



Adult Dysphagia Voice of the Patient Report

The Externally-Led Patient-Focused Drug Development Meeting on Adult Dysphagia was held on June 10, 2025, co-hosted by the National Foundation of Swallowing Disorders (NFOSD) and the THANC (Thyroid, Head and Neck Cancer) Foundation

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Voice of the Patient Report on Adult Dysphagia

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Executive Summary: Key Dysphagia Insights

Several important key insights that emerged from the Externally-Led Patient Focused Drug Development (EL-PFDD) Meeting on Adult Dysphagia, held virtually on June 10, 2025:

1. **Dysphagia is a swallowing disorder that can affect people very differently.** The causes vary and can be complex.
2. **Dysphagia can exhibit degenerative or progressive characteristics, especially in individuals with a history of radiation therapy.**
3. **Most individuals living with dysphagia experience multiple symptoms, which can range in severity and vary greatly from person to person.** For those diagnosed with dysphagia, difficulty swallowing is the most frequent and troublesome health concern, followed by choking, gagging and frequent coughing, anxiety, depression and social isolation. Secondary symptoms include aspiration pneumonia, speech/voice impairment, malnutrition, dehydration, and dry mouth.
4. **Dysphagia causes significant declines in quality of life by disrupting fundamental activities of daily living.** Enjoying meals and eating by mouth, socializing, and going to restaurants are especially difficult. Participating in recreational activities, events, travel, vacations, sleeping, intimacy, dating and maintaining relationships, attending school and having a job are all affected.
5. **Individuals living with dysphagia, as well as their caregivers, experience persistent concerns related to aspiration pneumonia, uncertainty of disease progression, and the risk of premature mortality.** Additional worries include declining nutritional status and the possible need for enteral feeding, loss of independence, and an increased caregiver burden. The unanticipated magnitude of caregiver burden associated with dysphagia emerged as a prominent theme during the meeting. Other areas of concern include social isolation, deteriorating communication abilities, and financial insecurity.
6. **Dysphagia is a complex condition with no singular treatment, arising from a variety of underlying causes.** Treatment often focuses on compensatory strategies rather than addressing or resolving the underlying cause.
7. **Dysphagia treatments vary broadly based on the cause of the disorder, with a modified diet as the top symptom management approach.** Other approaches include but are not limited to adaptive equipment, medical devices, medications, surgery and other medical procedures, supplements to improve GI health. These approaches may address symptoms, reduce the risk of aspiration or improve nutritional intake, but are not curative and must be maintained for a lifetime.
8. **Respondents reported that effective management of dysphagia symptoms often requires multiple non-medical approaches, with modifications to eating and drinking habits, swallowing and speech therapy, and feeding tubes identified as the most commonly used interventions.** In addition, community members emphasized the importance of strong social support as an essential component in coping with the daily challenges of living with dysphagia.
9. **There is a critical need for new therapies to address dysphagia.**
10. **The dysphagia community needs more research and clinical trials to address all aspects of dysphagia.**



Introduction

Clinical summary of adult dysphagia

Dysphagia is defined as the difficulty or discomfort with swallowing. Dysphagia can be caused by a pathology or impairment at any level in the upper gastrointestinal tract, from the mouth through the esophagus.

Dysphagia is not a disease itself, but a symptom of an underlying disease or condition. The causes can include neurologic, structural, iatrogenic, and functional impairments. Dysphagia manifestations vary greatly.

Dysphagia is a common, but often invisible disorder. An estimated one in 17 Americans are affected by dysphagia, with higher rates in the elderly, the hospitalized and in cancer patients.¹ In the United States alone, an estimated 15.1 million adults are living with dysphagia.¹

No universal medical therapies exist to address or resolve the underlying causes of dysphagia. Because the causes and manifestations of dysphagia vary widely, individualized rehabilitation and compensatory strategies are used to manage symptoms.

The ultimate goal of dysphagia treatment is to improve the health and quality of life of those living with the disorder. This includes preventing premature death by ensuring that patients consume adequate nutrition and hydration in a safe and efficient manner. Dysphagia treatment is a multi-disciplinary effort and includes speech language pathologists (SLP) specializing in the treatment of dysphagia, otolaryngologists, gastroenterologists, general and foregut surgeons, radiologists, dietitians and physical medicine and rehabilitation practitioners.

EL-PFDD meeting summary

The Externally-Led Patient-Focused Drug Development (EL-PFDD) meeting on Adult Dysphagia was held virtually on June 10, 2025. Patient-focused drug development (PFDD) is a systematic approach to help ensure that patients' experience, perspectives, needs and priorities are captured and meaningfully incorporated into drug development and evaluation. This meeting was an important opportunity for the entire dysphagia community to share patient and caregiver perspectives regarding the symptoms and daily impact of dysphagia, and to discuss current and future approaches to therapies.

The meeting was focused on two key topics: *Dysphagia Symptoms and Daily Impacts* and *Current and Future Approaches to Dysphagia Treatment*. The meeting featured recorded presentations, moderated discussion between individuals on live Zoom panels and those who dialed in by phone. Individuals living with dysphagia contributed through online polling, calling in by phone, and by submitting comments through the online portal. The [meeting video recording](#), [meeting agenda](#), [meeting discussion questions](#), [meeting attendee demographics](#), [online polling results](#), as well as [additional written comments](#) submitted through the online portal are available

¹Hong I, Bae S, Lee HK, et al: Prevalence of Dysphonia and Dysphagia Among Adults in the United States in 2012 and 2022. Am J Speech Lang Pathol 33:1868-1879, 2024



through the links provided as well as through the NFOSD (<https://swallowingdisorderfoundation.com/>) and the THANC (<https://thancfoundation.org/>) websites.

The Dysphagia Voice of the Patient report

This *Voice of the Patient* report is provided to all dysphagia community supporters including the FDA, other government agencies, regulatory authorities, medical product developers, academics, clinicians, and any other interested individuals. The content of this report may help inform the development of dysphagia-specific, clinically meaningful endpoints for current and future clinical trials, as well as encourage researchers and industry to investigate better treatment. The input received from the June 10, 2025, EL-PFDD Meeting on Adult Dysphagia reflects a wide range of experiences of individuals living with dysphagia, however not all symptoms and impacts may be captured in this report. The final report is available through the NFOSD (<https://swallowingdisorderfoundation.com/>) and the THANC (<https://thancfoundation.org/>) websites.



TOPIC 1 – DYSPHAGIA SYMPTOMS AND DAILY IMPACTS

This *Voice of the Patient* report is organized to highlight insights that emerged at the June 10, 2025 EL-PFDD Meeting on Adult Dysphagia as well as the results of online polling. Both insights and poll results are illustrated by select quotes from patients and caregivers.

Dysphagia Insights

Dysphagia is a swallowing disorder that can affect people very differently. The causes vary and can be complex.

During the meeting and through [online polling](#), individuals living with dysphagia described the range of conditions and causes of their swallowing disorder. Many experience dysphagia as a result of head and neck cancer and/or its treatment, including surgery, chemotherapy, and radiation, with some describing unbearable pain with swallowing. Some experience swallowing difficulties because of residual scar tissue, acid reflux, dementia or a stroke. Some described how they developed strictures, or a narrowing of the esophagus, blocking the flow of food and drink into the stomach. During the meeting, participants spoke about esophageal dysmotility, pharyngeal wall weakening, cervical spine issues, eosinophilic esophagitis, hiatal hernia, laryngeal and esophageal spasms, lack of saliva (xerostomia), inability to move or retract the tongue, nerve issues or loss of the teeth and jaw. For some, the root cause of their dysphagia is unknown.

