

COMMONWEALTH of VIRGINIA

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# Office of Integrated Health Health & Safety Alert/Information Dysphagia Health & Safety Alert

# **Dysphagia Introduction**

A diagnosis of dysphagia means a person has difficulty swallowing. Swallowing difficulties are not uncommon, as the process of swallowing is complex and uses many muscles of the mouth and throat. The terms "dysphagia" and "swallowing disorder" are used interchangeably. A diagnosis of dysphagia can also mean the individual has difficulty with sucking, chewing, tongue control, controlling saliva, protecting the airway, as well as swallowing (3).

The following are brief descriptions of each phase of the swallowing process:

*Oral Preparatory Phase* – Occurs when food is introduced into the mouth, then chewed and mixed with saliva. At this point, a bolus (ball) is formed. Liquids are sipped or sucked into the mouth during this phase (24).

*Oral Phase* – Happens when the food bolus is sealed between the roof of the mouth and tongue. The tongue moves the bolus in a wave motion into the back of the throat

(Pharynx) (24).

*Pharyngeal Phase* – Initiates when the soft palate elevates and the tongue moves back to contact the pharyngeal wall. The voice box then moves up and forward. The epiglottis tilts down and back to guide the food bolus past the airway. Vocal folds come together to protect the airway, as the muscles of the pharynx contract. Lastly, the upper esophageal sphincter relaxes to open and the bolus moves into the esophagus (24).

**Esophageal Phase** – Starts when a wave contraction moves the bolus through the esophagus. The lower esophagus sphincter then relaxes to open, so the bolus can then move into the stomach (24).

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# Signs and Symptoms of Dysphagia

Individuals having difficulty swallowing at mealtimes should be evaluated immediately by a healthcare professional. If you observe any of the following, ask the individual's PCP for a referral to a Speech Language Pathologist (SLP) who will assess the individual's swallowing ability.

- Inability to swallow food or liquid.
- Being hoarse (clearing throat often).
- Changes in the sound of the individual's voice.
- Pain when swallowing.
- Drooling.
- Intermittent fevers.
- Vomiting after meals.
- Regurgitation (bringing food back up).
- Frequent heartburn.
- A choking or gagging incident.
- Repetitive dehydration or unexpected weight loss.
- Coughing or gagging when swallowing.
- Feeling of food getting stuck in the mouth, or observing food in the mouth during oral care.
- Having to cut food up into small pieces.
- Taking a long time to eat a meal.
- Poor oral management.
- Food/liquid remaining in the mouth after swallowing.
- Food/liquid leaking from mouth.
- Gurgling or wet breathing or voice.
- Recurrent respiratory infections or aspiration pneumonia.
- Changes in eating habits.
- Sticking fingers down throat, or trying to put fist in mouth (19) (2).

# Dysphagia and the Individual with Intellectual and Developmental Disabilities (I/DD)

Individuals with intellectual and developmental disabilities (IDD) who are diagnosed with dysphagia may have further complications due to medical, psychiatric, and behavioral issues. Multiple medication interactions and side effects can contribute to swallowing issues and nutritional intake (12) (26).

Within the IDD population, dysphagia has been associated with aspiration pneumonia, choking, impaired nutritional intake, an increased need for mealtime supports, emergency hospitalizations, readmissions, and premature death (12) (26).

Eighty-five percent of individuals diagnosed with Cerebral Palsy (CP) are at increased risk for dysphagia due to muscular weakness, skeletal impairments, reduced mobility, and cognitive defects (10) (12) (26). Excessive drooling is often a sign of dysphagia, as it represents an individual's poor control of saliva in the oral cavity (29).

Seventy-four percent of individuals diagnosed with Down syndrome (DS) have some degree of mental impairments and physical abnormalities of the face and mouth, such as reduced muscle tone of the lips, tongue, jaw, and soft palate, along with widely spaced teeth affecting their ability to chew and swallow. Individuals with DS are also at increased risk for developing dysphagia due to characteristics of early onset dementia (12) (20).

