

Dysphagia—like being waterboarded 24 hours a day

March 15 2016, by Bryn Nelson

Toast is an unlikely agent of death. But there you are in your kitchen on a Saturday morning, inexplicably choking on a mouthful, trying not to panic.

The day begins like any other for Samantha Anderson, a goldsmith and mother of three from Brisbane, Australia. She has made her usual breakfast of tea and toast with peanut butter and lets her mind wander as she takes her first bite.

And then, nothing. Wait, why didn't I swallow?

She tries again, pressing her lips together and pushing the food back further in her mouth where her throat can take over. But it doesn't, and now she's choking.

Don't panic, she tells herself. She manages to slowly suck a bit of air past the blockage until she can muster up a forceful cough. And again. And again, finally dislodging the toast on the third try.

She is temporarily jolted by the episode, her heart racing. That was odd, she thinks, though it doesn't stop her from having another bite. She has absolute faith that it won't happen again. But it does, over and over.

Seemingly overnight, at the age of 39, Anderson has lost her ability to swallow.

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People who struggle to swallow can easily choke. They can breathe food or water into their lungs and develop aspiration pneumonia, or get so little food to go down the right way that they become dehydrated and malnourished. Their teeth may start to rot as the mouth's natural flushing system falters, while their emotional and psychological health begins to decay as they withdraw from public life.

If it gets bad enough, they may have to switch to a fully liquid diet. And in severe cases, they may have to survive via a feeding tube inserted through their abdominal wall and into their stomach, as Anderson eventually did for 18 months.

Peter Belafsky, director of the University of California at Davis Voice and Swallowing Center and an adviser on Anderson's case, says the hardest-hit patients can choke on up to 1.5 litres of spit every day – the upper limit pumped out by our salivary glands. "It's like being constantly waterboarded," says Belafsky, because of the sensation of drowning that it produces. "That's the best way I had a patient describe it to me: 24 hours a day being waterboarded."

Swallowing is one of the body's most complex actions, which means plenty can go wrong. It's so complicated, in fact, that experts don't yet agree on all of the essential components, though some estimate that 22 muscle pairs and 7 of the 12 cranial nerves (which emerge from the brain) take part. Firm statistics on the prevalence of swallowing disorders are also sparse, but a recent survey in the Netherlands estimated that they affect as many as 1 in 8 adults.

Some of the problems derive from oesophageal conditions such as acid reflux disease. Others are a consequence of an infection, muscle dysfunction, stroke or advancing age. Hospital neonatal units also

routinely see infants struggling to suckle due to prematurity, disease, developmental delay or other disorder. Some people lose their ability to swallow permanently due to amyotrophic lateral sclerosis, Parkinson's, Alzheimer's or other neurologic conditions, or from traumatic injury or nerve-damaging radiation therapy for head and neck cancer.

Dysphagia is like being constantly waterboarded

And yet, support groups are rare and the relatively small research community has only recently begun to make significant headway in improving the lot of a largely fragmented and voiceless population. For Anderson, who didn't fall into an obvious high-risk group, the problem was even more basic: her doctors initially told her that what she was experiencing was all in her head. One gave her Valium for what he assumed was stress. At her hospital bedside, she says, another concluded: "Sweetheart, I think you've just forgotten how to swallow." To get her confidence back, the doctor suggested that she get dressed up and go out with her husband to a nice restaurant.

Six months after choking on the toast, after losing more than 30 pounds, becoming virtually housebound and feeling like she was "staring death in the face", after being sent to the hospital with dehydration but receiving few answers from a parade of doctors, Anderson finally heard the term that described what had happened to her. Dysphagia. "I was bowled over actually knowing there was a word for it," she recalls.

This is the harsh reality of [dysphagia](#): it's a major symptom of multiple diseases, disorders and injuries, it can strike both young and old, and yet its repercussions often flummox doctors and play out far from public view. Advocates call dysphagia an invisible disorder and a silent epidemic. The cruelty is compounded by how it distorts eating, which is not only a physical necessity but also a way for our highly social species to bond, relax and savour favourite foods.