“Dysphagia is a daily reminder of the battle I fought. I’m grateful to be cancer free, but the price was steep. The radiation burns in my throat were beyond anything I could have imagined. Every meal is a reminder of that pain, a reminder of everything I had been through, and a reminder of what is potentially yet to come. Every swallow brings me back to the grueling treatment that saved my life but stole my ability to eat freely.” - Brian, living with dysphagia

“My dysphagia first started when I had a brain stem stroke in February 2022 that left me 100% unable to speak or swallow at all, not even my own spit.” - Kevin, living with dysphagia

Dysphagia can exhibit degenerative or progressive characteristics, especially in individuals with a history of radiation.

Radiation therapy may cause muscles in the throat and/or esophagus to become fibrotic, tightening over time, leading to narrowing or strictures in the upper digestive tract. Some individuals must remain vigilant for changes and regressions in their swallowing ability.

“Radiation is a gift that keeps on giving and giving, and making the muscles in my neck tighter and tighter.” - Amy, living with dysphagia

“At my last exam, I was told my swallowing ability may decrease. I suspect that’s a fairly certain ‘may’, stated gently to avoid my catastrophizing.” - Vincent, living with dysphagia

Poll Response

Most individuals living with dysphagia experience multiple symptoms, which can range in severity and vary greatly from person to person.

During the EL-PFDD Meeting on Adult Dysphagia, those living with dysphagia and their caregivers first identified all of the dysphagia-related health concerns that they had experienced using online polling. Most individuals living with dysphagia experience a combination of symptoms and in the poll they each selected an average of seven different health concerns. Meeting participants then used online polling to identify their three most troublesome health concerns. Difficulty swallowing is both the most frequent and the most troublesome dysphagia related health concern, followed by choking and frequent coughing, anxiety and depression. These symptoms are shown in the [polls](#) and are listed in descending order of most troublesome with patient quotes below.

Difficulty swallowing

Swallowing difficulties may arise from a broad range of underlying conditions, and the severity of symptoms can differ significantly. Some participants living with dysphagia shared that their ability to swallow may fluctuate. Others noted limitations in what they can consume safely by mouth and may need to modify their diet by altering the consistencies of solids and liquids, accordingly. Others living with dysphagia shared that they cannot swallow anything at all and rely on feeding tubes for nutrition and hydration.

“My dysphagia manifests as food and liquid getting stuck in my esophagus. On my worst days, it feels like I can't swallow at all despite my best efforts.” - Eva, living with dysphagia

“My primary swallowing deficit is that I cannot retract my tongue to move a poorly formed bolus from my mouth, into my throat, into the top of my esophagus.” - Ed, living with dysphagia

“Radiation fibrosis had damaged my swallowing. If I don't chew carefully, food gets stuck in the back of my mouth, triggering gagging episodes. ...At first, [gagging] episodes were frequent and terrifying. Over time, I learned to concentrate on my eating, testing the boundaries of what I could and could not eat. Chronic dry mouth makes swallowing even more difficult. I live on a soft, moist diet. Even drinking water demands caution as aspiration is a real risk.” - Brian, living with dysphagia

Choking, gagging and frequent coughing

Impaired coordination and timing of swallowing can result in choking, gagging, and/or coughing for many individuals with dysphagia. Overt choking results when there is an obstruction, such as food, blocking the airway, and can result in life-threatening consequences and requires emergent action, such as the Heimlich maneuver. For some, extreme coughing can cause food or drink to back up into their nasal passage.



"I have major damage to my throat from the procedures and radiation therapy. Once, I nearly choked to death on a thoughtless bite of food." - Vincent, living with dysphagia.

"He has been having more and more issues coughing consistently. ...It's mostly coughing during mealtime and leads to a lot of embarrassment for him where he will walk away from the table or he doesn't want to be as involved in the mealtimes and family get-togethers." - Cindy, caregiver for her father living with dysphagia

"It's anxiety producing ... it's unpredictable. I don't know when I'm going to cough and when I'm not. And especially in a doctor's office, people look at me like I'm going to give them a disease or they move away from me. It's very isolating. It's very unpredictable." - Karen, living with dysphagia

Anxiety or depression

Dysphagia has a tremendous and often overlooked emotional burden. Many experience a lack of pleasure when eating. Some feel anxious about choking. Others worry about being a burden to others, especially when they take a long time to eat or require their meals to be modified. Many of those living with dysphagia experience social isolation and grief over the loss of the communal experience of a shared meal. Personal dignity and self image can be affected, especially for those who come from cultures where food is central to social roles.

"Dealing with near catastrophic events such as cancer and dysphagia can take a toll on one's spirit. Feelings of isolation, self-doubt, guilt, and very unhealthy doses of "why me" can be difficult to deal with." - Charlie, living with dysphagia

"Many months after radiation when I decided to attempt to eat a small portion of mashed or pureed food, I noticed how hyper-aware I was of choking. ... I still have anxiety around gagging and choking when I eat, and this is an aspect of dysphagia that I continue to live with daily." - Elfie, living with dysphagia

"When I couldn't fully eat by mouth, social gatherings were very difficult for me because there was always a food component to the gathering. It really messed with my mental health." - Danny, living with dysphagia

Aspiration pneumonia

Many participants with dysphagia noted that they are at increased risk for aspiration of food, liquids, or saliva—where material enters the airway and lungs. Aspiration may occur multiple times per day, including during sleep. In some cases, participants shared that aspiration led to aspiration pneumonia, and voiced concern that this could result in hospitalization or, in severe instances, death.

"Over the past two-plus years I have had repeated aspiration pneumonia and am accumulating lung damage." - Michael, living with dysphagia

"Jeff started having swallowing problems and aspiration pneumonia... They did a lung resection because they found food in his lungs from aspiration pneumonia, and they put in a feeding tube." - Patti, caregiver for a loved one living with dysphagia

Speech/voice impairment

Dysphonia is often a concomitant symptom of dysphagia, as the anatomy and physiology required for swallowing, speaking and voicing significantly overlap. Speech and voice impairments can vary in severity and may lead to communication challenges that contribute to isolation. Some individuals experience vocal changes such as quivering/tremor or difficulty producing certain sounds, resulting in discomfort or embarrassment during conversation. Others living with dysphagia have lost the ability to speak entirely, sometimes due to laryngectomy. At the EL-PFDD meeting, several panelists pre-recorded their presentations so that the presentations could be captioned and some used AI-generated voices to deliver their remarks.

“Imagine trying to explain even a simple idea with a mouth full of cotton balls, or a mouthful of saliva that you cannot swallow. Even simple conversations become an elaborate game of charades where I’m trying to gesture and bridge the gap between what I mean to say and what actually comes out. Frustrated and embarrassed listeners usually nod as if they understand, but I see the confusion in their eyes.” - Teresa, living with dysphagia

“Speaking clearly is almost impossible. Only a few people can understand what I was talking about. This condition has seriously limited my ability to be with family and friends. My life has changed dramatically.” - Shannon, living with dysphagia

Malnutrition or dehydration

Malnutrition and dehydration are two of the more medically serious secondary effects of dysphagia. The ability to get enough nutrition to maintain strength and quality of life can be a daily struggle. Profound weight loss can have a cascading effect that can lead to increasing frailty and illness, and near-death experiences. Dehydration can lead to urinary tract infections and kidney damage. Many individuals with dysphagia require feeding tubes to obtain adequate nutrition and hydration.

