A Disorder That's Hard to Swallow

Dysphagia can cripple your quality of life and lead to other (deadly) conditions.

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The condition can be caused by neurological conditions such as Parkinson's disease or stroke, digestive disorders or head injuries.

Ed Steger's last meal was a bowl of soup in Las Vegas. "I remember it all too clearly, as if it were yesterday," he says. But it wasn't yesterday – it was 2006. "Life is very different" now, says Steger, a 63-year-old former program manager in Houston.

Steger was diagnosed with head and neck cancer in 2005. In addition to 36 rounds of radiation and eight regimens of chemotherapy, he underwent six surgeries, including one that replaced a portion of his pharynx and removed parts of his left jawbone, tongue, epiglottis and soft palate.

"The part that makes it odd is that I'm alive after having four recurrences," Steger says. The part that makes it distressing is that he can't eat solid foods.

"There are many case studies I've seen where patients have said [their] swallowing disorder is the worst part of their disease – and I believe this to be true," says Steger, who's president of the National Foundation of Swallowing Disorders. His daily diet consists of four 8-ounce cans of the nutritional drink Boost Plus, along with two to four bottled Starbucks Frappuccinos, which he buys at his local supermarket. "It's a very boring diet that allows me to maintain my weight," says Steger, who's 5 feet 10 inches tall and 155 pounds.

It's unknown how many people have dysphagia, or difficulty swallowing, but the condition can be caused by any one of 30 diverse health events, Steger says. While his dysphagia is a result of surgery, other people have difficulty swallowing due to neurological conditions such as Parkinson's disease or stroke, digestive disorders including acid reflux or head injuries. Children with developmental disabilities like autism also often have dysphagia.

“[Dysphagia] isn’t a disease, it’s a sign or an outcome of a disease,” says James Coyle, an associate professor in the University of Pittsburgh’s School of Health and Rehabilitation Sciences who specializes in treating adults with swallowing disorders.

Difficulty swallowing can also be a part of normal aging, suggests research led by Teresa Lever, an assistant professor of otolaryngology at the University of Missouri School of Medicine. But that doesn’t mean it’s without consequence. For example, people with dysphagia are at risk for choking, dehydration, malnutrition and pneumonia, which can be triggered when food or drink enter the lungs.

“If you can’t walk, you don’t die. If your skin looks horrible, you don’t die. But if you can’t eat and drink, you die,” Lever says. “[Swallowing] is a vital biological function that is a hugely overlooked contribution to morbidity and mortality.”

Aiming to Eat and Drink Again

How clinicians treat dysphagia depends on its cause. If, for example, the condition is brought on by a stroke that paralyzes one side of the throat, a swallowing specialist like a speech-language pathologist first might use an imaging test to identify what exactly is going wrong, and then coach the patient on ways to tilt his or her head while eating in order to better prevent food from getting into the airway. Such “compensatory strategies,” Coyle says, are “more or less exploiting either gravity or using the change in position to redirect the swallowed material more efficiently and with better airway protection.”

Steger, for one, was trained to swallow by holding his breath, reclining and “letting the liquid flow” down the back of his esophagus and avoiding the airway. “When I swallow, I need to concentrate very hard,” he says.

Mouth and throat exercises can also help patients boost their swallowing abilities. One mouthpiece-like device called SwallowSTRONG, for instance, senses how hard the patient pushes the tongue against the roof of the mouth and progressively guides him or her in resistance exercises. “It’s like weightlifting,” Coyle says. “You start off doing low levels of exercise, and we increase the targets every two weeks until the tongue is stronger.”

Other exercises use a similar technique but to improve respiratory function rather than tongue strength. When patients blow against progressively increasing resistance, for example, they’ll develop a better cough reflex. That, in turn, will make it more likely that any food particles or liquids inhaled into the airways will be expelled and not enter the lungs to cause harm, Coyle says. “Dysphagia doesn’t always go away,” he says. “Sometimes we have to teach the person

to swallow differently, sometimes we have to beef up other parts of the body to compensate for the fact that the swallowing isn't going to get better."

If dysphagia is caused by dementia or another condition that compromises someone's ability to learn, clinicians must defer to environmental or dietary modifications like prescribing a diet of thickened liquids. The route is a last resort, Coyle says, since "gobs of studies" show that people don't like thickened liquids, don't drink them and therefore, are at risk for dehydration.

"All of our cases aren't successful," he says, "but when we do have a successful case, it's so rewarding – the ability to restore a person's ability to eat and drink."

Food is Secondary

If Steger woke up tomorrow without dysphagia, he'd eat a T-bone steak grilled with Lawry's spice, a baked potato with all the fixings and crème brulee for dessert. But what he'd look forward to most is going to a restaurant with friends, ordering anything he wants and keeping pace with his companions. "The food is secondary at this point," he says.

Living with dysphagia isn't just a medical risk, but can also hamper one's quality of life and mental health. People with the condition can feel isolated not only because they avoid social eating situations, but also because many of them have medical conditions that affect their voices and compromise their communication. In the support groups for people with Parkinson's that Steger sometimes attends, the participants, many of whom have dysphagia, "are embarrassed to go out, they're ashamed, it's sad," he says.

One of his goals is to boost funding for dysphagia research, which is slow-going since major funding organizations like the National Institutes of Health are more focused on the diseases that underlie the condition, Steger says. "[Swallowing] is never top of mind when you have head and neck cancer or Parkinson's until it happens to you," he says .But a focus on swallowing itself is not trivial since, for example, hospital patients with dysphagia stay in the hospital 40 percent longer than patients without it, Coyle says. "It's very important to identify early."

It's also important to dedicate resources to the disorder since it will affect more and more people as the population ages, Lever says. She's now working to identify traits that protect mice – and hopefully, people – from developing dysphagia as they grow old. "Now that we can diagnose dysphagia, we can identify which mouse models have it, and then we can use those mouse models to try to understand what is going wrong to cause dysphagia," she says. That, in turn, "can then give [us] some targets for treatment."