Lost sense of smell often invisible, untreatable problem

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Mimi Koberlein woke up one morning unable to smell the bacon her husband was frying for breakfast. Confused, she ran to the shower, grabbed her shampoo and inhaled deeply. Nothing. Two years later, Koberlein, 47, still can't smell lemons, freshly cut grass, her three boys or any other fragrances of life. Diagnosed with anosmia, or smell loss, she has tried decongestants, nasal irrigation, oral steroids and acupuncture. But nothing has worked.

Without scented cues to guide her, Koberlein said she now feels anxious about personal hygiene, frequently changing her clothes on hot days. She often forgets to eat, throws away perfectly good food in case it has spoiled and puts up with remarks about how "great" it must be not to have to smell stinky feet or dog poop.

Smell is often considered the most expendable of the five senses, the one people often say they would sacrifice if forced to give one up. But the olfactory system is far from dispensable; it warns about gas leaks or smoke and makes food and drink palatable. Smells communicate information, connect us to the environment and play a vital role in emotions and mood, arousal, memory and quality of life.

There are no evidence-based preventive measures, interventions or treatment options for smell disorders and fewer scientists in taste and smell research than in other fields, according to the National Institutes of Health.

That leaves anosmics - and there are millions of them - on their own as they struggle with a life upended by a disability few understand.

Anosmics report higher levels of depression, anxiety and social isolation. Eating and drinking become difficult; they lose their appetite, have trouble cooking and gain or lose weight. They also frequently describe themselves as "frustrated," "disconnected," "missing out on something" and "lost," according to published studies.

Sufferers seek validation - or at the very least some empathy - but the condition is often trivialized. They sometimes receive disinterested, rude or callous "help" from doctors and are subjected to "smell tests" by disbelieving friends and family or strangers, according to interviews and published surveys.

"I feel a little bit like a freak show," said Koberlein of Redwood City, Calif., who has lost 30 pounds since her sense of smell vanished. "If a person loses any other sense, there are fundraising drives, public education or awareness campaigns - at least some sympathy for the situation. With anosmia, it's just, 'eh, that's weird,' and people move on. For those of us who suffer from it, a big piece of our life experiences are gone."

At least 6.3 million Americans report problems with their sense of smell, a figure that is likely underestimated because many people aren't aware of their problem until it's severe or doctors fail to perform adequate tests, according to the National Institute on Deafness and Other Communication Disorders, or NIDCD.

Standardized olfactory tests have been available since the mid-1980s, but very few physicians use them, making it difficult to track the number of people affected.

The prevalence of smell loss increases dramatically with age, affecting more men than women. Smell disorders also can be caused by a physical blockage, viruses associated with the common cold, head trauma and exposure to toxins.

Evidence of smell and taste disorders in association with other health problems is also increasing, according to the NIDCD. People with early stage Alzheimer's disease, nongenetic forms of Parkinson's and polycystic kidney disease all report a reduced sense of smell. In addition, about 3 percent of those with olfactory disorders were born without the ability to smell.

Even though there have been no breakthroughs in treatments, some smell and taste clinics boast about outright cures or measurable improvements for their patients. But claims of cures are "unfortunate and misleading," said olfactory researcher Richard Doty, director of the University of Pennsylvania's Smell and Taste Center.

"Every hope is false hope," said Andreas Keller, a research associate at The Rockefeller University, who has studied the hidden consequences of olfactory dysfunction. "There's not much we can tell people."

At the Monell Chemical Senses Center in Philadelphia, where scientists conduct basic research on taste and smell, staffers regularly receive desperate emails from people who have lost their sense of smell and want advice on treatment. "All we can say is, 'I'm sorry, there's nothing we can do,' " said Leslie Stein, Monell's director of science communications.

Jack Hickey, 68, who lost his sense of smell four years ago after a viral infection, wasn't satisfied with that answer. Frustrated, he fired off a challenge. "If Monell doesn't lead the way in this area, who will?" Hickey wrote in an email to Monell Director Gary Beauchamp.

Beauchamp, in a thoughtful three-page letter, explained the hurdles - including the absence of public interest and funding to support research in the field - and invited Hickey to meet with him. The result was the seed money for the Monell Anosmia Project, a research and advocacy program, made possible by a six-figure donation from Hickey and his wife.