Other neurological disorders, which contribute to dysphagia, are stroke, all types of brain injuries, spinal cord injuries, Multiple Sclerosis, Muscular Dystrophy and Amyotrophic Lateral Sclerosis (ALS). Individuals diagnosed with any type of dementia, such as Parkinson's disease and/or Alzheimer's are also at increased risk (22).

# **Dysphagia and Quality of Life**

Eating should be an enjoyable event, without complications. Dysphagia may cause the individual to feel shame, and loss of pride or self-respect, which directly affects their quality of life and socialization (28). Individuals may also feel uncomfortable or embarrassed while eating in front of others and may suffer increased depression and/or anxiety. Altered diets have also been linked to difficulty maintaining weight, which is problematic if individuals have a diagnosis of "failure to thrive" (21).

# **Prevalence of Dysphagia**

The prevalence of dysphagia is growing within the general population because people are living longer. For individuals residing in assisted living facilities or in nursing homes, estimates are between 40-60% (4). For individuals with intellectual and developmental

disabilities it is estimated 8% have difficulty swallowing and 15% require some type of mealtime support (25).

The International Dysphagia Diet Standardization Initiative estimates that 8% of the world population is affected by dysphagia (14). In a study completed in 2020, of 597 participants the prevalence of dysphagia ranged from 25-34%. Participants who did not receive mealtime supports were at a higher risk for choking (17).

# **Physical Conditions which Contribute to Dysphagia**

## **Esophageal Strictures**

An esophageal stricture is a narrowing of the esophagus and can be a contributing factor for dysphagia. In general, strictures are categorized as complex or simple. Esophageal strictures make it difficult for food to move downward toward the stomach; however, liquids can usually pass without issue. Untreated gastroesophageal reflux disorder (GERD) may also lead to scarring of the esophageal tissue, which builds up causing narrowing of the esophagus (8).



## Tardive Dyskinesia (TD)

Tardive Dyskinesia (TD) is an irreversible condition caused by taking neuroleptic medications long-term and can result in facial, tongue and throat muscle issues, which may affect the ability to chew or swallow (16). The involuntary movements of the mouth make it difficult to control food and swallow safely. A qualified medical professional should assess individuals on neuroleptic medications for tardive dyskinesia every 6 months (16).

## **Tooth Loss (Edentulous)**

Tooth loss reduces an individual's ability to chew food adequately. Chewing, food transport, and swallowing, work as a combined coordinated process. Tooth loss directly affects the swallowing process (17). Other factors in poor oral health are ill-fitting dentures, difficulty performing oral care, inability to keep mouth open for care, and inability to keep head and body in correct position for oral care (11). A study completed in 2020 with 597 individuals diagnosed with intellectual disability and no teeth demonstrated the risk of choking increased between 1.30-3.61 times over peers with natural teeth (17).

## Dry Mouth (Xerostomia)

Saliva contains digestive enzymes which start the process of breaking down food as it is chewed. Those suffering from dry mouth have difficulty forming a food bolus (ball). Increasing saliva production can be accomplished by stimulating the oral tissue through brushing. Oral moisturizers such as Biotene may prove to be helpful to coat, lubricate, and clean the oral cavity (1).

Dry mouth has significant negative effects on eating. The chewing process requires saliva to moisten and form the bolus (ball of food). Medications for depression, hypertension, anxiety, antihistamines, decongestants, chemo drugs, muscle relaxants, ADD/ADHD (methamphetamine), marijuana, and pain medications have a dry mouth side effect (18).

## Gastroesophageal Reflux Disease (GERD)

Untreated long-term GERD results in damage to the esophageal mucosa. GERD is a chronic disease characterized by symptoms of heartburn (a burning sensation in the center of the chest behind the breastbone) and regurgitation of stomach contents, which causes damage to the lining of the esophagus. The combination of acidic contents from the stomach, and the lower esophageal sphincter not closing properly, set the stage for GERD and further complicates dysphagia (7).