A growing awareness of dysphagia's complexity and crippling toll on quality of life has spurred fresh debates about the benefits and limitations of existing therapies. These include exercise, electrical stimulation, and an all-liquid diet or feeding tube in more serious cases.

Researchers are studying an assortment of animals to piece together the signs of a bad swallow. And innovations based on dissolving taste strips, 3D printers and body piercing are providing additional glimpses of a more hopeful future. Some of the efforts are aimed at aiding or bypassing steps in the swallowing process, while others are reimagining what to put in someone's mouth. Ultimately, a range of advances may be needed to support people for whom eating has mutated from a pleasurable experience to a solitary effort; one that's devoid of joy, but full of danger.

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Put your index finger on the tip of your chin, and slide it down the midline of your neck until you reach the first protruding landmark. That's your Adam's apple, a lumpy piece of cartilage that wraps around your larynx, or voice box, and is considerably more pronounced in men than in women. Now swallow, and feel how your Adam's apple bobs up and slightly forward before returning to its original position.

Here's what's happening on the inside: when you swallow something, your tongue pushes up and back against the roof of your mouth to send the packet of food or liquid into your throat. Your soft palate and uvula (dangling down from the top) close off the upper airway from your nose to your mouth.

Then in quick succession, your larynx slides up and forward as a separate flap of cartilage called the epiglottis swings down like the lid of a dustbin to close off the larynx's entryway. The mechanism is a necessary

remedy for a physiological quirk in mammals: the air and food intake systems cross paths in the throat. "This is a fundamental design flaw, and it's part of our evolutionary history," says Rebecca German, an anatomist and neurobiologist at Northeast Ohio Medical University in Rootstown. Every time you swallow, she says, you momentarily stop breathing until your throat is clear.

As your windpipe closes off, your throat expands to receive the delivery from your mouth. A valve at the base of the throat, the upper oesophageal sphincter, initially relaxes to allow the tea or wad of bread into the oesophagus before contracting again to prevent any backflow. A coordinated wave of muscle contractions then pushes everything along until it reaches the lower oesophageal sphincter. This valve similarly relaxes to empty the contents into the stomach, and then constricts to seal the portal.

This is a fundamental design flaw

Voluntary swallowing is what you use to eat and drink, while spontaneous swallowing, a more reflexive action that occurs round the clock, disposes of mucus and saliva. Although triggered by different signals from the brain, both actions follow the same general sequence of events, and both can suffer from malfunctions in timing, coordination or strength.

Human saliva is mostly water, with small amounts of mucus, electrolytes, digestive enzymes and sloughed-off skin cells mixed in. Depending on how clean your mouth is, a millilitre of saliva can contain 1 million to 100 million bacterial cells. The microbes are meddlesome when they cause bad breath but can be deadly if they're breathed into the lungs, or aspirated.

To keep the airway clear, young adults spontaneously swallow about

once every minute. This rate slows during sleep and with advancing age or disease. A complete failure of the reflex, however, can cause chronic choking. And when someone weak and bedridden has lost their ability to spontaneously swallow and even the strength to cough up aspirated mucus or spit, a build-up in the airway can produce the 'death rattle' sounds we associate with the dying.

Therein lies another major problem in acknowledging the havoc wreaked by dysphagia. We associate the breakdown of such a seemingly basic process with the end of life. It happens in hospitals, sure, and in hospices and beds that will soon be empty. It's much harder to understand how things can go so badly wrong for a apparently healthy 39-year-old who runs her own business, or a military veteran in his 20s, or a toddler who has barely graduated from his crib.

Anderson recalls some of her darkest times, when she would wake herself up in the middle of the night by choking on her own saliva. Her children would come into her bedroom and tell her they couldn't sleep because they were so scared she would die. "I would say, 'Look, it's all right'," she says. "But I actually felt the same way."

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A good way to make someone self-conscious about eating a blueberry muffin is to arrange a breakfast buffet – with muffins, say, and hard-boiled eggs and cantaloupe and coffee – in a hotel foyer surrounded by ten large video monitors on continuous loop depicting good and bad swallows in all their magnified, high-resolution glory. Gulp. Gulp. Gulp.