“He’s stuck in this cycle where the dysphagia is resulting in this weight loss, but the weight loss is resulting in more muscle weakness, which is making the dysphagia worse. ... It’s like a domino effect of the dysphagia causing the weight loss, which is causing more of the muscle atrophy and lack of ability to participate in things he’s always participated in.” - Cindy, caregiver for her father living with dysphagia

“My dysphagia was almost the death of me.” Ed contracted influenza A, which progressed to severe double pneumonia and sepsis. “I was deemed too weak to undergo surgery for a feeding tube placement, an attempt at a nasal feeding tube failed, and the only option left was nutrition through an IV. ... One physician hypothesized that it was my lack of nutrition that was causing this failure. Shortly thereafter, a PEG tube was placed in my stomach. The nutrition provided by the tube allowed me to become stable and eventually to thrive.” - Ed, living with dysphagia

Dry mouth (xerostomia)

Dry mouth, or xerostomia, impacts both the ability to swallow and to speak and is most common in individuals with dysphagia caused by treatment for head/neck cancer. Many participants share



that they have to carry water with them at all times, taking frequent sips. They expressed that dry mouth can be very painful, can lead to tooth decay, and requires a complicated oral care regimen.

“For me on a daily basis, it's the dry mouth, just the constant dry mouth. ... You'll never find me without water. I just have constantly made it a habit to keep that water bottle with me because the dry mouth is just so intense. It's just always in the forefront of my mind.”
- Melissa, living with dysphagia

“Spontaneous conversation has been replaced by a mental word find where I search my internal thesaurus for synonyms that I can pronounce. ... I never know if I'll have Sahara Desert dry mouth or Niagara Falls drooling.” - Teresa, living with dysphagia

“Dry mouth is painful and few realize how much it can hurt! I changed to dental cleanings four times per year, use an electric toothbrush, wear a night guard and always brush before going to bed.” - Keri, living with dysphagia

Other dysphagia related health concerns

Other dysphagia-related health concerns selected in the polls include **diarrhea or constipation** or other gastrointestinal upset, often related to the use of supplemental nutrition administered through a feeding tube, **regurgitation and reflux, drooling and oral secretions**. Other dysphagia related health concerns mentioned during the meeting include **lost teeth** or **missing jaws** which can impair the ability to chew and swallow.

Poll Response

Dysphagia causes significant declines in quality of life by disrupting fundamental activities of daily living.

During the EL-PFDD Meeting on Adult Dysphagia, many spoke about the negative impact that dysphagia has had on their quality of life, in physical, emotional and social domains. [In the poll](#), the top three daily activities important to those living with dysphagia or their loved ones that were impacted by dysphagia are enjoying meals, socializing, and going to restaurants, however, every single option in the poll was selected. Impacts are listed in descending order and described with patient quotes below. Despite having a profound impact on quality of life, dysphagia can seem invisible, and many expressed that the impacts of dysphagia are minimized.

Enjoying meals and the ability to eat through the mouth

Eating is a source of pleasure and the loss of that ability can be devastating. For those with dysphagia, meals can take a long time to prepare and eat, resulting in self consciousness about the amount of time it takes to consume their food. For others, if food isn't blended properly, it can become stuck in the upper gastrointestinal tract, which can be painful and dangerous if it interferes with breathing or is aspirated into the lungs. Those who can no longer safely consume food orally, may rely on feeding tubes.



“Struggle drinking eight glasses of water a day? Try drinking your entire diet every single day. Exhausting. The calorie game is no joke. Without enough intake, I lose weight fast, so I eat all day. By eat, I mean drink. And by drink, I mean coax thick sludge into my mouth, maneuver it around using cheek muscles and a bit of neck choreography and try not to wear it. Because fun fact, the tongue is kind of the MVP [most valuable player] of swallowing. Who knew? Physically, it's just easier to drink from a cup than eat with a spoon.”- Sonya, living with dysphagia

“I have also lost teeth that cannot be replaced, making eating a tedious and unenjoyable process. I also cough with meals and frequently throughout the day.” - Pat, living with dysphagia

“Food is love. It's how we express ourselves, it's how we maintain our health. It's a deeply cultural experience. It's a central experience for people too. ... Getting those senses met is so important. And so it just changes everything when you can't swallow.” - Laura, living with dysphagia, and caregiver to her father who is also living with dysphagia

Socializing

Dysphagia interrupts the social interactions associated with shared mealtimes. The inability to eat, or eat in a socially-acceptable manner, results in isolation. Many individuals with dysphagia choose to eat meals alone, due to embarrassment or need for increased concentration to eat safely. Unfortunately, meals are often central to birthdays, weddings, community gatherings and other special occasions or celebrations. In this way, dysphagia can affect the entire family. Those who have speech challenges or who cannot speak, which is common in people with dysphagia, as noted in the polls above, experience increased social impacts related to connection and communication.

“The loss of food as a joyful social experience still stings.”- Sonya, living with dysphagia

“I eat very slowly and cannot participate in conversations during the meal. I have experienced embarrassment many times over the years, due to food causing me to cough and clear my throat during these gatherings. These swallowing events have caused me to rapidly leave the table many times in restaurants and other people's homes.” - James, living with dysphagia

“When a prominent family member loses his ability to break bread with others, it dramatically affects the entire family. You do not realize how much of our lives are focused on the ability to eat and drink until it's taken away.” - Lisa, caregiver for her late father who lived with dysphagia

Going to restaurants

Unlike eating at home, where meals can be more easily prepared in a modified manner, restaurants present many challenges for individuals with dysphagia. Some preview online menus to ensure that they will have something that they can safely consume. Some will stick to a few favorite restaurants that are willing to modify or puree foods and others bring their own food and drinks or a blender. Some simply avoid restaurants altogether.



“Food choice is easier at home where I usually add liquid and blend what I make for everyone else.” - Teresa, living with dysphagia

“Dining out is a battlefield. Before going to a restaurant, I scour the menu for something I can eat. If there's nothing, I decline the invitation. ... And even when I do go out to eat, I can never fully relax. Every bite is a calculation. Every swallow a risk. I pass on foods that are tough to eat, so I don't slow down the timing of the meal for everyone else.” - Brian, living with dysphagia

“Emotionally, I went through a period of grieving, a grief and a loss of, I used to be able to eat everything. Everything was on the table. I remember eating meat, chicken, fish, you name it. Any food that I desired, could go out to a restaurant, eat, and then now I can't consume anything like that. ... It has impacted me emotionally.” - Karen, living with dysphagia

Participating in recreational activities, events, travel and vacationing

Dysphagia can interfere with physical exercises and activities like swimming, water sports and even brisk walking. Spontaneity and eating “on the run” are things of the past, because so much effort is required for meal planning, preparation, and for safe consumption. Many participants shared the need for increased planning prior to traveling to assure they bring all of the required equipment, such as blenders or thickening agents.