## Dehydration

Dysphagia is directly linked to dehydration. Monitoring fluid intake for individuals with coexisting factors (immobility, medications, and dysphagia) is important for prevention of dehydration. For individuals prescribed laxatives and diuretics, additional monitoring due to fluid loss may be recommended (27).

## **Respiratory Infections**

There is a correlation between dysphagia and recurrent or chronic respiratory infections, such as bronchitis, as well as aspiration pneumonia (25). Aspiration pneumonia results from inhaling a foreign substance into the lungs (saliva, food, liquids, and stomach contents). Aspiration pneumonia can be difficult to recognize if it presents with non-specific symptoms such as fever, headache, nausea, vomiting, confusion, and discomfort (34).

In a study of individuals with intellectual disabilities diagnosed with dysphagia and epilepsy, 29% suffered a respiratory infection. Within the same study, it was determined that participants with swallowing difficulties were five (5) times more likely of developing a respiratory infection than peers with no swallowing difficulty (26).

## **Deaths**

In 2018 a review of 1,050 medical records of individuals with intellectual disability revealed the most common cause of death to be respiratory related (32.1%). Within this study group 77.4% had dysphagia (23). This sounds the alarm for closer monitoring of individuals due to higher risk for choking, asphyxiation (lack of oxygen), and aspiration.

# **Dysphagia Diagnosis**

Once an individual has been evaluated by their PCP, they may be referred to a Speech Language Pathologist for a complete assessment. The assessment may also include:

- A complete review of their medical/clinical records, as well as an interview with caregivers, parents, or other healthcare professionals familiar with the individual.
- A structural assessment of face, jaw, lips, tongue, hard and soft palate, oral pharynx, and oral mucosa.
- A functional assessment of muscles and structures used in swallowing, including symmetry, sensation, strength, tone, range and rate of motion, and coordination of movement.
- An observation of head-neck control, posture, oral reflexes, and involuntary movements (6) (2).
- A video-fluoroscopic swallow study (VFSS), also known as a Modified Barium Swallow. During the VFSS, the individual will consume several foods or liquids, (along with the mineral barium), to improve visibility of the digestive tract. A videotaped X-ray will record their entire swallowing process.

- A Flexible Endoscopic Evaluation of Swallowing with Sensory Testing (FEESST), uses a lighted fiber optic tube, or endoscope, to view the mouth and throat while examining how the swallowing mechanism responds to such stimuli as a puff of air, food, or liquids. Fiber optic endoscopic evaluation of swallowing (FEES) is sometimes used as an alternative to the MBS.
- Pharyngeal manometry is sometimes used to assess the pressure inside the individual's esophagus.
- An X-ray with contrast material. This requires the consumption of a barium solution drink, which allows for coating of the esophagus and other structures. Muscle activity can also be assessed (6).

# **Dietary Modifications**

After an individual has undergone a swallow study, they may receive a recommendation for a modified diet, such as a pureed texture, or thickened liquids. Their PCP would then write orders for this diet based on the SLP's recommendations. The struggle with dietary modifications is producing the same consistency throughout all environments of an individual's life. It is important for the safety of the individual that all providers follow the PCP's orders for diet modifications. NEVER IMPLEMENT A MODIFIED DIET WITHOUT THE CONSULTATION OF A SPEECH AND LANGUAGE PATHOLOGIST AND PHYSICIAN ORDERS.

In 2013, the International Dysphagia Diet Standardization, <u>https://iddsi.org/</u>, initiative was established to provide a systematic format of terminology and definitions for modified textures, which could be used globally. According to the IDDSI, dysphagia is an issue affecting nearly 600 million people worldwide (14). In 2015, the IDDSI developed the framework and supporting documents in response to the global need for consistency.

Color photos and diagrams help to minimize confusion and miscommunication regarding textures and drink consistencies. Foods and liquids not properly prepared can increase the risk of aspiration and death (14). Special permission is not required to use the framework, instructions, or resources. However, alterations to the *methods* outlined in the IDDSI framework are not recommended and could result in severe consequences.