On the second floor of the Westin Michigan Avenue hotel in Chicago, attendees at the annual Dysphagia Research Society conference are picking over the remnants of a breakfast buffet while vendors showcase their competing imaging systems. Some show video from endoscopes

that have been threaded through a patient's nose and down the back of the throat until the camera at the end of the flexible tube is hovering just above the larynx. Others depict a barium swallow, an X-ray-based method in which patients drink a chalky, milkshake-like drink that coats the surfaces of the mouth and throat and can highlight places where the sequence of events is going awry.

For Anderson, one of the first clear signs of a process gone haywire came from a barium swallow that suggested she was swallowing long after she should have been, and that the liquid was meanwhile spilling over the back of her mouth and into her throat. Other tests revealed that she had lost all sensation in the back two-thirds of her tongue. Even when she did swallow, her reflex was as weak as a 90-year-old's and her epiglottis didn't always neatly seal off her windpipe.

Here's a very rough simulation of what people like Anderson face every day. Stick your tongue out between your front teeth and gently bite down on it near the tip. Now hold this position while swallowing hard in quick succession.

Without the tongue's assistance, swallowing is suddenly much more difficult. To help compensate, speech-language pathologists and other dysphagia experts have developed a repertoire of a dozen or so [swallowing exercises](#) to build up strength in the tongue and throat muscles. The tongue-bite swallow, called the Masako Manoeuvre, is one of Peter Belafsky's favourites.

Studies suggest that the manoeuvre strengthens the base of the tongue and forces some muscles in the back of the throat to constrict harder to aid the swallow. Michael Crary and Giselle Carnaby, co-directors of the Swallowing Research Laboratory at the University of Central Florida in Orlando, have developed their own battery of four exercises – a "pharyngocise" routine, as they've dubbed it – that has shown early

promise in preventing or minimising dysphagia among people having radiation therapy for head and neck cancer.

Other exercise trials have proliferated but, so far, have yielded conflicting evidence. Ditto for electrical stimulation to coax the throat muscles to contract, and researchers such as Rebecca German maintain that we still have much to learn about correcting or minimising the faulty mechanics of a bad swallow.

Some of that knowledge may emerge from careful observations of animals with similar difficulties. An abnormal licking motion in dysphagia-susceptible mice fed chocolate syrup, for example, may provide an early sign of swallowing difficulties; researchers hope the data may benefit people with degenerative conditions. Another approach is to film the swallowing mechanics of dogs diagnosed with a variety of dysphagia-inducing disorders. As the dogs eat food of varying consistency in glass-walled kennels, a frame-by-frame video analysis may point out consistent signs of trouble that could help them as well as their human counterparts.

German is using suckling pigs, for example, as stand-ins for swallow-challenged newborns to better understand "silent aspiration", in which the body makes little or no attempt to eject food or water breathed into the lungs. Researchers are even training rats to do tongue exercises in the hope that the increased strength will improve their swallowing ability.

Outside of the clinic or lab, however, conveying the seriousness of dysphagia can be surprisingly challenging. During an afternoon break in the Chicago conference, German gestures to the street beyond the hotel's lobby. Outside, college basketball fans in town for the Big Ten Conference tournament are mingling with tourists wearing "Kiss me I'm Irish" T-shirts and leprechaun hats in anticipation of Chicago's famous St Patrick's Day parade.

"If someone has Parkinson's and they're walking down the street, you can see the characteristic traits," German says. Not so for dysphagia, which she refers to as a "doubly hidden" disorder. Doctors often can't tell from a cursory inspection, and many patients underestimate or lack the wherewithal to understand how often food is going down the wrong way. But silent aspiration causes a dramatic rise in pneumonia risk.

How then, can the public hope to grasp the magnitude of the problem? As German puts it: "No one has telethons for kids with dysphagia."

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Ed Steger would love a slice of New York-style pizza ("nice and greasy with a lot of pepperoni on it") or a good T-bone steak. Although he may never again get that chance, the 63-year-old Texan is quietly determined to help younger people with dysphagia, such as Anderson, avoid a similar fate.