“The brisk walk I used to take several times a week was no longer possible as it would leave me winded and gasping for air. Until more recently, dysphagia did not allow me to do my personal workout at the gym. I used to enjoy swimming as a form of exercise. Now my difficulty in swallowing, along with the anxiety of breathing and swallowing and perhaps ingesting water while in the pool, have taken the joy and relaxation out of this activity.” - Elfie, living with dysphagia

“I have tremendous difficulty the minute I go out: whether it's a restaurant; whether it's a walk or hike where we've been told to bring lunch or to bring a meal with us; if it's a car trip where I have to take something in the car; if it's a travel experience where I've signed up for a tour and meals are included and they bring the menu and there's virtually nothing on the menu that I can eat. Those are the experiences that both embarrass me and leave me feeling really depleted because I walk away basically not having eaten.” - Judy, living with dysphagia

“The loss of spontaneity affects me, and also my loved ones. Eating on the run is a luxury of the past.” - Teresa, living with dysphagia

Sleeping

Dysphagia can negatively impact sleep. Some worry about aspirating their secretions in their sleep, choosing to sleep in a recliner or with their head raised to minimize the risk of aspiration, including aspiration from material refluxed from the stomach. For others, xerostomia prevents them from resting comfortably, waking frequently to take sips of water.



“I have esophageal dysphagia, GERD and a hiatal hernia. I wake up at night aspirating on reflux and fumes. It’s traumatic. I elevate the head of my bed, stop eating by 6pm (most nights), drink plenty of water, avoid trigger foods.” - Robyn, living with dysphagia

“I’m even at risk for aspiration on my limited saliva while I’m sleeping, which could result in a life-threatening pneumonia.” - Brian, living with dysphagia

Intimacy, dating and maintaining relationships

Dysphagia can interfere with and change relationships. Food is considered by many to be a “love language”, so not participating in meals is particularly impactful on relationships. Family members are often stressed by watching their loved ones being unable to eat during meals or worry about them choking.

“Living with dysphagia is isolating. ... This makes me avoid social outings or even dates for fear of having to watch others eat while I’m hungry or embarrass myself by choking or spitting out food.” - Michele, living with dysphagia

“A lot of times dysphagia changes the dynamic in a relationship, whether it’s a spouse relationship or a parent-child relationship. You go from being a partner to then needing to be a caregiver. ... You go from being this independent person who is in charge to needing that help, and sometimes it’s hard for people.” - Laura, living with dysphagia, and caregiver to her father who is also living with dysphagia

Dysphagia emotionally impacted Melissa’s son. *“The first time that I really had a serious choking incident, I was at home by myself with my nine-year-old son.” - Melissa, living with dysphagia*

Working/attending school

At school or in the workplace, dysphagia can make everyday tasks difficult—causing interruptions like choking, coughing, or voice changes during classes, meetings, or virtual calls. For some, the condition extends beyond communication challenges, threatening their financial stability when symptoms prevent them from maintaining employment.

“My mental health got so bad that I withdrew from college. I could not stand being around my peers between classes, watching them eat and enjoying themselves while I was being fed through a feeding tube.” - Danny, living with dysphagia

“I suffered three strokes. ... How can I be a chef and not swallow? Is my life and career over?... I feared I needed a feeding tube and the loss of my career.” - Michael John, a professional chef living with dysphagia

Other impacts on daily activities

Other dysphagia impacts described during the meeting and in the submitted patient comments included the **interference in religious practices** (e.g., inability to take Communion), needing to endure a **complicated oral care regimen**, and difficulty in **taking pills and other medications**.

Poll Response

Individuals living with dysphagia, as well as their caregivers, experience persistent concerns related to aspiration pneumonia, uncertainty of disease progression, and the risk of premature mortality.

Individuals living with dysphagia or their loved ones selected their top three worries about their or their loved one's condition in the future using [online polling](#).

The top three worries include aspiration pneumonia, not knowing how dysphagia will progress, and premature mortality, however every worry in the poll was selected. Worries are listed in descending order and are described within the patient quotes below.

Aspiration pneumonia

Aspiration pneumonia is one of the most serious—and sometimes fatal—complications of dysphagia. Many people live with constant anxiety about “silent aspiration,” when food or liquid enters the airway without obvious signs like coughing. For some, even the fear of aspirating while asleep weighs heavily on daily life.

“Silent aspiration has the most significant impact on my son's life, as well as mine and my husband's. This is something we have to worry about always and forever. He is technically never safe when eating - it can happen at any time, and in my son's case it has. My son had to be rushed by ambulance to the hospital one evening after starting to complain about having difficulty breathing and then passing out. His life was in danger and my husband and I felt helpless.” - Cindy, caregiver for her adult son living with dysphagia

“I worry that things will get worse with age and that I will develop pneumonia because of it.” - Matt, living with dysphagia

The stress of not knowing how dysphagia will progress

Because dysphagia can involve both progressive decline and, in some cases, potential improvement through rehabilitation, depending on the underlying cause, individuals often face significant uncertainty about the future. Concerns may include radiation-related deterioration, like fibrosis of swallowing muscles, further weakening of swallowing muscles, cognitive changes, and the possibility of additional surgeries that could impact swallowing function. As dysphagia advances, food options may become increasingly restricted, further affecting quality of life.

Danny worked incredibly hard through swallowing therapy to advance from a feeding tube to eating a minced and moist diet. *“I am proud of what I have achieved, but I live in fear that another surgery will take me one step forward and two steps back.”* - Danny, living with dysphagia

“What happens as I age if my swallowing muscles weaken further, if my cognitive capacity diminishes to where I can't recall or attend to the swallowing techniques I need to use while staying safe while eating and drinking? And I know what comes next,



aspiration, pneumonias, hospitalizations, feeding tube placement.” - Brian, living with dysphagia

“A combination, or a worsening of existing symptoms. ... Just the unknown of how it will progress. And of course, we all hope that it won't progress. ... The difficulty in swallowing over the years has progressively gotten worse, and then just all the what-ifs of if there are new symptoms that make the dysphagia worse.” - Melissa, living with dysphagia

“The thought of not being able to eat or drink for the remaining years is unbearable. We take it for granted but it's such a special gift like breathing, being mobile, sight, hearing and the rest of our senses.” - Dan K., living with dysphagia

Premature death and mortality

Many individuals living with dysphagia are survivors of cancer or other serious illnesses and have already undergone extensive treatments and surgeries. Despite these hardships, due to dysphagia, they continue to live with the persistent fear of life-threatening complications such as choking or aspiration pneumonia.

“My chief concern ... is the fear that this will kill me. Three weeks in the hospital for aspiration pneumonia with serious pleurisy left me afraid that the worst is still ahead. Several severe choking incidents keenly remind me that every bite can kill.” - Vincent, living with dysphagia

“I struggle daily with serious swallowing issues. I fear that I'll choke to death. I wish there were more options for me.” - Lorna, living with dysphagia

“Our experience with dysphagia has been devastating. It goes beyond not being able to eat normally. Dysphagia played a role in the deaths of my devoted dad and my sweet, beautiful, beloved brother.” - Lucy, caregiver for her late brother living with dysphagia

Worsening nutrition concerns and potential feeding tube dependence

Individuals living with dysphagia often experience ongoing anxiety about meeting their nutritional needs, particularly adequate protein intake. As swallowing difficulties progress, the risk of malnutrition may increase, heightening concerns about the potential need for feeding tube placement.