The temperature of food or liquid is a factor in preparing the right consistency. Fluids should be prepared to the correct thickness at the time of consumption for best results. Being able to enjoy food and liquids at the preferred temperature is part of the pleasure of consuming that item (14). However, there are thickening agents available, which maintain their consistency once mixed.

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# **The IDDSI Framework**

Providing a common terminology for describing food textures and drink thicknesses to improve safety for individuals with swallowing difficulties.



### © The International Dysphagia Diet Standardisation Initiative 2019 @ https://iddsi.org/framework/

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Below are examples of the IDDSI framework and supporting diagrams for various diet modifications (13).

		_
👌 мор	ERATELY THICK	
Description/characteristics	<ul> <li>Can be drunk from a cup</li> <li>Moderate effort is required to suck through a standard bore or wide bore straw (wide bore straw = 0.275 inch or 6.9 mm)</li> <li>Cannot be piped, layered or molded on a plate because it will not retain its shape</li> <li>Cannot be eaten with a fork because it drips slowly in dollops through the prongs</li> <li>Can be eaten with a spoon</li> <li>No oral processing or chewing required – can be swallowed directly</li> <li>Smooth texture with no 'bits' (lumps, fibers, bits of shell or skin, husk, particles of gristle or bone)</li> </ul>	
Physiological rationale for this level of thickness	<ul> <li>If tongue control is insufficient to manage Mildly Thick drinks (Level 2 this Liquidised/Moderately thick level may be suitable</li> <li>Allows more time for oral control</li> <li>Needs some tongue propulsion effort</li> <li>Pain on swallowing</li> </ul>	!),
See also IDDSI Testing Methods d https://iddsi.org/framework/foo IDDSI Flow Test*	Iocument or <a href="https://iddsi.org/framework/drink-testing-methods/">https://iddsi.org/framework/drink-testing-methods/</a> • Test liquid flows through a 10 ml slip tip syringe leaving > 8 ml in the syringe after 10 seconds (see IDDSI Flow Test Guide*)	
Fork Drip Test	<ul> <li>Drips slowly in dollops through the prongs of a fork</li> <li>When a fork is pressed on the surface of Level 3 Moderately Thick Liquid/Liquidised food, the tines/prongs of a fork do not leave a clear pattern on the surface</li> <li>Spreads out if spilled onto a flat surface</li> </ul>	
Spoon Tilt Test	Easily pours from spoon when tilted; does not stick to spoon	
Where forks are not available Chopstick Test	Chopsticks are not suitable for this texture	
Where forks are not available Finger Test	<ul> <li>It is not possible to hold a sample of this food texture using fingers, however, this texture slides smoothly and easily between the thumb and fingers, leaving a coating</li> </ul>	
	The full state in the second fit is the DB fit is set 10.	
Food specific or	The following items may fit into IDDSI Level 3:	
Other examples	<ul> <li>Infant "first foods" (runny rice cereal or runny pureed fruit)</li> </ul>	
Food specific or Other examples (NB. this list is not exhaustive)		