After being diagnosed with a type of head and neck cancer in 2005, he endured 36 rounds of radiation, eight rounds of chemotherapy and six surgeries. His cancer has recurred four times and twice, doctors gave him only months to live. In the most extensive operation, surgeons at the University of Texas MD Anderson Cancer Center in Houston removed his cancer-riddled lower left jaw and four teeth and replaced the bone with an eight-inch length of titanium and a portion of his right shinbone. They removed a chunk of his cancer-infected throat and replaced it with muscle and tissue from his right calf. They cut away part of his tongue and punched a quarter-sized hole in his soft upper palate to remove other tumours. "Most people would say, 'You look pretty normal, you look very healthy'," he says. "But I'm very busted inside."

Steger now wears a prosthetic device called an obturator, which resembles a retainer attached to a pink plug that allows him to talk

without most of the sound whistling away through the hole. He relied on feeding and breathing tubes for about four months after the surgery, and hasn't had a bite of solid food since then. He has had "no evidence of disease" since the end of 2007, and in 2015 he saw his daughter graduate from Carnegie Mellon University in Pittsburgh.

Life has changed dramatically, however. With so many nerves damaged or removed, he has virtually no control over his swallowing and depends on gravity to guide liquid food safely past his airway and down his reconstructed throat. For the better part of a decade, he has eaten standing up, in isolation.

"My wife and I went from having what I consider a very good, rich life – where eating out six times a month was not unusual, travelling around the world was not unusual – to a much more limited life," he says. "It's really pulled the social fabric out from under us." Now, he might join people at a restaurant three or four times a year. He still orders food on occasion; it makes others at the table feel more comfortable. But it's hard for him to talk loudly and he doesn't touch what he orders.

Trips are especially tricky. For a rare week-long vacation in 2015, to the Virgin Islands, Steger filled a suitcase with 40 pounds of carefully wrapped essentials:

- 5 six-packs of Very Vanilla-flavoured Boost Plus, in 8-ounce bottles
- 1 empty 20-ounce PowerAde bottle (to mix each Boost drink with low-fat milk or prune juice to the correct consistency)
- 3 four-packs of coffee-flavoured Starbucks Frappuccino
- 3 four-packs of vanilla-flavoured Starbucks Frappuccino
- 2 tubes of Biotene Oral Balance dry mouth moisturising gel
- 1 16-ounce bottle of Biotene dry mouth oral rinse
- 1 squeezable water bottle with attached straw for the oral rinse

(with the hole in his soft palate, Steger must look down while sucking up the mouthwash to avoid sending it into his nasal cavity; gargling would be especially problematic)

- 1 Roscoe portable suction machine to clean his mouth after every meal
- 1 tube of Biotene toothpaste and a battery-powered toothbrush
- 1 tongue scraper (with a dry mouth, Steger's tongue readily absorbs the Boost mixture, which complicates the task of keeping his tongue and mouth clean)

He made similar calculations for his three-day trip to the Dysphagia Research Society conference, where he has become a regular since taking over as president of the National Foundation of Swallowing Disorders in 2012.

Steger has sought to transform the foundation into an increasingly visible and growing community of patients and caregivers. "It allows me to really have a purpose in life," he says. His booth at the Chicago conference features a range of informational pamphlets and T-shirts that exclaim, "Swallow hard!" or depict the outline of a swallow (the bird). In exchange for a donation, attendees can also mix their evening glass of wine with a colourless xanthan gum thickener to get a taste of what a modified diet might be like. (Thin liquids, such as water and wine, tend to flow quickly and splash around, meaning that they can easily lead to trouble if the timing of a swallow is even slightly off. Thicker liquids can slow down the process and keep everything moving together.)

Although in-person dysphagia support groups are still relatively rare and usually linked to nearby speech-language pathology practices, the foundation is working to build a wider network throughout the US. Patients from around the world have likewise sought out the foundation for crucial advice, support and commiseration.

On its website, Anderson and others have shared similar stories of spending hours trying to consume enough calories and remain hydrated, of eating alone to avoid embarrassment or concentrate on swallowing without choking, of becoming isolated even from family members. For many, the sense of loss can be nearly overwhelming, and the aroma of a once-favourite meal can reduce them to tears.