“My biggest fear is winding up needing a feeding tube because now I'm having nutritional deficiencies due to other GI issues that seem to have cropped up that I'm trying to work out with my GI specialist. But it impacts me daily after every meal. Even though I just had a smoothie for breakfast and coffee with a thickener, I'm still coughing. I'm still choking.” - Karen, living with dysphagia

“Dining and cooking are a key passion, so my key fear as the dysphagia advances is needing to rely on a feeding tube, which while it may meet calorie demand, is not assured to prevent pneumonia.” - Michael, living with dysphagia

Loss of independence and increased caregiver burden

Concerns about loss of independence and caregiver burden are closely intertwined. Many individuals with dysphagia fear becoming a burden on their family as their care needs grow, while others worry about entering a care facility where their nutritional needs may not receive sufficient attention. The unanticipated demands placed on caregivers emerged as a central theme during the meeting. Caregiving responsibilities often extend beyond routine support to include preparing specialized meals, assisting with swallowing exercises, monitoring for choking or coughing, and managing feeding tubes.

“My mom gave up her job, retired early from her career to stay home and take care of dad because... when you have to modify every bite you put into your mouth, it adds a whole other level of activity or action that needs to be taken so you can even get to eating.” - Laura, living with dysphagia, and caregiver to her father who is also living with dysphagia

“I don't want to be a burden to my family. I want to make sure that that is all prevented as much as possible. I don't want somebody to have to care and give up their whole lifestyle to take care of me.” - Ruth, living with dysphagia

Fears of isolation and worsening communication challenges

Social isolation is one of the most profound concerns for individuals living with dysphagia. Fears about declining communication abilities often intensify this sense of isolation, compounding worries about future quality of life.

“Not being able to eat is socially isolating on all days. He rarely sees family and friends as most interactions [involve] eating. Before his feeding tube was placed, we often attended family dinners and met friends for lunch or dinner. If it's a major holiday, I attend on my own, while he stays home by himself, which of course, I feel bad about it.” - J, caregiver for her husband living with dysphagia

Ed's progressive tongue weakness affects his swallowing and speech. *“This dual impairment has led to increasing social isolation. The ongoing deterioration feels akin to a degenerative neurological disease such as Parkinson's or ALS—relentless, with limited treatment or compensatory options available. The cumulative toll is profoundly demoralizing and emotionally draining.” - Ed, living with dysphagia*

Concern of financial strain on families and loved ones

Financial stability is often compromised by the impact of dysphagia on employment, coupled with loss of independence and the added responsibilities placed on caregivers.

“He is often sick and cannot work. I worry about the future as there are still gaps for available support in the community, if you are not able to work there is no source of revenue for paying for housing, daily activities and bills.” - Laurie, caregiver for her brother living with dysphagia



TOPIC 2 - PERSPECTIVES ON CURRENT AND FUTURE APPROACHES TO TREATMENT

Dysphagia Insight

Dysphagia is a complex condition with no singular treatment, arising from a variety of underlying causes.

Dysphagia is a disorder that arises from a variety of underlying causes, and no single treatment can effectively address all its forms. Participants shared that management is particularly challenging when dysphagia results from radiation-induced damage, and treatments often focus on compensatory strategies to support safe swallowing rather than directly addressing the root cause.

Poll Responses

Dysphagia treatments vary broadly based on the cause of the disorder, with a modified diet as the top symptom management approach.

During the EL-PFDD Meeting on Adult Dysphagia, participants living with dysphagia and their caregivers used [online polling](#) to indicate all medications and medical approaches they use to manage dysphagia-related symptoms. On average, each respondent reported using three different approaches.

Respondents also indicated how well their current treatment regimen controls their or their loved one's dysphagia symptoms overall and identified the three biggest drawbacks of their current approaches. Only 36% indicated that their symptoms were controlled "to a great extent", 29% indicated that their symptoms were controlled "somewhat", and 35% indicated that their current treatment regimen controls their symptoms "very little" or "not at all". The top dysphagia treatment drawbacks are "requires too much effort and/or time commitment" (selected by 60%), and "only treats some, not all symptoms" (selected by 50%). Respondents also indicated that treatments were "not very effective at treating target symptoms" (40%), had a "high cost or co-pay, and were not covered by insurance" (40%). [Online poll results are shown here.](#)

Different medications and medical approaches used to treat dysphagia are listed below, along with patient comments about efficacy and drawbacks.

Diet modification

Participants indicated that the primary clinical approach for managing their dysphagia is a modified diet. This strategy involves adjusting the consistency and texture of foods and liquids based on the type and severity of the swallowing disorder. Modifications can include careful food selection, moistening, mincing, or pureeing foods, as well as thickening liquids or providing fully liquefied diets. Several participants referenced the International Dysphagia Diet Standardisation Initiative (IDDSI), which provides a standardized numerical system for classifying food and liquid modification levels, with a lower IDDSI level corresponding to greater diet modification.

"I started out at an IDDSI (International Dysphagia Diet Standardisation Initiative) level 6, which was soft and bite sized, and now I'm basically consuming thick liquids (level 3), possibly even lower than that. ... Over time, I just had to keep doing that until I could reduce the symptoms of coughing. ... It's getting worse over time." - Karen, living with dysphagia

"I can manage to meet my nutritional needs by mouth, but with a restricted diet, washing food down, and eating slowly." - Michael, living with dysphagia

After the removal of her tongue and a total laryngectomy, "I basically became a one-woman test kitchen for liquefied vegetables, fruits, legumes, nuts, grains, and anything else that might keep my weight up. ... I can only consume liquids forever." - Sonya, living with dysphagia

Drawbacks: Modified diets demand significant time and effort to prepare and consume, and even when properly implemented, they do not always guarantee adequate nutritional intake.

"In late 2006, I could eat just about anything, but there was a caveat. It took three times longer than normal to safely eat a meal, and the bolus had to be washed down. ... Over the years, my food choices have become more and more limited. ... During the past five years, my worsening dysphagia resulted in a purely liquid diet that took more strength, coordination, and solitude." - Ed, living with dysphagia

Supplements and medications to support gastrointestinal health

This category includes a variety of interventions aimed at managing gastrointestinal symptoms associated with dysphagia. Participants listed commonly used medications including antacids such as proton pump inhibitors (PPIs) (e.g., omeprazole, lansoprazole, Prevacid®) and histamine H₂ receptor antagonists (e.g., famotidine [Pepcid®]), which help reduce or suppress gastroesophageal reflux. TUMS® may also be used for similar purposes. Additional options include antispasmodics to reduce gastrointestinal motility and alginates, which form a protective barrier over the esophageal lining.

"I am 62 years old and I take 40mg of famotidine twice a day (morning & evening) for acid reflux and hiatal hernia. Some days I have no challenges and other days I get - what I refer to as - a bubble in my throat that stops me from swallowing my food." - Terry, living with dysphagia

"In hopes of preventing a reoccurrence [of esophageal stricture], I was prescribed a PPI to help reduce the symptoms of reflux which had contributed to inflammation in my esophagus. ... I was also prescribed an antispasmodic medication to address the laryngeal and esophageal spasms that I experience several times a day. These spasms cause sharp, deep pain in my esophagus and chest when involuntary contractions occur." - Eva, living with dysphagia

Drawbacks: Many medications target only specific symptoms, requiring some individuals with dysphagia to take multiple medications concurrently. For those who have difficulty swallowing



pills, crushing medications may be necessary to safely swallow, however may potentially reduce the medication's efficacy.

Adaptive equipment (special utensils, plates, etc.)

Some individuals with dysphagia rely on adaptive equipment to support safe eating and swallowing. Those who have undergone cancer treatment or reconstructive surgery may require prosthetic devices to assist with swallowing.