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	ED			
Description/characteristics	<ul> <li>Usually eaten with a spoon (a fork is possible)</li> <li>Cannot be drunk from a cup because it does not flow easily</li> <li>Cannot be sucked through a straw</li> <li>Does not require chewing</li> <li>Can be piped, layered or molded because it retains its shape, but should <u>not</u> require chewing if presented in this form</li> <li>Shows some very slow movement under gravity but cannot be poured</li> <li>Falls off spoon in a single spoonful when tilted and continues to hold shape on a plate</li> <li>No lumps</li> <li><u>Not</u> sticky</li> <li>Liquid must not separate from solid</li> </ul>			
ow to test consistency, nd how much effort it ould take to consume.	<ul> <li>If tongue control is significantly reduced, this category may be easiest to control</li> <li>Requires less propulsion effort than Minced &amp; Moist (level 5), Soft &amp; Bite-Sized (Level 6) and Regular and Regular Easy to Chew (Level 7) but more than Liquidised/Moderately thick (Level 3)</li> <li>No biting or chewing is required</li> <li>Increased oral and/or pharyngeal residue is a risk if too sticky</li> <li>Any food that requires chewing, controlled manipulation or bolus formation are not suitable</li> <li>Pain on chewing or swallowing</li> <li>Missing teeth, poorly fitting dentures</li> </ul>			
TESTING METHODS	<ul> <li>d, use IDDSI Testing methods to decide if the food/liquid meets IDDSI Level 4.</li> <li>ncument or <a href="https://iddsi.org/framework/food-testing-methods/">https://iddsi.org/framework/food-testing-methods/</a> </li> <li>n/a. The IDDSI Flow test is not applicable, please use the Fork Drip Test and Spoon Tilt Test</li> </ul>			
Fork Pressure test	<ul> <li>Smooth with no lumps and minimal granulation</li> <li>When a fork is pressed on the surface of Level 4 Extremely Thick Liquid/Pureed food, the tines/prongs of a fork can make a clear pattern on the surface, and/or the food retains the indentation from the fork</li> </ul>			
Fork Drip test	<ul> <li>Sample sits in a mound/pile above the fork; a small amount may flow through and form a short tail below the fork tines/prongs, but it does</li> </ul>			

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	picture below)	The narrative gives a description of the food and
Spoon Tilt test	<ul> <li>Cohesive enough to hold its shape on t</li> <li>A full spoonful must plop off the spoor sideways; a very gentle flick (using only necessary to dislodge the sample from should slide off easily with very little for film remaining on the spoon after the however, you should still be able to se film; i.e. the sample should <u>not</u> be firm</li> <li>May spread out slightly or slump very</li> </ul>	texture. The spoon and/or fork guide is also helpful to let you know if food is prepared correctly.
Where forks are not available Chopstick test	Chopsticks are not suitable for this tex	ture
Where forks are not available Finger test	<ul> <li>It is just possible to hold a sample of th texture slides smoothly and easily betw noticeable coating</li> </ul>	
Indicators that a sample is too thick	Does not fall off the spoon when tilted     Sticks to spoon	1
FOOD SPECIFIC OR OTHER EXAMPLES		
The following item may be suitable for	r IDDSI Level 4:	
Purees suitable for infants (e.g. pu	reed meat, thick cereal)	
	all amount may flow through and form a short ta	all below the fork the fork prongs
Spoon Tilt Test: Holds	s shape on spoon; not firm and sticky; little fo	bod left on spoon
CreativeComm	mework and Descriptors are licensed under nons Attribution-Sharealike 4.0 International ://creativecommons.org/licenses/by-sa/4.0/ IDDSI 2.0   July, 2019	License

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The following images show examples of foods that would be suitable or unsuitable for Level 4 according to the IDDSI Spoon Tilt Test



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Provides a list of	vn from international autopsy reports	
at should be avoided and the reason why.	king risk because they require good chewing ability to break down and noist enough to be safe to swallow. nuts, raw carrots, crackling, hard crusty rolls	
	a choking risk because they require good chewing ability, and sustained n to small enough pieces that are safe to swallow. <a href="https://www.communication.com">https://www.communication.com</a> <a href="https://www.com">https://www.com</a> <a href="https://www.com"></a> www.com	
mouth, the teeth or cheeks a	g risk because they are sticky and can become stuck to the roof of the nd fall into the airway ndies/lollies/sweets, cheese chunks, marshmallows, chewing gum, sticky	
with saliva to make them soft	risk because they require good chewing ability to break down and mix t, rounded and moist enough to be safe to swallow. ckling, crisp bacon, some dry cereals	
	ng risk because they require good chewing ability, and sustained in into small enough pieces and mix with saliva so that they are safe to aw carrot, raw apple, popcorn	
	choking risk because they require good chewing ability to break them ded pieces and moist enough to be safe to swallow. res: dry corn chips	
together and mix with enoug	ing risk because they need good tongue control to bring crumbly pieces h saliva to hold together to be moist and safe to swallow. rumbly dry cakes, dry cookies, dry biscuits or scones	
hard or fibrous textures, mak	arts of fruit are a choking risk because they are hard and part of other ing it a complex process to separate and remove them from the mouth ite parts of fruit include apple or pumpkin seeds, the white part of oranges	
needing good chewing skills t enough skill to remove the pi gums and catch in the throat	re a choking risk because the pieces are often fibrous, spiky, and dry to make the pieces smaller, and enough saliva to make it moist, OR eces from the mouth. These small pieces become stuck to teeth and when swallowed. It shells include pea shells, grape skin, bran, psyllium	
champles of skins, husks of oute		