"There are millions of people who suffer from this, and I think Monell has a chance to do something in the next eight to 10 years," Hickey said.

Though he missed the new baby smell of his first grandchild, "you count your blessings," he said. "But if I could just enjoy chocolate ice cream or one cold beer again, that's what I'm looking for."

The chemical senses of smell and taste, the oldest from an evolutionary perspective, interact with each other to produce flavor sensations. The loss of smell affects flavor, significantly affecting the dining experience. (Those with smell loss, however, still can often detect the five basic tastes - sweet, sour, salty, bitter and savory - along with spicy.)

Odors are created when objects in the environment release molecules. These molecules stimulate specialized sensory cells called olfactory neurons, which are found in a small patch of tissue high inside the nose, between the eyes. Once the neurons detect the molecules - whether from baking bread or rain hitting hot asphalt - they send messages to the brain, which identifies the smell.

Sensory neurons are routinely killed when subjected to everyday toxins. But remarkably, the epithelium in the nose has adult tissue stem cells that can regenerate to replace those sensory neurons, an ability that seems to decrease with age.

About half of people between the ages of 60 and 85 have an impaired

sense of smell, according to Doty's research. Doty points out that a disproportionate number of elderly die in accidental gas poisonings and suggests that smell loss, along with factors related to mobility, may play a role.

Among the elderly, "we think the system burns itself out," said Dr. Robert Kern, chairman of the Department of Otolaryngology and Head and Neck Surgery at Northwestern University's Feinberg School of Medicine. "The olfactory sensory nerves are constantly sampling the environment. It's thought they get injured with viruses, bacteria and pollution, and are replaced more slowly as we age."

In trauma cases, such as a blow to the head, the brain moves around in the skull. The force can shear off the connections between the olfactory neurons in the nose and the olfactory bulb in the brain, said John Ngai, a professor of neuroscience at the University of California, Berkeley. "It's like cutting through a telephone cable," he said. "Once you lose the connection, the patient loses the ability to smell."

But even if the sensory neurons are replaced by new cells, "they usually don't reconnect properly, which results in permanent loss," Ngai said. "Some people have described a partial recovery but if the connections are not made correctly, they can have weird smells."

Those with nasal polyps or chronic sinus disease can potentially regain their sense of smell through surgery or anti-inflammatory steroids. "The problem is those diseases tend to be chronic," said Beverly Cowart, director of Monell's Chemosensory Clinical Research Program. "You treat them, they get better and come back. There's a limit to how frequently you should be taking something like prednisone."

Jennifer Leigh, 40, who lost her sense of smell in her early 20s, underwent two sinus surgeries to help with breathing and hearing

problems caused by sinusitis. Her smell returned for several months after each surgery but then vanished again. On the rare occasion when she gets a whiff of something, she said, the usually unpleasant odor haunts her for a week straight.

"It bums me out if I think about it," said Leigh, of Evanston, Ill. "I haven't smelled what my husband smells like in years, I didn't get the baby smell with my kids and I eat food really spicy to give it a taste." One night she heard someone pounding on her door in the middle of the night. A neighbor in her building had smelled gas and alerted the gas company, which detected it under her door. Leigh didn't realize the burner on the stove hadn't fully clicked off.

"With three senses (smell, taste and hearing) affected, in some ways, I do feel it is similar to a disability," she said. "I've had to adjust to being closed off in some ways."

Some patients with smell disorders perceive the smells to be different from how they remember them, perhaps because olfactory receptor neurons are missing or damaged. Others experience phantom smells or the sensation of an odor that's not there. These smells are typically described as "burned, foul, rotten fecal or chemical smells."

For Koberlein, CT scans and MRIs ruled out brain tumors and polyps; the results showed the pathway to the olfactory tissue and the connection between the olfactory nerve and the brain were normal, said her physician, Dr. Winston Vaughn, director of the California Sinus Centers in the San Francisco Bay Area.

"Exactly what knocked it out, we have no clue," said Vaughn. He suspects her smell loss might have been caused by a short-lived virus, one she didn't know she had.

Koberlein isn't giving up. She still inhales deeply as she kisses her three boys on the top of their heads and tries smelling lotions, cooking and other odorous items. And she hopes to participate in clinical trials to help scientists find treatments.

"It's so frustrating" she said. "Life without stinks, stinks."