“The obturator designed by a prosthodontist fits like a retainer on the roof of my mouth held in place by wires that wrap around my back teeth. It's built up to about 3/4 inch thick at the back to take up space in my mouth left by the absence of my tongue. It improves my speech by removing the hollow tone and allowing some sounds I cannot produce without it. It also helps with swallowing my pureed diet by reducing the food pocketing at the roof of my mouth. It's not perfect, but a major improvement. I would say that I feel dependent on it now for socializing and eating/swallowing.” - Teresa, living with dysphagia

Drawbacks: While adaptive equipment can be highly effective, it often requires customization and can be costly, with some expenses not covered by insurance or requiring significant co-pays.

Medical devices

A variety of medical devices are used to support individuals with dysphagia by improving swallowing function, targeting muscle strength, coordination, and sensory feedback throughout the oral, pharyngeal, and upper gastrointestinal systems. Examples shared by participants include VitalStim®, Phagenyx®, Tongueometer™, the EMST150 (Expiratory Muscle Strength Trainer), and Mobil-T®. Other devices, such as the Swallow Expansion Device (SED), involve a small titanium implant designed to open the upper esophageal sphincter, facilitating easier passage of food and liquids during swallowing. Other commonly used equipment includes steam inhalers to hydrate the mouth and suction devices to manage saliva or phlegm.

Michael John reported success with the Phagenyx®. “It’s a small diameter catheter inserted through your nose down your throat providing small electrical pulses to stimulate the muscle memory of the action of swallowing.... During the treatment your throat muscles twitch causing you to swallow involuntarily.” - Micheal John, living with dysphagia

Vincent tried the Aspire EMST150. “My swallowing therapist gave it to me as a way to prevent later on having to have a balloon put down my throat... by keeping my throat in tone better in addition to the Mendelsohn maneuvers and all those exercises. When I feel my throat tightening up and swallowing getting harder, I use this EMST150 device....It's been a real helpful thing.” - Vincent, living with dysphagia

“I was also introduced to a personal steam inhaler, which I now use multiple times a day to keep my sinuses and esophagus hydrated and relaxed to make swallowing easier.” - Eva, living with dysphagia



Drawbacks: Use of these devices often requires significant time, effort, and training. While some individuals experience notable improvement in swallowing function, others see limited or no benefit. Participants also highlighted challenges such as limited availability in North America and a lack of accessible information about these options.

Surgery and other medical procedures

Individuals with dysphagia may require surgical or medical interventions of varying invasiveness, ranging from minimally invasive procedures—such as endoscopic visualization — to extensive reconstructive surgeries following head and neck cancer treatment, or even total laryngectomy to prevent aspiration. This also includes augmentation procedures and dilations, described below.

“I have had my esophagus stretched one time and they put a camera down my throat to take pictures. My esophagus is long and has a slight curve in it, the pictures showed some scar tissue and ulcers from the stomach acid. The procedure was done about two years ago and I am scheduled to have it done again in about three weeks.” - Terry, living with dysphagia

“He had a total laryngectomy with a fibula flap that resolved the aspiration pneumonia because then he couldn't get anything in his lungs. ... With the total laryngectomy, he had to make the decision where he couldn't talk anymore.” The surgery had other benefits in addition to resolving aspiration pneumonia. “No feeding tube, that's the biggest benefit. There's lots of downsides, but that's the biggest benefit.” - Patti, caregiver for a loved one living with dysphagia

Augmentation procedures may involve surgical incisions, tissue removal, or targeted injections to modify or reinforce anatomical structures that impact swallowing. These interventions can include removal of obstructive lesions or bony growths (such as osteophytes), as well as augmentation of the posterior pharyngeal wall or vocal folds using natural or synthetic materials.

“He has already had Restylane® and GORE-TEX® inserted onto his vocal cords thinking that would thicken up his vocal cords to prevent food from going into his lungs.” - J, caregiver for her husband living with dysphagia

Dilations are performed to widen a narrowed esophagus and are particularly common among individuals who have undergone radiation therapy. Dilations can be performed in an inpatient or outpatient setting, involving an endoscopic procedure where the esophagus is stretched. In some cases, dilations are combined with steroid injections.

“[My doctor] has performed multiple esophageal dilations and pharyngeal augmentations over the past few years. These procedures have helped to improve my swallowing for a period of time.” - James, living with dysphagia

Patrice has experienced nine balloon dilation procedures with intraesophageal steroid injections and trans-nasal endoscopies. *“My esophagus was down to one millimeter open, and so I was having trouble swallowing anything. ... It worked. It got from one millimeter to 16-1/2 millimeters and I was able to eat normally.” - Patrice, living with dysphagia*



Drawbacks: Surgical interventions carry inherent risks. The esophagus presents anatomical challenges for visualization and access, and specialized equipment is limited. Additionally, the benefits of certain procedures, including dilations, are often temporary and may require repeated interventions.

“We discussed the advantages and disadvantages of further endoscopies, dilation, Botox injections, and the use of stents as I’ve had a history of developing strictures and have undergone these procedures before. In my experience, the relief was short-lived and the efficacy diminished with each procedure, so I opted not to repeat these interventions and instead focused on expanding my testing to find the root cause.” - Eva, living with dysphagia

Other medications

Anxiety and depression medications, medications to treat infection and sleep medications were selected in the polls. Poll results indicated that individuals with dysphagia also use medications for anxiety, depression, infection, and sleep management. Additional treatments may include injected or oral steroids, as well as botulinum toxin injections to relax the cricopharyngeus muscle, which is responsible for opening and closing the upper esophageal sphincter during swallowing to allow food and liquid to pass from the throat into the esophagus. For dysphagia associated with eosinophilic esophagitis (EoE), monoclonal antibody therapy, such as Dupilumab (Dupixent®), may be used. Some individuals may also use medications to manage dry mouth, such as pilocarpine.

“I had vocal cord cancer and ended up with a total laryngectomy. I had trouble swallowing and had several dilatations in a few months. My doctor finally found help for me by injecting a steroid to stop the swelling during the dilatation. I was on a feeding tube during that time. I am now able to eat slowly and with water.” - Ron, living with dysphagia

Drawbacks: While some treatments can be restorative or curative depending on the cause of dysphagia, many are not and require ongoing, indefinite use. Swallowed steroids can increase the risk of chronic fungal laryngitis, while therapies such as monoclonal antibodies often involve high costs or significant co-pays.

Supplements to improve growth, hydration and nutrition

Interventions to support nutritional status and hydration include oral nutritional supplements such as Boost® or Ensure®, tube feeding formulas like Kate Farms®, and protein powders often added to smoothies or pureed foods. In some cases, individuals may rely on intravenous fluids to maintain adequate hydration.

“I was living on Ensure and Boost for quite a long time. And then as I went through radiation, probably like everybody else, I lost my sense of taste and the dry mouth. But coming out of that, about a month later, [my SLP] was very proactive in teaching me swallowing exercises and I had to ease into the more solid foods.” - Vinny, living with dysphagia

Drawbacks: Many individuals are hesitant to rely on supplements long-term due to concerns about incomplete nutrition, absorption, cost, and potential side effects.