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DBHDS has descriptive pictures available along with a narrative as a reference guide to modifications:



# **Examples of Thickening Agents**

Thickening agents improve swallowing by slowing the flow of liquid. When the flow of liquids is slowed, the individual can better control the substance in their mouth, which allows time for the airway to close before swallowing. However, sometimes thickeners decrease the acceptance of liquids by individuals because they do change the texture and flavor of liquids slightly. Thickeners can also leave a coating in the mouth, which can negatively affect an individual's acceptance. In a study, which compared various powdered thickeners and commercially made, ready-to-drink, thickened liquids, the commercially prepared drinks were better accepted by individuals and increased their overall fluid intake (27).

Examples of common products used to thicken liquids and foods are pictured below. Each product has specific instructions. Most companies who produce thickening agents also offer ready-made products such as juices, pureed vegetables, main dishes, and fruit. Instructions for Simply Thick, Thick-it, and Thicken Up refer to the International Dysphagia Diet Standardization Initiative (30) (31) (32).



# **Caregiver Considerations**

- Mealtime supports (while eating and/or drinking), may be required for individuals with IDD who struggle with dysphagia, and/or other physical or behavioral difficulties, in order to decrease risk of choking and/or aspiration (5) (33).
- Caregivers should ensure proper positioning of an individual at a 90° angle (a normal upright sitting posture) to reduce risk of choking and/or aspiration when the individual is eating or drinking (5) (33).
- Mealtime supports may also include protocols for: sitting with an individual during meals; verbal prompting for the individual to take another bite of food or drink; or 100% assistance, which would require a caregiver to spoon feed an individual their meals (33) (26).
- Mealtime protocols should include input from an individual's Speech Language Pathologist (SLP), and their PCP, and must be signed by a physician.
- Mealtime protocols ensure caregivers deliver a consistent level of support to individuals at risk for dysphagia, while ensuring safe and adequate nutritional intake (5).
- Feelings of being "left out" of social events which include a particular food, (e.g. movie and popcorn night) and/or an individual's dissatisfaction with the taste and texture of their modified diet are common reasons for non-compliance (15).
- Training on how to prepare food/drink texture modifications is strongly recommended and will increase a caregiver's level of confidence and ability to follow recommendations and PCP orders accurately (33) (26).
- <u>All caregivers providing care and assistance to an individual with dysphagia should</u> be warned that the individual is at an increased risk of choking, aspiration and death, when/if dietary modifications and recommendations are not followed consistently.

# Resources

International Dysphagia Diet Standard Initiative: Free resources. <u>https://iddsi.org/</u>

American Speech Language Hearing Association (ASHA): Information on Adult Dysphagia. <u>https://www.asha.org/Practice-Portal/Clinical-Topics/Adult-Dysphagia/</u>

The Office of Integrated Health at DBHDS: If you have any questions about the information contained in this Health & Safety Alert, or need additional resources or support, please email your questions to the Office of Integrated Health's nursing team at: communitynursing@dbhds.virginia.gov

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<u>1DeB56fXjNwWEy5aOunPTxAP3CPPwBRsxmSGA0mZXI5RtSgKfoUTGwjBIeN5pe4L</u> K3w3alx4q2u1IrZaN1LSkvLY1IR2LjHOb0wndBcqifqKYzZkckzXtcuNwYIzCJZ

## **DBHDS Human Rights Department:**

For more information on individuals' human rights in relation to psychotropic medications. <u>https://dbhds.virginia.gov/quality-management/human-rights</u>

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