increased concern over smell loss is prompting new research

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One day in kindergarten, Alex Pieraccini sat and watched her peers pass around spices, sniffing them up as a sensory exercise.



Pieraccini, now 30, couldn't smell anything.

"I was like, 'Nothing is happening,'" said Pieraccini, a psychologist living in Baltimore. "I remember telling adults and not being believed for a long time."

Pieraccini has congenital anosmia, the chronic inability to smell. It is a rare condition—approximately 1 in 10,000 people had it according to 2016 figures from the U.S. Department of Health and Human Services' Genetic and Rare Diseases Information Center.

But now, millions more lost their smell as the preeminent symptom of COVID-19, and many haven't regained all of it.

The increased attention afforded to <u>smell loss</u> as a chronic condition has prompted new studies, piquing the interest of olfactory researchers bent on understanding more about the coronavirus. Meanwhile, scientists have not yet found conclusive treatments for smell loss.

At a minimum, the pandemic has highlighted the everyday struggles of people living with what some have termed an "invisible disability," one that makes life more difficult but might not be easily detected. It could also prompt breakthroughs for scientists and researchers in the field.

"I was made to feel invisible because people don't understand, so a little part of me has had a lot of validating experiences" during the pandemic, Pieraccini said. "Another part of me is like, 'Why did it take this long for it to be a visible thing?'"

## A spike in recognition

According to Google Trends, Google searches for the term "loss of smell" in the United States jumped from an interest value of 3 to 100,



the maximum, the week of March 22, 2020. Searches hit another high in the last week of December, as the nation approached a peak in average new cases per week.

Dr. Andrew Lane, the director of the Johns Hopkins Sinus Center, said the virus appears to specifically target olfactory cell tissue, which is necessary for the development of odor-sensing cells. This is why smell loss is a common symptom of COVID-19.

"People may not even know it, because people aren't that in tune to their sense of smell," Lane said. "If you test people formally, you would probably find even more of it."

Pamela Dalton, an olfactory researcher at the Monell Chemical Senses Center in Philadelphia, said the pandemic may have caused people to pay attention to the long-term effects of anosmia. The center has been busy fielding frantic calls for help, she said.

The rush in attention has caused some resentment among people who have dealt with loss of smell in the long term, Dalton said.

"Not surprisingly, people are like, 'I've had this for 20 years and I've coped with it.' They're resentful that there wasn't more attention paid to it before," Dalton said.

Lane hopes the added attention will lead to more treatment options for all kinds of smell loss.

"This will potentially be a boon to people who've lost their sense of smell for other reasons, because all this attention and research will potentially lead to some better understanding," Lane said.

Ken Halstead, 38, says he is cautious now about disclosing his long-term



inability to smell because of its association with COVID-19. Around Christmas, he was in a liquor store when a woman recommended he check out new perpermint Smirnoff bottles with scratch-and-sniff labels.

"I said, 'Oh, I have no sense of smell," said Halstead, an information technology specialist living in Alexandria, Virginia. "She nearly dropped the bottle," thinking he had COVID.

Dana Pair, who works in international development, contracted COVID-19 a few days before Christmas when traveling from her home in Upper Fells Point to visit family. She couldn't smell or taste anything at Christmas dinner. Pair, 27, hadn't known much about chronic smell loss before losing her own. She's regained some of her smell, but still experiences intense smell distortion.

"There really isn't a way for other people to fully understand it, especially if they haven't experienced anything similar themselves," said Pair, who has since moved to Knoxville, Tennessee.

It's a lonely condition, Pair said. She tries not to dwell on it, though.

"In the grand scheme of things, a sense of smell versus being alive are two very different things," Pair said. "You don't want to be considered ungrateful and the complainer."

## A condition with varying types and causes

There are several different types of anosmia, or smell loss disorders, ranging from temporary and partial to chronic and permanent. Some people grow up without the ability to smell, while others acquire the condition through traumatic brain injuries, severe burns or viruses. Some people, especially those recovering from COVID, experience parosmia,



or smell distortion.

Some people lose some of their ability to smell due to age. And there are environmental and occupational factors that can erode the sense over time, Dalton said, such as air pollution or toxic fumes. She has worked closely with firefighters who responded to the 9/11 attacks, for example.

COVID-19 attacks cells and causes inflammation, including in the areas around the receptors in a person's nose. The inflammation can last days or weeks, even months. But unlike other viruses that can affect a person's ability to smell or taste, such as the common cold, the coronavirus is not typically accompanied by congestion, Dalton said, making it more unusual.

"The way it shuts down the system is like a light switch," Dalton said. "People go to sleep or they have breakfast and all of a sudden everything's changed. It's really dramatic."

A study published in January looked at 2,581 patients from 18 European hospitals and found that almost 86% of people with mild COVID-19 develop anosmia. Ninety-five percent of them regained their sense of smell after six months. But for some, symptoms that included anosmia persisted—an occurrence known as long-haul COVID.

Dalton said it's not clear why some people lost their sense of smell as a symptom of the disease while others didn't, though there may be an underlying biological reason.

Christine Creed, 51, said it was frustrating to see friends who'd contracted COVID recover their smell after only two weeks. Creed, who lives in Dundalk, caught the virus in November and couldn't smell for about a month or so.



Now, she's still experiencing smell distortion. Some days, she'll smell nonexistent cigarette smoke. Vegetables have no taste, beef tastes rancid and peanut butter is a "no-go."

"You just never know from day to day what you can eat, you don't ever get that real hunger feeling," Creed said. "I wouldn't wish this on my worst enemy."

While there are no life-threatening side effects to losing the ability to smell, Dalton said "strong evidence" points to smell loss causing depression, especially among those who lost it suddenly.

There are also safety implications, as people can't smell dangers like smoke, natural gas and rotten food. It can also cause weight loss.

## Treatment options, or lack thereof

Treatment depends on the cause of the loss of smell, said Lane, of the Hopkins Sinus Center. He'll treat patients with sinus problems with anti-inflammatory steroids or, if the case is severe, surgery. Unfortunately, there's not much doctors can do for congenital, viral or trauma-related anosmia

Younger people stand a better chance of recovering their <u>sense of smell</u>, Dalton said, though nothing is guaranteed. Recovery may be linked to the passage of time, she said, since the olfactory tissue can regenerate.

Smell retraining therapy is one method people use to try to rehabilitate the sense. Dalton said people who enroll in olfactory training or smell retraining sessions earlier tend to report more thorough recoveries. The treatment doesn't work, however, for people who could never smell.

Creed has used a smell training kit with scents like orange, tea tree oil



and peppermint, though she hasn't had much success. She can remember what each is supposed to smell like but the scents still emerge distorted.

Halstead has made some casual attempts to find the cause of his anosmia. Ultimately, though, he feels he doesn't need treatment. His anosmia isn't as emotionally distressing compared to those who acquired it—he hasn't lost anything.

"To me, it's not life-altering," Halstead said. "It's just a quirk."

The Monell Center has developed a smell test to screen for COVID, which tends to be a better predictor for the virus than taking temperatures or testing for respiratory symptoms. More people are reaching out to be included in research trials, Dalton said.

In the meantime, with no effective treatment in sight, Canton's Pieraccini has found it helpful to ask friends or loved ones to help her fill in the gaps when she's afraid of missing something.

"Having people you can trust—who will be there to help you out and understand and believe you when you say you're having this difficulty—is really important," she said.

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