“The average hospital dietitian's go-to? Meal replacement shakes like Boost or Ensure. You know the ones, sugar, milk protein, and vegetable oil topping the ingredients list. I'm vegan and more intentional than ever about what I put into my body. So yeah, hard pass. Challenge number one, find a vegan, high calorie, whole food-based liquid nutrition option with no sugar. They exist, but they're not exactly lining the shelves, and they definitely aren't cheap. So, I began researching and experimenting because long-term, living on processed shakes is a no-go.” - Sonya, living with dysphagia

Investigational therapies and devices in clinical trials

Many individuals living with dysphagia described various clinical trials in which they had participated.

After an eight-week trial, “While the Tonguometer™ device showed my tongue strength had increased, the only real thing I noticed about swallowing was I went from a single sip swallow of liquids to multiple swallows in a row for the same drink. ... This may seem trivial but meant the world to my overall quality of life, where I went from trying to avoid drinking to seeking out more water to drink.” - Kevin, living with dysphagia

“I was able to be part of a clinical trial for Mobil-T®, which is a small device that enabled me to re-build the muscles in my tongue and throat. I have been able to swallow almost anything now as opposed to being dependent on Ensure and smoothies for nutrition.” - Ted, living with dysphagia

Drawbacks: Participation in clinical trials often requires significant time, effort, and travel. Some individuals express concerns about potential discomfort or pain associated with the intervention. Additionally, not all participants are guaranteed to receive the treatment being studied or to experience any therapeutic benefit.

“Participation in the study is a challenge as I am the sole caregiver for my husband but the promise of improved swallow function and the potential benefit to other dysphagia patients is worth whatever sacrifices I make. The physical requirements of the study have been tolerable and reasonable.” - Kathryn, living with dysphagia

“My hope is that I received my actual stem cells and that I begin noticing improvements due to the injections!” - John, living with dysphagia

Poll Response

Respondents reported that effective management of dysphagia symptoms often requires multiple non-medical approaches, with modifications to eating and drinking habits, swallowing and speech therapy, and feeding tubes identified as the most commonly used interventions.

Respondents living with dysphagia and caregivers used online polling to identify non-medical approaches they employ to manage dysphagia symptoms. On average, each participant reported using [2.5 different strategies](#). The approaches listed below include patient-reported insights on effectiveness and associated drawbacks.

Modifying eating/drinking habits

Adjusting eating and drinking behaviors is the most commonly used clinical strategy for managing dysphagia symptoms. Most commonly, respondents noted that they avoid items that trigger choking, gagging, or coughing. Some individuals choose only warm or tepid foods to avoid burns. Many adopt compensatory strategies, such as limiting conversation during meals to maintain focus, practicing techniques to reduce anxiety while eating, or scheduling meals earlier in the day to minimize nighttime reflux. Maintaining adequate hydration is a constant challenge, and many individuals carry water with them throughout the day.

“I also eliminated trigger foods and beverages that can worsen these symptoms and focused on texture, density, and temperatures of my meals.” - Eva, living with dysphagia

“I have to focus on my chewing and being smart what I order when going out with friends. This has not stopped me from eating out, I just need to be careful when eating and pay attention or it will trigger coughing spells. Can’t stop living life - just need to be more careful.” - Jym, living with dysphagia

“For me, I have to sit very upright [when I eat]. I have to make sure that I am calm and relaxed when I eat. I don't like noisy situations. I cannot eat if it's really noisy in a restaurant because foods will stick right here.” - Laura, living with dysphagia, and caregiver to her father who is also living with dysphagia

Drawbacks: Modified eating and drinking habits often must be maintained indefinitely. These adaptations can also make shared or social dining experiences difficult or impractical.

Speech and swallowing therapy

Individuals with dysphagia participated in targeted therapeutic exercises aimed at enhancing oropharyngeal muscle awareness and strengthening the swallowing musculature to promote safer swallowing and reduce aspiration risk. Interventions may include biofeedback-assisted techniques and neuromuscular electrical stimulation. Many participants reported that these interventions were highly effective in improving their swallowing function.

“Speech therapy ... has helped improve both my voice and swallowing ability. The exercises made me more aware of how I was using my muscles while I was eating and speaking, and I learned the techniques to reduce strain and tension.” - Eva, living with dysphagia

“Now that my swallow is somewhat stronger than it was - thanks to swallow therapy, I don't develop aspiration pneumonia as much.” - Danny, living with dysphagia

“My physical condition is as good as it will get, but it's dependent on doing my swallowing exercises each and every day. If I don't, I've been warned that my swallow can and will get worse.” Vincent's routine, “Consists of effortful swallowing, jaw thrusts, and opening exercises, Mendelsohn maneuvers, tongue thrusts, and my favorite, purposeful yawning.” - Vincent, living with dysphagia

Drawbacks: These exercises require a great amount of effort and time and, for some, must be adhered to indefinitely. Many participants described how it took a long time before their friends and family could fully understand their swallowing impairment.

“I have a very nice swallowing and speech therapist. She has me do five exercises, and I religiously do them three times a day, morning, noon, and evening. And so, when I don't do them, I can tell that it's even more difficult to swallow. ...I know no matter what, I have to continue this.” - Amy, living with dysphagia

Feeding tubes

Various types of feeding tubes are used to provide nutrition and hydration for individuals who are unable to swallow safely. Some tubes are used temporarily during recovery from radiotherapy or reconstructive surgery, while others are required for longer-term support. In certain cases, individuals who retain some swallowing ability choose to use a feeding tube to supplement oral intake.

“To this day, I cannot swallow. ... I used to be able to jump out of the bed and head downstairs for that beloved first cup of coffee. Now I head downstairs for the morning hook up to the feeding tube and two cartons of formula to start the day.” - Charlie, living with dysphagia

“To reduce that likelihood of further hospitalizations [from aspiration pneumonia], I quit eating or drinking by mouth and take all my nutrition through a PEG [percutaneous endoscopic gastrostomy] tube. Despite that effort, I just recovered from another aspirational pneumonia. I'm worried that I'm becoming resistant to certain antibiotics and that is a major issue.” - William, living with dysphagia

“I'm hesitant to have the feeding tube taken out because, as I said, it saved me a couple of times...and I don't know what I would've done otherwise.” - Patrice, living with dysphagia

Drawbacks: Feeding tube use carries risk of infection and does not eliminate the risk of aspiration. Disuse atrophy of swallowing muscles may occur if patients are not actively

participating in rehabilitation. Individuals may also face challenges in identifying suitable supplemental nutrition for use through their feeding tube, particularly if they have dietary sensitivities.

“I have a G-tube. The site is always reddened and drains infected material all through the day, especially acidic foods/fluids. Because of this all day it’s on my mind.” - Jill, living with dysphagia

Other approaches mentioned in the polls

Other symptom-management approaches mentioned in the poll **include communication aids/devices, chiropractic, craniosacral, or massage therapy, physical therapy/occupational therapy, and acupuncture.**

Sonya demonstrated her communication device during the EL-PFDD meeting. “I communicate using virtual voicing, or type to talk. What you’re hearing is an AI-generated version of my original voice.” - Sonya, living with dysphagia

“I have tried speech and physical therapy and lymphatic massage, which may have slowed to some extent but not stopped the progression of symptoms. I have just started with a new therapist that I hope will be more effective. The massage and swallowing exercises are time consuming, and it is difficult to fit them into my life. I feel like most of my day is working around health-related activities.” - Pat, living with dysphagia

“I have dysphagia from treatment for throat cancer. I treat it with acupuncture for dry mouth (not covered by Medicare), lozenges, throat exercise and always having fluid handy, especially when eating (essential to preventing choking on my food).” - Matt, living with dysphagia

Other approaches not mentioned in the polls

Individuals living with dysphagia often use a variety of additional strategies to manage their symptoms. These may include saliva stimulants or substitutes, such as Biotène® gel, xanthan gum, ACT® Dry Mouth Lozenges, and Oralbalance® moisturizing gel. Other approaches include engaging in exercise and sports, cultivating acceptance and support from friends and the community, participating in support groups, receiving counseling for depression or grief, and practicing therapeutic writing.