The cumulative stress of dysphagia, as researchers are finding, can profoundly degrade the quality of life for both patients and their loved ones. In an ongoing study, Giselle Carnaby's lab is finding that people receiving radiation treatment for head and [neck cancer](#) (most of whom develop swallowing difficulties) and their caregivers experience similar psychological and social difficulties. "Unfortunately, the issues of the caregivers often go unrecognised as healthcare is focused upon the patient alone," she says. Based on a pilot study and a follow-up awaiting publication, however, her lab's results suggest that both groups need support during and after the treatment.

Anderson avoided eating in the same room as her kids to keep them from worrying, but made sure she was always within striking distance of someone who could help in case of a choking emergency. Eventually, her husband became her spotter for every meal, while friends awkwardly joked that they wanted to be on her diet. Embarrassed, frightened and famished, she could no longer stand to be around others during mealtimes and even stopped working in her own jewellery gallery. When doctors finally put her on a feeding tube to halt her spiralling weight loss, she felt full for the first time in months.

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Angela Dietsch is well acquainted with the strong desire – the desperation, even – that otherwise healthy people with dysphagia have to taste pizza, a doughnut or another reminder of a once-normal life.

Dietsch, an assistant professor of special education and communication disorders at the University of Nebraska in Lincoln, has worked often with "wounded warriors", military veterans who return home with trauma-related dysphagia. There's a reason this happens, she says: military flak jackets often reach only up to the base of the neck, while helmets and visors extend down to the nose and mouth. That leaves the jaw, chin and neck dangerously exposed to battle injuries.

For many of these young men and women, the idea that they can never again eat a solid meal with their families is unfathomable. "I can't tell you the number who say, 'I just want to taste it and then I'll spit it back out'," Dietsch says.

She stumbled upon one of the more intriguing possibilities for improving their lives while studying xerostomia, or chronic dry mouth. Xerostomia is caused by decreased saliva flow and can make dysphagia worse. In an experiment exploring whether different tastes might increase saliva flow, Dietsch repurposed taste strips that mimic real foods but dissolve safely on the tongue.

Reminiscent of Willy Wonka's lickable wallpaper, some are sold as breath fresheners while others have appeared in supermarkets or magazine adverts to introduce consumers to grape juice, Cabernet Sauvignon – even a non-alcoholic lime mojito.

For her experiment with the veterans, Dietsch tried strips with glazed doughnut, buttered popcorn, lemon-lime and icy mint flavours. She put gauze pads beneath each participant's tongue to absorb the saliva, told them not to swallow, and then applied one of the strips.

The glazed doughnut strip – the biggest crowd-pleaser – yielded the most saliva production. One veteran exclaimed, "That was better than a real doughnut!" The buttered popcorn strip, on the other hand, proved rather

less successful: "That tasted like the bottom of a shoe," another said.

The veterans began requesting – and fighting over – the strips, including ones flavoured like margarita and honey-bourbon. Some even used them during family dinners. "They would literally sit at the table with their family and open four to five of these taste strips," Dietsch recalls.

Amazed, she realised that the strips could provide a low-risk strategy for stimulating taste and aiding dysphagia therapy. "People are more likely to be compliant in a therapy if they're enjoying it," she says. The strips also might provide a big psychological lift during communal meals such as Thanksgiving or Christmas. What if one strip was turkey-flavoured, another reminiscent of relish, and a third like apple pie? It might sound ridiculous, Dietsch says. "But for somebody who has been excluded from those events for the last five years because they can't eat safely, it could be life-changing," she says. "I can't think of a patient who wouldn't be really excited about trying this."

There's just one catch: the biggest company producing the tasting strips has since gone under, forcing Dietsch and colleagues to try developing some on their own. One of the only commercially available options, apart from breath fresheners, is a line of chocolate, watermelon, strawberry and mango tasting strips sold as adult novelties to aid oral sex.