“I found my refuge on the tennis court. I try to play five times a week. I think of nothing more than hitting a cross-court forehand, or a sliced backhand shot. I play the game for exercise, both mental and physical. I find solace in that my tennis friends don’t make fun of my surgically induced broken speech pattern. That acceptance is important.” - Charlie, living with dysphagia.

“The mental side of this is the real tough part. I want to live a modified normal life so I go out with friends and my wife. I tell my friends to ‘not worry about me not eating’ and ‘don’t let it bother you! Enjoy your meal because I’m okay with all of this!’ I golf and play drums again and my wife and I went to a baseball game yesterday. I’m over feeling sorry for



myself! I want to live my new normal life! We have to carry on with what we are now!" - Bob H., living with dysphagia

"When I was fully on a feeding tube, I wasn't sure of how I'd be able to go out with my friends because going out to eat was a main component of our hangouts. Luckily, I have very supportive friends who would pick sushi places to eat at because they knew I hated sushi and they really wanted to have me be part of the experience." - Danny, living with dysphagia

Poll Response

There is a critical need for new therapies to address dysphagia.

Durable and effective treatment options for the diverse forms of dysphagia remain limited. When asked to identify the top three areas they would like a new therapy to address, individuals living with dysphagia and their caregivers ranked "swallowing difficulties" as the highest priority. Maintaining nutrition and hydration, along with addressing speech or voice impairments, were tied for second. [Poll results](#), along with representative patient quotes, are presented below.

Swallowing difficulties

Individuals living with dysphagia expressed a strong desire for therapies that enable easier, safer, and more efficient swallowing. Goals included regenerating tongue tissue, improving tongue strength and function, repairing structural and functional damage, and preserving existing swallowing ability. Many participants emphasized they wish to reach a point where swallowing could occur naturally, without conscious effort or anxiety.

"If a treatment option existed that would increase my tongue strength, especially one where it would allow my tongue to retract properly, this would be a game changer for me. I would welcome and participate in any treatment that would address my tongue deficiency. This type of therapy would improve my nutrition along with my social and emotional well-being." - Ed, living with dysphagia

"An ideal treatment would arrest further loss in swallowing ability and provide some durable structural or functional compensation of the damage caused by the radiation." - Michael, living with dysphagia

"The only thing that I want is at some point not to have to think about it. That it's not a hindrance anymore, whether it's getting better or getting more used to it, but it just not being an issue anymore." - Amy, living with dysphagia

Maintaining nutrition/hydration, weight loss, eating/chewing difficulties

Given the challenges many individuals with dysphagia face in maintaining adequate nutrition and hydration, it is unsurprising that these areas were identified as important targets for treatment. Closely related concerns—such as weight loss and difficulties with eating or chewing—were also frequently selected in the polls.



“Imagine trying to explain even a simple idea with a mouth full of cotton balls, or a mouthful of saliva that you cannot swallow. ...I never know if I'll have Sahara Desert dry mouth or Niagara Falls drooling.” - Teresa, living with dysphagia

“I've learned that I cannot be without a water bottle because after a while of talking, ... the quivering in my voice or sometimes just completely not being able to speak because my mouth will literally just be so dry, it freezes up and I cannot speak. ... I definitely cannot be without water in those moments.” - Melissa, living with dysphagia

“Without saliva, difficulty eating chewable food resulted in excessive loss of weight, strength and stamina, impacting both my health and quality of life.” - Barbara, living with dysphagia

Speech or voice impairment

Addressing speech or voice impairment were also identified as important targets for those living with dysphagia, as improvements in communication could reduce social isolation.

“Our wish list would be for him to be able to speak again. It's been a very hard thing for him and family and me to deal with. I have to do all of his speaking, but speech would be our wish.” - Patti, caregiver for a loved one who has had a total laryngectomy, living with dysphagia

Emotional/behavioral issues

Living with dysphagia is a daily struggle. Respondents emphasized the need for more emotional support, both for people living with dysphagia as well as their loved ones and caregivers.

“While dysphagia is a physical disorder, it absolutely affects mental health. For me, an ideal comprehensive treatment plan for dysphagia would include both physical treatments like VitalStim® and treatment for mental health like individual talk therapy.” - Danny, living with dysphagia

“As a caregiver, you need emotional support as you care for somebody with dysphagia. ... this is existential stuff we're dealing with.” - Laura, living with dysphagia, and caregiver to her father who is also living with dysphagia

Other therapeutic aspects selected in the polls

Those living with dysphagia selected other dysphagia aspects as important for a possible new therapeutic including **oral motor difficulties** and **pain**.

Additional needs of the dysphagia community

The dysphagia community identified several key needs and priorities for future therapeutic development. The dysphagia community needs **better information, education and awareness about the condition, better screening, proactive and preventative treatment including treatment for those with underlying degenerative conditions where dysphagia is expected to become more severe as the underlying condition progresses**. The dysphagia community requested **nonsurgical interventions, assistance in managing secretions, better detection and**



prevention approaches for aspiration, and therapies to address esophageal reflux and improve peristalsis.

Dysphagia Insight

The dysphagia community needs more research and clinical trials to address all aspects of dysphagia.

The dysphagia community urgently requires expanded research and clinical trials to develop effective interventions that address the full spectrum of dysphagia-related challenges. This need for comprehensive investigation and innovation was a central theme emphasized throughout the meeting.

“Anything I could do to help the research and learning I would gladly donate my time towards. My reasoning and willingness is simple: to further science and to help others regain some form of swallowing again. I learned on the way that every form of dysphagia is extremely personal and that everyone's treatment should be individually set.” - Kevin, living with dysphagia

“I would gladly participate in any clinical trials on improving long term outcomes.” - Vincent, living with dysphagia



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We also wish to thank all the investigators who have dedicated their careers to seeking improvements for people living with dysphagia and who are moving us closer to future clinical trials and treatments.

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Finally, and most importantly, we are grateful to members of our dysphagia community: people impacted by swallowing disorders and their loved ones. Thank you to our many speakers, panelists and callers for sharing their personal experiences, for helping us understand what living with dysphagia is like day in and day out. We are grateful to have had this opportunity to ensure that patient and caregiver's perspectives are considered in the drug development and regulatory process. Our hope is that this meeting will encourage future research and successful new treatment options for people living with dysphagia.

About the NFOSD and THANC

The mission of the **National Foundation of Swallowing Disorders (NFOSD)** is to advance the treatment of swallowing disorders in our lifetime, by providing direct patient and caregiver support, providing free high-quality education, supporting promising research, and raising awareness of the impact of dysphagia.

The **THANC** (Thyroid, Head & Neck Cancer) Foundation is committed to supporting research and education in the early detection and treatment of thyroid and head and neck cancer; to advancing new therapeutic approaches; and to alleviating the suffering and functional impairment of patients who undergo treatment.