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Steve McCloskey, a community college professor from Seattle, admits that he's a risk taker. The gung-ho 57-year-old, a father of a preschooler and two grown children, remains an avid bicyclist despite a series of accidents that left him with five broken ribs, a titanium plate in his neck, and a surgically repaired right hand. He's also had cancer twice in recent years: metastatic tonsil cancer in 2005 and prostate cancer in 2012.

The radiation therapy that beat back his tonsil cancer also undermined both his swallowing and speaking abilities, once leading a hotel clerk to assume that he was deaf. Others have accused him of being drunk. Undaunted, he still teaches classes on business and law and hopes to ride across Honduras in 2017 to raise money for charity.

As McCloskey concedes during a dysphagia support group meeting at the University of Washington in Seattle, he's also not one to always play by the rules. He knows he should be eating more purées and fewer solids that can cause problems on the way down. But he doesn't. Instead, he plays Russian roulette with one of his favourite foods: his wife's lefse, a Norwegian flatbread made from potatoes and flour.

The dilemma faced by McCloskey and others has posed a major controversy for the field. Researchers such as Laurie Slovarp, a voice and swallowing specialist at the University of Montana in Missoula, are questioning whether an overemphasis on reducing aspiration risk to prevent pneumonia might also be needlessly diminishing some patients' quality of life.

Modifying the diets of those with dysphagia seems understandable when you consider that bacterial pneumonia is one of the most common killers of older adults (some researchers blame aspiration pneumonia for a significant fraction of that toll). People with dysphagia not only breathe in more food and liquid but also tend to have worse oral hygiene, raising the risk that anything reaching their lungs will contain a dangerous glut of bacteria.

Scientists haven't yet established a safe threshold for aspiration. Slovarp, however, maintains that many people with dysphagia who are otherwise healthy and active are at low risk for pneumonia even if they do aspirate relatively small amounts of food. Frequent oral care can also reduce the threat. Dramatically restructuring their diet, however, could do more

harm than good, Slovarp says.

Patients taking thickened liquids aren't necessarily protected from pneumonia; studies suggest that they do tend to drink less, however, raising the risk of dehydration, urinary tract infections and confusion in older patients. "It kind of becomes this decision on the lesser of two evils," she says. Slovarp, Michael Crary and others believe that speech-language pathologists could do a better job of gauging the real risk – pneumonia – and balancing their patients' physiological and psychological health.

As a small concession, McCloskey tears the lefse into little pieces before eating it. A feeding tube, he says, would be a sign of defeat. Maybe that's denial, but he's not ready for it yet. That defiance may have come at a cost. He's had pneumonia three times within the last year, including one bout that rapidly led to sepsis, a potentially fatal complication marked by an overblown immune response.

He can no longer tolerate spicy food because it burns his throat, perhaps due to tissue damage from the radiation treatments. The same is often true for red wine, beer and liquor, but he still has them on occasion, including a hot toddy some nights. "I'm still going to enjoy life," he says.

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Whether it takes the form of lefse or pizza or toast, bread is loved around the world. It is also the arch-enemy of those with dysphagia, as one of the hardest of all foods to swallow. Tests have found that as a person chews bread, it tends to readily absorb saliva that would otherwise lubricate the throat. It also forms into hard, sticky balls that can prevent a smooth journey on to the oesophagus. Unadulterated white bread purée, although easier to swallow, looks a bit like cereal left overnight in a bowl of milk and tends to be at the low end of what

researchers call the "meal appeal" spectrum.

In October 2015, Japan's EN Otsuka Pharmaceutical Co. Ltd began selling an engineered substitute called iEat Bread, which has been treated with enzymes to alter its physical properties. The reformulated bread is being marketed directly to consumers with chewing or swallowing impairments and to medical institutions and nursing care homes. At the dysphagia conference in Chicago, Shingo Umene and Masahiro Hayashi explained how they and colleagues in the company's Tokyo lab had put iEat Bread through its paces. Although it looks, feels and tastes like the real thing, their experiments suggested that it absorbs virtually no saliva, is easily mashed up by the tongue, and is roughly only one-fifteenth as sticky as normal bread.

Other researchers are experimenting with moulds that shape purées into more natural-looking dishes such as sliced roast in Burgundy sauce with asparagus or currywurst with tomato mousse. Efforts like the European Union-funded PERFORMANCE consortium have taken the concept one step further by using 3D printing to design nutritious and appealing foods with a gel-like consistency. Led by the German company Biozoon, the consortium unveiled 3D-printed peas and pasta in 2014. The group followed up with the first fully 3D-printed meal, roast pork with gnocchi, in October 2015. Similar meals may be commercially available within three to five years, according to the company.

Better-looking food may help ensure that people with dysphagia eat enough to remain nourished and hydrated – especially those who have lost their sense of smell or taste, or all enjoyment from eating. There's another twist: Michael Crary and Giselle Carnaby recently discovered that in the week after a stroke, people who were put on a modified diet of thick liquids or puréed foods were more likely to become dehydrated than those who remained on a regular diet. Crary says the provocative finding raises the question of whether the dehydration resulted from

people eating less of the modified food because they found it unappealing or from some other biological response to the food itself. If it's the former, the research could add new weight to the importance of palatability.

For people who lack the strength in their throat muscles to swallow anything at all, one of the most eagerly anticipated advances closely resembles the kind of stud earring that daring youngsters might use to pierce their necks. Every time a user of Belafsky's Swallow Expansion Device pulls this titanium rod, a connected plate embedded in the throat mechanically moves the larynx forward and opens the upper oesophageal sphincter to allow food or liquid to move into the oesophagus. When the user lets go of the piercing, the valve snaps shut. After first implanting the device in a Uruguayan doctor in 2010, Belafsky has launched a phase I clinical trial.

Belafsky and colleagues are also experimenting with nerve-aiding medications such as the Alzheimer's drug donepezil, and are running a clinical trial to determine whether muscle stem cells could help strengthen damaged tongue muscles. (Steger's foundation raised \$40,000 in 2013 to support the latter effort.) Other groups are working to limit the collateral damage wrought by [radiation therapy](#), or trying to develop new ways of dilating the oesophagus to help food move through an abnormally constricted space.

No single approach is likely to help everyone, except for one: a basic awareness of how swallowing disorders can afflict young and old, active and moribund. For Anderson, after months of misery, an alert specialist finally linked her seemingly sudden dysphagia to a severe case of shingles that had damaged four of her cranial nerves – a viral infection that she initially thought was little more than painful cold sores in her left ear. With the mystery solved, she turned to Steger's foundation for help in how to address her condition and was referred to Belafsky for

critical medical advice.

During a phone consultation that Anderson describes as "the turning point in my life", Belafsky recommended a high dose of donepezil to improve the function of her damaged nerves. With the drug and the safety cushion of her feeding tube, Anderson embarked on a regimen of strengthening exercises, like the tongue-biting Masako Manoeuvre, and training to practise her new swallowing technique, the manual tongue-push method commonly used to swallow pills.

A few months after weaning herself from her [feeding tube](#), Anderson is slowly regaining her strength. Bad choking episodes happen only once a week instead of nearly every day. She can eat solid foods as long as each bite dissolves in a follow-up sip of water, she keeps her chin tucked while chewing, and she holds her breath while swallowing to protect her airway (always after an 'in' breath in case she needs to cough). Her sense of taste is improving as she regains sensation in the back of her tongue and throat, but she must still keep track of each bite. Her husband still eats every meal with her as a precaution.

The joy is returning, and she and her husband have dared to consider a work-related relocation to Connecticut. "It's my life and I'm desperately trying to get it back," she says. Her case has also created a ripple effect in Australia. Some of the doctors who initially doubted her condition have since told her they've seen other patients with similar symptoms – even another case of shingles-induced dysphagia – and now have a better sense of what to do.

On a Thursday three-and-a-half years after her swallow disappeared, Anderson is starting her day with a breakfast of oatmeal, strawberries, blueberries and milk, washed down with two-and-a-half glasses of water. She's one of the lucky ones, perhaps: her diagnosis, therapy and determination are helping re-establish a measured, more normal morning

routine. But her breakfast is more than just sustenance. It's another step in regaining what she never imagined she could lose – and a simple pleasure that she savours all the more.

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